

Patients as Partners in Research

Patient/Caregiver Surveys

EVALUATING THE PATIENT PARTNERSHIP IN RESEARCH

Initial Survey
Mid Project Survey
End Project Survey

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Overview

Purpose

The patient/caregiver partner 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. The questions are practical and look to identify behaviours that support productive partnerships.

Description

There are three draft surveys. The three surveys will allow for the tracking of the relationship over the duration of the project.

- 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

Developing the Surveys

The questions have been developed by the four authors who are patient/caregivers 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 patient/caregiver partners in research who had no part in the development of the questionnaires.

We have also developed three similar surveys for researchers partnering with patients and caregivers that are meant to follow closely the questions asked of patients and caregivers 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

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

Acknowledgements

We would like to acknowledge our reviewers, led by Julia Abelson, PhD, Professor, Department of Clinical Epidemiology & Biostatistics, McMaster University, and Antoine Boivin, MD, PhD, Canada Research Chair in Patient and Public Partnership, Université de Montréal. The reviewers were:

- Audrey L'Esperance
- François-Pierre Gauvin
- Laura Tripp

The responsibility for which changes to adopt rests solely with the authors.

Initial Survey

Questions for Patient/Caregiver Partners on Research Teams

Help us to understand your experience of partnering on a research team so we can learn what patient/caregiver partners could use for support in future. This is the first of 3 surveys we are asking you to complete: An initial one early in your involvement, 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 contact person on this project?	_____
6	Where are you located?	City _____ Prov/Terr _____
7	Including you, how many patient/caregiver partners are on this project at this time? <i>(Do not include patients/caregivers on an advisory panel.)</i>	_____
8	When you started with the team, at what stage was the project? <i>(Select one)</i>	<ul style="list-style-type: none"> • Working on the LOI (Letter of Intent) or EOI (Expression of Intent) • Working on the application • Funding received and project in process

MEETING THE TEAM

9	Did the Principal Investigator (PI) or someone else introduce you to the other team members?	Y/N
10	Did the PI or someone else introduce each team member to you?	Y/N
11	Have you worked as a <u>patient/caregiver partner</u> on a research project prior to this one?	Y/N

GETTING BRIEFED - LEARNING ABOUT THE PROJECT

12	Was there enough time for you to learn about the project and get to know the other team members prior to the application being submitted?	Y/N
13	Was the project described to you before you started working with the team?	Y/N

If you answered "No" to question 13, skip the following questions and go to question 17.

14	How did the team explain the project to you at the start? <i>(Pick all that apply)</i>	<ul style="list-style-type: none"> • Sent you the funding application • Sent other briefing documents • Held meeting or teleconference
15	If there was a meeting or teleconference to explain the project to you, who did the briefing? <i>(Select one)</i>	<ul style="list-style-type: none"> • PI or main project person • Someone else (role) _____ • No meeting/ teleconference
16	If there was a meeting or teleconference to explain the project to you, was it for patient/caregiver partners only or for the whole team? <i>(Select one)</i>	<ul style="list-style-type: none"> • Patient/caregiver partners only • The whole team
17	Were the communication tools the team is using explained? <i>(examples: teleconference, web-based meetings like GoToMeeting, any shareware or central file storage, online calendar)</i>	Y/N
	Explain any issues or challenges you faced	_____

DEFINING AND UNDERSTANDING ROLES

18	Did you and the PI and/or team together discuss your role on the team?	Y/N
19	Were the roles of the other members of the team explained to you?	Y/N
	Comments	_____

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

Skip the questions in this section if you joined the team during the application phase or after the project was funded.

In some cases a Letter of Intent (LOI) or Expression of Interest (EOI) is requested by the funder as a pre-screening exercise.

If the funder accepts the LOI or EOI, then the team moves to developing a full, formal application for funding.

20	A letter of Intent or Expression of Interest was required.	Y/N/Don't know
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If you answered "No" or "Don't know" to question 20, skip the following questions and go to question 23.

21	Was there enough time for you 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
22	Were you sent copies of the Letter of Intent or Expression of Interest drafts to review?	Y/N

DEVELOPING THE APPLICATION

The team usually comes together to develop the details of the research during the application phase.

23	Were you actively involved in discussing the application?	Y/N/Don't know
24	Is working on the application the sort of work you think you should be doing as a patient/caregiver partner on the team?	(Use a 7 point scale) (1) Never --- (7) Definitely
	Comments	_____

If you answered "No" or "Don't know" to question 23, skip the following questions and go to question 31.

25	Was there enough time for you to learn about the project and get to know the other team members prior to submitting the application?	Y/N/Joined after application submitted
26	Were you invited to participate in a strengthening workshop put on by the funder to improve the applications?	Y/N/Not applicable
27	Were you sent copies of the funding application drafts to review?	Y/N

28	Were you involved in the development and wording of the research question?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never --- (7) Definitely
29	Were you asked to draft the Patient Engagement section of the application?	Y/N
30	Is writing parts of the application the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never --- (7) Definitely
	Comments	_____

DEVELOPING THE PROJECT

31	Did you use a Planning Guideline tool to discuss the elements of the project with the researchers on the team?	Y/N
	Comments	_____
32	How involved were you in discussing the planning of the project with the PI or the team members?	<i>(Use a 7 point scale)</i> (1) Not involved --- (7) Highly involved
	Provide details	_____
33	During the planning of the research, did you participate and contribute to the following: <i>(Pick all that apply)</i>	<ul style="list-style-type: none"> • Designing the methodology (the way the research is to be done) • 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

		<p>key people who should get these results (sometimes called Knowledge Translation or KT) stakeholders</p> <ul style="list-style-type: none"> • 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 to you
34	To what degree were you involved in any discussions around the outcomes expected from this research?	<p><i>(Use a 7 point scale)</i></p> <p>(1) Not involved --- (7) Highly involved</p>
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<p><i>(Use a 7 point scale)</i></p> <p>(1) Never --- (7) Definitely</p>
35	Did your research team require the following from you: <i>(Pick all that apply)</i>	<ul style="list-style-type: none"> • Letter of Support from the organization that put you forward as a patient/caregiver partner candidate • Testimonial from you personally • If other, please specify _____
36	Were you required to provide a CIHR CCV? <i>(This is a specialized CV or bio entered into the CIHR - Canadian Institutes of Health Research - website)</i>	Y/N
	If yes, did the team provide help in creating the CCV or do it for you?	Y/N
	Comments	_____

37	Were you required to complete an ethics course? (example: TCPS-2 the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans series of modules)	Y/N
	If yes, comment on your experience	_____
38	Were you required to get or provide proof of an ethics certification? (example: TCPS-2)	Y/N
	If yes, comment on your experience	_____

GETTING STARTED ON THE FUNDED PROJECT

The project formally begins when the funding is granted.

39	Was there enough time for you to learn about the project prior to starting the project?	Y/N
	Comments	_____
40	Was there enough time for you to get to know the other team members prior to starting the project?	Y/N
	Comments	_____
41	Were you provided with the final, accepted funding application?	Y/N

SUPPORTING YOU

42	Were the meetings scheduled with consideration to your schedule and timeframes?	Y/N
43	Does the research team work with you to accommodate for your challenges and ensure that it is easy for you to participate? <i>(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.)</i>	Y/N
	Comments	_____
44	Are you invited to attend in-person meetings when they are out of town?	Y/N
45	If yes, does the team handle all hotel and transportation arrangements for you? <i>(Example: Book and pay for the hotel and your travel in advance)</i>	Y/N
	Comments	_____

COMPENSATION (NOT EXPENSES)

46	Has the team discussed compensation with you?	Y/N
47	What sort of compensation has been offered to you? <i>(Select one)</i>	<ul style="list-style-type: none"> • Gift card • Honoraria or one time payment • Regular salary or regular payments for the duration of the project • Other _____
48	Have you received any compensation yet?	Y/N
	Comments	_____

HANDLING EXPENSES

49	Is managing the expenses an issue for you?	Y/N
	Comments	_____
50	What expenses does the team cover for you? <i>(Select all that apply)</i>	<ul style="list-style-type: none"> • Accommodation for out of town meetings • Meals • Transit/mileage • Parking • Assistance to care for children • Assistance to care for your patients if you are a caregiver • Other _____
	Comments	_____
51	How quickly are your expenses repaid?	<ul style="list-style-type: none"> • On the spot • Within 1 month of submitting the expense claim • Later than one month of submitting the expense claim
	Comments	_____
52	Is the expense repayment timing ok for you?	Y/N
53	Is it necessary to have help with doing your expenses?	Y/N

54	Are you provided with administrative help in managing the expense form and submitting it?	Y/N
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YOUR OVERALL ASSESSMENT

Please let us know what you think of your involvement on this project to date.

55	In your opinion, have your insights and comments impacted the decisions of the team?	<i>(Use a 7 point scale)</i> (1) Never --- (7) Definitely
56	Have you shared your personal experience as a patient/caregiver as part of your role as patient/caregiver partner on this research team?	Y/N
57	What preparation would you have liked to have had prior to partnering on your first research team? <i>(example: information about research in general, your role on the team, information about the specific area of research)</i>	_____
58	If you could start over again as a patient/caregiver partner with this team, what would you do differently? <i>(example: Determine my role with the team at the start, get to know more about my team members)</i>	_____
59	What 3 things do you learn from the experience of partnering with researchers?	* _____ * _____ * _____
60	What 3 things could the research team have done to improve your experience?	* _____ * _____ * _____
61	Did you feel the patient/caregiver partnership was productive and enriched the process and outcome of the research project?	Y/N
	Comments	_____
62	Do you feel you are equipped to contribute to your research project?	Y/N
	Comments	_____

A BIT ABOUT YOURSELF

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

63	You have experience with the healthcare system as: <i>(Pick all that apply)</i>	<ul style="list-style-type: none"> • A patient • A caregiver • Paid healthcare professional in any capacity • Academic health researcher
64	How did you learn about this project? <i>(Select one)</i>	<ul style="list-style-type: none"> • social media/ website • through a friend/ colleague • through an organization • invitation from a researcher • Other _____
65	What made you decide to do this work? <i>(example: I wanted to give back, this area of research affects me personally)</i>	_____

Mid Project Survey

Questions for Patient/Caregiver Partners on Research Teams

Help us to understand your experience of partnering on a research team so we can learn what patient/caregiver 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 your involvement, 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 initial survey based on the unique identifier provided and ask to verify.]

PARTICIPATING ON THE PROJECT

Please verify or update your answers from the previous survey.

1	What is the project or topic name?	_____
2	Including you, how many patient/caregiver partners are on this project at this time? <i>(Do not include patients/caregivers on an advisory panel.)</i>	_____
3	When you started with the team, at what stage was the project? <i>(Select one)</i>	<ul style="list-style-type: none"> • 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 an initial discussion with the Principal Investigator (PI) about your role on the team at the start of the project?	Y/N
5	Do you understand the roles of the other members of the team?	<i>(Use a 7 point scale)</i> (1) Not at all ---(7) Completely
	Comments	_____
6	Has your role changed from how it was defined initially?	Y/N/Not initially defined
	If so, how?	_____

PARTICIPATING ON THE PROJECT TEAM

7	How comfortable do you think you are now with your understanding of the project?	(Use a 7 point scale) (1) Very uncomfortable --- (7) Very comfortable
	Comments	_____
8	Which of the following are you on? (Pick all that apply)	<ul style="list-style-type: none"> • Steering committee • Executive committee • Recruitment committee • Operations committee • Main team • Patient engagement committee • Other _____ • Don't know
9	So we can understand any difficulties you might have, were you able to attend every meeting you were invited to up to now?	Y/N
	Explain any problems you might have had attending meetings	_____
10	How comfortable do you feel speaking up in meetings?	(Use a 7 point scale) (1) Very uncomfortable --- (7) Very comfortable
	Comments	_____
11	If there is more than one patient/caregiver on the team, does that (or would that) make it easier for you to speak up?	Y/N
	Explain	_____
12	So far, do you feel the team listened to and absorbed your input?	Y/N
	Comments	_____
13	Did any of the researchers on the team have problems dealing with patient/caregiver partners?	Y/N
	What was the nature of the problem?	_____
14	If there were problems, how was this handled by the PI?	_____
15	If there were problems, how was this handled by you and the other patient/caregiver partners, if any?	_____

16	Did you or the other patients/caregivers express any concerns to the team about how you were being treated by any members of the team to date?	Y/N
	If so, please describe	_____

PATIENT/CAREGIVER PANEL

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

If you answered "No" to question 17, skip the following questions and go to question 21.

18	Did you or will you help create materials for panelists?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	(Use a 7 point scale) (1) Never --- (7) Definitely
19	Are you helping to recruit patients/caregivers for a panel?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	(Use a 7 point scale) (1) Never --- (7) Definitely
20	Did you or will you help screen the panelists and/or orient them to the project?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	(Use a 7 point scale) (1) Never --- (7) Definitely

CONTRIBUTION TO THE PHASES OF THE RESEARCH

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

If you answered "No" to question 21, skip the following questions and go to question 24.

22	Did you discuss and help decide how patient/caregiver subjects will be communicated with?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	(Use a 7 point scale) (1) Never --- (7) Definitely

23	Did or will you help create materials for patients/caregivers who were subjects of the research?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	(Use a 7 point scale) (1) Never --- (7) Definitely

SUPPORTING YOU

Please verify or update your answers from the previous survey.

24	Were the meetings scheduled with consideration to your schedule and timeframes?	Y/N
25	Does the research team work with you to accommodate for your challenges and ensure that it is easy for you to participate? <i>(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.)</i>	Y/N
	Comments	_____
26	Are you invited to attend in-person meetings when they are out of town?	Y/N
27	If yes, does the team handle all hotel and transportation arrangements for you? <i>(Example: Book and pay for the hotel and your travel in advance)</i>	Y/N
	Comments	_____

HANDLING EXPENSES

Please verify or update your answers from the previous survey.

28	Is managing the expenses an issue for you?	Y/N
	Comments	_____

29	What expenses does the team cover for you? <i>(Pick all that apply)</i>	<ul style="list-style-type: none"> • Accommodation for out of town meetings • Meals • Transit/mileage • Parking • Assistance to care for children • Assistance to care for your patients if you are a caregiver • Other _____
	Comments	_____
30	How quickly are your expenses repaid?	<ul style="list-style-type: none"> • On the spot • Within 1 month of submitting the expense claim • Later than one month of submitting the expense claim
	Comments	_____
31	Is the expense repayment timing ok for you?	Y/N
32	Is it necessary to have help with doing your expenses?	Y/N
33	Are you provided with administrative help in managing the expense form and submitting it?	Y/N

YOUR OVERALL ASSESSMENT

Please let us know what you think of your involvement on this project to date.

34	In your opinion, have your insights and comments impacted the decisions of the team?	<i>(Use a 7 point scale)</i> (1) Not at all --- (7) Definitely
	Comments	_____
35	Have you shared your personal experience as a patient/caregiver as part of your role as patient/caregiver partner on this research team?	Y/N
36	What preparation would you have liked to have had prior to partnering on your first research team? <i>(example: information about research in general, your role on the team, information about the specific area of research)</i>	_____

37	<p>If you could start over again as a patient/caregiver partner with this team, what would you do differently?</p> <p><i>(example: Determine my role with the team at the start, get to know more about my team members)</i></p>	<p>_____</p>
38	<p>What 3 things did you learn so far from the experience of partnering with researchers?</p>	<p>* _____</p> <p>* _____</p> <p>* _____</p>
39	<p>What 3 things could the research team have done to improve your experience?</p>	<p>* _____</p> <p>* _____</p> <p>* _____</p>
40	<p>Did you feel the patient/caregiver partnership was productive and enriched the process and outcome of the research project to date?</p>	<p>Y/N</p>
	<p>Comments</p>	<p>_____</p>
41	<p>Do you feel you are equipped to contribute to your research project?</p>	<p>Y/N</p>
	<p>Comments</p>	<p>_____</p>

End Project Survey

Questions for Patient/Caregiver Partners on Research Teams

Help us to understand your experience of partnering on a research team so we can learn what patient/caregiver 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 your involvement, 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 second mid project survey based on the unique identifier provided and ask to verify.]

PARTICIPATING ON THE PROJECT

Please verify or update your answers from the previous survey.

1	What is the project or topic name?	_____
2	Including you, how many patient/caregiver partners are on this project at this time? <i>(Do not include patients/caregivers on an advisory panel.)</i>	_____
3	When you started with the team, at what stage was the project? <i>(Select one)</i>	<ul style="list-style-type: none"> • 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 an initial discussion with the Principal Investigator (PI) about your role on the team at the start of the project?	Y/N
5	Do you understand the roles of the other members of the team?	<i>(Use a 7 point scale)</i> (1) Not at all ---(7) Completely
	Comments	_____
6	Has your role changed from how it was defined initially?	Y/N
	If so, how?	_____

PARTICIPATING ON THE PROJECT TEAM

Please verify or update your answers from the previous survey.

7	How comfortable do you think you are now with your understanding of the project?	(Use a 7 point scale) (1) Very uncomfortable -- -(7) Very comfortable
	Comments	_____
8	Which of the following are you on? (Pick all that apply)	<ul style="list-style-type: none"> • Steering committee • Executive committee • Recruitment committee • Operations committee • Main team • Patient engagement committee • Other _____ • Don't know
	If there are changes, explain	_____
9	So we can understand any difficulties you might have, were you able to attend every meeting you were invited to up to now?	Y/N
	Explain any problems you might have had attending meetings	_____
10	How comfortable did you feel speaking up in meetings?	(Use a 7 point scale) (1) Very uncomfortable -- - (7) Very comfortable
	Comments	_____
11	If there is more than one patient/caregiver on the team, does that (or would that) make it easier for you to speak up?	Y/N
	Explain	_____
12	Do you feel the team listened to and absorbed your input?	Y/N
	Comments	_____
13	Did any of the researchers on the team have problems dealing with patient/caregiver partners?	Y/N
	What was the nature of the problem?	_____
14	If there were problems, how was this handled by the PI?	_____
15	If there were problems, how was this handled by you and the other patient/caregiver partners, if any?	_____

16	Did you or the other patients/caregivers express any concerns to the team about how you were being treated by any members of the team?	Y/N
	If so, please describe	_____

CONTRIBUTION TO THE PHASES OF THE RESEARCH

17	Did you review and discuss the findings of the research prior to the final report?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never ---(7) Definitely

If you answered "No" to question 17, skip the following questions and go to question 20.

18	How comfortable were you reviewing and providing comments on the findings of the research?	<i>(Use a 7 point scale)</i> (1) Very uncomfortable --- (7) Very comfortable
	Comments	_____
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never ---(7) Definitely
19	Did your comments affect the final outcome of report?	Y/N

SPREADING THE KNOWLEDGE

20	Did you or will you co-present the results of the research or your perspective on the research by being on panels and speaking at conferences?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never ---(7) Definitely
21	Did or will you co-author a "lay" report about the research?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never ---(7) Definitely
22	Were you asked to use your contacts to send the results of the research to a wider audience?	Y/N
	Is this the sort of work you think you should be doing as a patient/caregiver partner on the team?	<i>(Use a 7 point scale)</i> (1) Never ---(7) Definitely
23	Describe any other activity that you participated in?	_____

SUPPORTING YOU

Please verify or update your answers from the previous survey.

24	Were the meetings scheduled with consideration to your schedule and timeframes?	Y/N
25	Does the research team work with you to accommodate for your challenges and ensure that it is easy for you to participate? <i>(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.)</i>	Y/N
	Comments	_____
26	Are you invited to attend in-person meetings when they are out of town?	Y/N
27	If yes, does the team handle all hotel and transportation arrangements for you? <i>(Example: Book and pay for the hotel and your travel in advance)</i>	Y/N
	Comments	_____

HANDLING EXPENSES

Please verify or update your answers from the previous survey.

28	Is managing the expenses an issue for you?	Y/N
	Comments	_____
29	What expenses does the team cover for you? <i>(Select all that apply)</i>	<ul style="list-style-type: none"> • Accommodation for out of town meetings • Meals • Transit/mileage • Parking • Assistance to care for children • Assistance to care for your patients if you are a caregiver • Other <p>_____</p>
	Comments	_____

30	How quickly are your expenses repaid?	<ul style="list-style-type: none"> • On the spot • Within 1 month of submitting the expense claim • Later than one month of submitting the expense claim
	Comments	_____
31	Is the expense repayment timing ok for you?	Y/N
32	Is it necessary to have help with doing your expenses?	Y/N
33	Are you provided with administrative help in managing the expense form and submitting it?	Y/N

YOUR OVERALL ASSESSMENT

Please let us know what you think of your involvement on this project to date.

34	In your opinion, have your insights and comments impacted the decisions of the team?	<i>(Use a 7 point scale)</i> (1) Never --- (7) Definitely
35	Have you shared your personal experience as a patient/caregiver as part of your role as patient/caregiver partner on this research team?	Y/N
36	What preparation would you have liked to have had prior to partnering on your first research team? <i>(example: information about research in general, your role on the team, information about the specific area of research)</i>	_____
37	If you could start over again as a patient/caregiver partner with this team, what would you do differently? <i>(example: Determine my role with the team at the start, get to know more about my team members)</i>	_____
38	What 3 things did you learn from the experience of partnering with researchers?	* _____ * _____ * _____
39	What 3 things could the research team have done to improve your experience?	* _____ * _____ * _____

40	Did you feel the patient/caregiver partnership was productive and enriched the process and outcome of the research project?	Y/N
	Comments	Y/N
41	Do you feel you are equipped to contribute to your research project?	_____
	Comments	
41	Where do you think your involvement mattered the most?	_____
43	Do you have any concerns about partnering with researchers at this point?	_____
	If so, what are they?	_____
	Comments	_____