

Supplemental Appendix S1

Following this page are the pdf versions of the three surveys used in the study. The Informed Consent information page for each is included as they are part of the qualification process. Skip logic and addition landing pages previously embedded in the live survey versions, to deliver ineligible or declining participants to appropriate disqualification or Thank You pages, have been removed.

Research Participant Perception Survey –Ultrashort (RPPS-U)

Research Participant Perception Survey –Short (RPPS-S)

Research Participant Perception Survey –Long (RPPS-L)

**Research Participant Perception Survey –Long (RPPS-L) Broadcast
Spanish version**

Research Participant Experience Survey - U

Research Participant Experience Survey -- Informed Consent Information

Welcome! This page provides information you may want in order to decide whether to join this research study.

1. The survey that follows is part of a research study conducted by Dr. Rhonda Kost at The Rockefeller University.
2. The purpose of the research is to understand research participants' experiences.
3. Participation involves completing the survey.

The survey asks about you and your most recent research experience.

It will take 3 - 5 minutes to complete the survey. In order for your answers to be saved, you have to click "Done" at the end of the survey. Plan to complete the survey in one sitting.

About 10% of people who join the study will be offered the survey again, within 2 weeks, to test its reliability. Re-taking the survey is optional.

4. There are no direct benefits to you. However, the survey results may help to improve the research participation experience at research centers across the country. We plan to share a summary of the study results on the www.RUCARES.org website by the end of 2015.
5. We will do our best to protect your information, but there is always a small risk of loss of confidentiality. To further minimize the risk:

We do NOT ask for any details about your prior research studies, doctors, hospitals, or any diagnoses.

Only the investigator (Dr. Kost) will know your name and email link provided by ResearchMatch, and we will destroy that information after the survey responses are collected.

We will NOT reveal any individual survey response in our publications.

The survey is hosted on the on-line site: SurveyMonkey; SurveyMonkey is forbidden from using your email for any other purpose.

Research Participant Experience Survey - U

6. Your participation is voluntary and you can change your mind. Your answers will not be recorded until you click "Done" at the end of the survey. There is no compensation for completing the survey.

QUALIFICATION QUESTION: Have you participated in a research study in the past two years? (It does not matter whether you completed, withdrew, or are still enrolled in the study, as long as it involved more than an on-line survey).

Yes

No

Research Participant Experience Survey - U

Consent to participate

Proceed to the survey?

- Yes, I would like to participate in the research by completing the survey
- No, I decline the survey. (One more question follows, About your information...)

Research Participant Experience Survey - U

Enter the Survey

Please answer the questions below regarding the research study you enrolled in within the past two years. If you enrolled in more than one study, answer for the most recent study.

When the survey questions refer to "the study," we are asking about your experiences enrolled in that clinical research study, not this online survey study.

Would you recommend joining a research study to your family and friends?

- Definitely no
- Probably no
- Probably yes
- Definitely yes

Did the Informed consent form prepare you for what to expect during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Did the research team members listen carefully to you?

- Never
- Sometimes
- Usually
- Always

Research Participant Experience Survey - U

Did the research team members treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always

When you were not at the research site did you know how to reach the research team if you had a question?

- Never
- Sometimes
- Usually
- Always

When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- Never
- Sometimes
- Usually
- Always
- Did not need to reach the research team

Please use the scale below to rate your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.

- 0 worst
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 best

Research Participant Experience Survey - U

What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

What is your age?

- 18-34
- 35-44
- 45-54
- 55-64
- 65 and over

What is your race? (Please choose one or more)

- Asian
- American Indian or Alaska Native
- Black or African American
- Native Hawaiian or other Pacific Islander
- White

Are you of Spanish or Hispanic or Latino origin or descent?

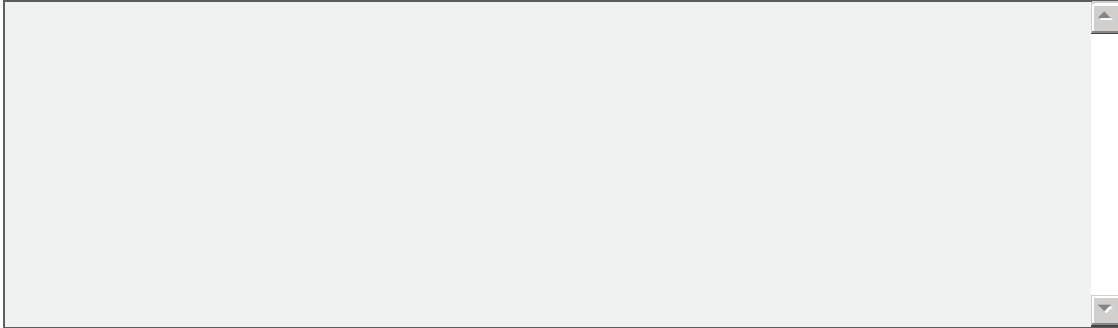
- No, not Spanish/Hispanic/Latino
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino

What is your sex/gender?

- Female
- Male
- Transgender or other

Research Participant Experience Survey - U

Is there anything else you would like to share about your experience in the study you most recently joined?



Research Participant Experience Survey - U

Thank you for completing the survey.

Thank you for your interest and the investment of your time. Your responses will help us to improve the research experience for participants.

Research Participant Perception Survey - S

Research Participant Experience Survey -- Informed Consent Information

Welcome! This page provides information you may want in order to decide whether to join this research study.

1. The survey that follows is part of a research study conducted by Dr. Rhonda Kost at The Rockefeller University.
2. The purpose of the research is to understand research participants' experiences.
3. Participation involves completing the survey.

The survey asks about you and your most recent research experience.

It will take 5-10 minutes to complete the survey. In order for your answers to be saved, you have to click "Done" at the end of the survey. Plan to complete the survey in one sitting.

About 10% of people who join the study will be offered the survey again, within 2 weeks, to test its reliability. Re-taking the survey is optional.

4. There are no direct benefits to you. However, the survey results may help to improve the research participation experience at research centers across the country. We plan to share a summary of the study results on the www.RUCARES.org website by the end of 2015.
5. We will do our best to protect your information, but there is always a small risk of loss of confidentiality. To further minimize the risk:

We do NOT ask for any details about your prior research studies, doctors, hospitals, or any diagnoses.

Only the investigator (Dr. Kost) will know your name and email link provided by ResearchMatch, and we will destroy that information after the survey responses are collected.

We will NOT reveal any individual survey response in our publications.

The survey is hosted on the on-line site: SurveyMonkey; SurveyMonkey is forbidden from using your email for any other purpose.

Research Participant Perception Survey - S

6. Your participation is voluntary and you can change your mind. Your answers will not be recorded until you click "Done" at the end of the survey. There is no compensation for completing the survey.

QUALIFICATION QUESTION: Have you participated in a research study in the past two years? (It does not matter whether you completed, withdrew, or are still enrolled in the study, as long as it involved more than an on-line survey).

Yes

No

Research Participant Perception Survey - S

Consent to participate

Proceed to the survey?

- Yes, I would like to participate in the research by completing the survey.
- No, I decline the survey. (One more question follows, About your information....)

Research Participant Perception Survey - S

Enter the Survey

Please answer the questions below regarding the research study you enrolled in within the past two years. If you enrolled in more than one study, answer for the most recent study.

When the survey questions refer to "the study," we are asking about your experiences enrolled in that clinical research study, not this online survey study.

Would you recommend joining a research study to your family and friends?

- Definitely no
- Probably no
- Probably yes
- Definitely yes

Research Participant Perception Survey - S

Below is a list of possible reasons for joining a research study. When you considered joining the study, how important were these reasons for you?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did the study require that you already have a disease or condition in order to enroll?

- Yes
 No

Research Participant Perception Survey - S

Did the study involve taking a drug or a supplement or the use of a new medical device, or undergoing a new medical procedure?

- Yes
- No
- Not sure

Did the Informed consent form prepare you for what to expect during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Did the research team members listen carefully to you?

- Never
- Sometimes
- Usually
- Always

Did the research team members treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always

Research Participant Perception Survey - S

During your discussion about the study, did you feel pressure from the research staff to join the study?

- Never
- Sometimes
- Usually
- Always

When you were not at the research site did you know how to reach the research team if you had a question?

- Never
- Sometimes
- Usually
- Always

When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- Never
- Sometimes
- Usually
- Always
- Did not need to reach the research team

Did you feel you were a valued partner in the research process?

- Never
- Sometimes
- Usually
- Always

If you considered leaving the study, did you feel pressure from the Research Team to stay?

- Never
- Sometimes
- Usually
- Always
- Did not consider leaving the study

Research Participant Perception Survey - S

Below is a list of possible reasons for leaving a research study. How important were the reasons for you in considering leaving the study?

	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about risks of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invasion of privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Too much time spent waiting around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time commitment required	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/work issues unrelated to the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions with research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not getting test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undue pressure to stay in study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with study payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected tests and procedures that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation/parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Research Participant Perception Survey - S

Please use the scale below to rate your overall experience in the research study, where 0 is the worst possible experience, and 10 is the best possible experience.

- 0 worst
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 best

Research Participant Perception Survey - S

Below is a list of possible reasons for staying in a research study. How important were these reasons for you in staying in the research study?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my relationship with the research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling valued as a research participant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved health or quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Research Participant Perception Survey - S

How much did the study demand of you? (Pick the answer that most closely describes your experience)

- 1. Simple (for example: a few visits or simple tests or surveys)
- 2. Moderate (for example: multiple visits or a short inpatient stay; only a few procedures, not risky or intense)
- 3. Intense (for example: long or multiple inpatient stays or many visits; procedure(s) that are intense, risky, or complex)

Which of the following things would be important for you in a future study?

- Access to computer, internet, and television
- Access to comfortable bed
- Payment/More Payment
- Support groups
- Volunteer appreciation
- Flexible Schedule
- Accessible parking and study location
- Planned discharge and proper goodbye to research team
- Summary of overall research results shared with me
- Results of personal lab tests shared with me or my doctor
- Other (please specify)

What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

Research Participant Perception Survey - S

What is your age?

- 18-34
- 35-44
- 45-54
- 55-64
- 65 and over

What is your race? (Please choose one or more)

- Asian
- American Indian or Alaska Native
- Black or African American
- Native Hawaiian or other Pacific Islander
- White

Are you of Spanish or Hispanic or Latino origin or descent?

- No, not Spanish/Hispanic/Latino
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino

What is your sex/gender?

- Female
- Male
- Transgender or other

Is there anything else you would like to share about your experience in the study you most recently joined?

Research Participant Perception Survey - S

Thank you for completing the survey.

Thank you for your interest and the investment of your time. Your responses will help us to improve the research experience for participants.

Research Participant Perception Survey - L

Research Participant Experience Survey -- Informed Consent Information

Welcome! This page provides information you may want in order to decide whether to join this research study.

1. The survey that follows is part of a research study conducted by Dr. Rhonda Kost at The Rockefeller University.
2. The purpose of the research is to understand research participants' experiences.
3. Participation involves completing the survey.

The survey asks about you and your most recent research experience.

It will take 20-30 minutes to complete the survey. In order for your answers to be saved, you have to click "Done" at the end of the survey. If you leave the survey before completing it, your responses will be lost, however the link will let you return to start the survey again. You should begin the survey when you anticipate having enough time to complete it in one sitting.

About 10% of people who join the study will be offered the survey again, within 2 weeks, to test its reliability. Re-taking the survey is optional.

4. There are no direct benefits to you. However, the survey results may help to improve the research participation experience at research centers across the country. We plan to share a summary of the study results on the www.RUCARES.org website by the end of 2015.

5. We will do our best to protect your information, but there is always a small risk of loss of confidentiality. To further minimize the risk:

We do NOT ask for any details about your prior research studies, doctors, hospitals, or any diagnoses.

Only the investigator (Dr. Kost) will know your name and email link provided by ResearchMatch, and we will destroy that information after the survey responses are collected.

We will NOT reveal any individual survey response in our publications.

The survey is hosted on the on-line site: SurveyMonkey; SurveyMonkey is

Research Participant Perception Survey - L

forbidden from using your email for any other purpose.

6. Your participation is voluntary and you can change your mind. Your answers will not be recorded until you click "Done" at the end of the survey. There is no compensation for completing the survey.

QUALIFICATION QUESTION: Have you participated in a research study in the past two years? (It does not matter whether you completed, withdrew, or are still enrolled in the study, as long as it involved more than an on-line survey).

Yes

No

Research Participant Perception Survey - L

Consent to participate

Proceed to the survey?

- Yes, I would like to participate in the research by completing the survey.
- No, I decline the survey. (One more question follows, About your information....)

Research Participant Perception Survey - L

Enter the Survey

Please answer the questions below regarding the research study you enrolled in within the past two years. (If you enrolled in more than one, answer for the most recent study)

RECRUITMENT

How did you find out about the research study? (Please select the one most important response option)

- Primary Care Doctor
- Specialty Doctor
- Nurse - non-research
- Research Nurse or coordinator
- Research Investigator
- Other healthcare professionals
- Media - flyer, newspaper, tv, radio
- Internet, websites, email
- Recruiting Center
- Word of Mouth
- Do not know

Other (please specify)

Is it easy for you to find out about research studies at your center/site?

- Never
- Sometimes
- Usually
- Always

Research Participant Perception Survey - L

Below is a list of possible reasons for joining a research study. When you considered joining the study, how important were these reasons for you?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

IN YOUR DISCUSSIONS ABOUT THE STUDY.....

Research Participant Perception Survey - L

Was the study explained to you in a way that you knew what you were being asked to do as a research subject?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Did you understand which tests/visits/procedures were regular medical care and which were for research?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- No regular medical care

Did someone take the time to answer all of your questions about the research study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- I did not have any questions
- Did not feel comfortable asking questions

Were the details about the research study described in a way that you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

Research Participant Perception Survey - L

Did someone explain the risks and benefits of joining the study in a way that you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

In explaining the same study, did staff members over give you conflicting information?

- Never
- Sometimes
- Usually
- Always
- Do not remember

WHEN THE RESEARCH TEAM WENT OVER THE FORMS DESCRIBING THE STUDY.....

Were the details about the study included in the informed consent form?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

Were the risks and benefits of joining the study included in the informed consent form?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

Research Participant Perception Survey - L

Was the informed consent form written in a way that you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

During your discussion about the study, did you feel pressure from the research staff to join the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

After the study was explained to you, did you have enough time to think about your decision before signing the informed consent form?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Did the Informed consent form prepare you for what to expect during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Was there one particular person organizing your involvement in the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not remember

Research Participant Perception Survey - L

How often was the research team ready and on time for your visit?

- Never
- Sometimes
- Usually
- Always

Did you ever have to wait too long for your study/visit procedures to begin?

- Never
- Sometimes
- Usually
- Always

Did you have to wait too long between procedures or tests at any of your visits?

- Never
- Sometimes
- Usually
- Always
- Only had one procedure or test during my visits

Did someone explain the reasons for any delays during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Did not have delays

Did you want to receive the results of any of your routine tests?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Did not have routine tests

Research Participant Perception Survey - L

Did you have enough physical privacy while you were in the study?

- Never
- Sometimes
- Usually
- Always

Did you feel that your personal and research information was handled in a way that protected it?

- Never
- Sometimes
- Usually
- Always

Were you ever concerned about your safety and health during the study?

- Never
- Sometimes
- Usually
- Always

During the informed consent process, did someone explain the pain or discomfort you might feel during the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- No pain expected

Did you experience pain or discomfort which you had not expected related to the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Research Participant Perception Survey - L

Was there anything that happened to you during the study, that you had not been prepared for in advance?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Do not know

Did you ever consider leaving the study?

- No
- Yes, briefly
- Yes, a great deal
- Yes, I left the study

Research Participant Perception Survey - L

Below is a list of possible reasons for leaving a research study. How important were the reasons for you in considering leaving the study?

	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worried about risks of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Side effects that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Invasion of privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Too much time spent waiting around	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Time commitment required	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family/work issues unrelated to the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interactions with research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not getting test results	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Undue pressure to stay in study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problems with study payments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected tests and procedures that occurred during the study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transportation/parking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Research Participant Perception Survey - L

Below is a list of possible reasons for staying in a research study. How important were these reasons for you in staying in the research study?

	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because no other medical options were available	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To gain access to new treatment/therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain free healthcare	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To help others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of the Research/Health Center's reputation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because I am concerned about the topic of study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To obtain education and learning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of a positive experience in another study	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of family influence/involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
To earn money/payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because my caregiver encouraged me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my relationship with the research team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling valued as a research participant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Improved health or quality of life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other reasons	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

RESEARCH COORDINATOR / RESEARCH NURSES

Research Participant Perception Survey - L

Did the research coordinator or research nurse listen carefully to you?

- Never
- Sometimes
- Usually
- Always
- No research coordinator/nurse involved

Did the research coordinator or research nurse treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always
- No research coordinator/nurse involved

Did the research coordinator or research nurse answer your questions in a way you could understand?

- Never
- Sometimes
- Usually
- Always
- No research coordinator/nurse involved

Did you have confidence and trust in the research coordinator or research nurse?

- Never
- Sometimes
- Usually
- Always
- No research coordinator/nurse involved

RESEARCH DOCTORS/INVESTIGATORS.....

Research Participant Perception Survey - L

Did the research doctor or investigator listen carefully to you?

- Never
- Sometimes
- Usually
- Always
- No research doctor/investigator involved

Did the research doctor or investigator treat you with courtesy and respect?

- Never
- Sometimes
- Usually
- Always
- No research doctor/investigator involved

Did the research doctor or investigator answer your questions in a way you could understand?

- Never
- Sometimes
- Usually
- Always
- No research doctor/investigator involved

Did you have confidence and trust in the research doctor or investigator leading the study?

- Never
- Sometimes
- Usually
- Always
- No research doctor/investigator involved

Research Participant Perception Survey - L

Did you meet with the research doctor or investigator as much as you wanted?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- No research doctor/investigator involved

RESEARCH TEAM OVERALL

During the course of the study, was it easy to get answers to your questions from the research team?

- Never
- Sometimes
- Usually
- Always
- Did not have questions during study

When you were not at the research site, did you know how to reach the research team if you had a question?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

When you were not at the research site and you needed to reach a member of the research team, were you able to reach him/her as soon as you wanted?

- Never
- Sometimes
- Usually
- Always
- Did not need the research team
- Did not know how to reach the research team

Research Participant Perception Survey - L

Did you feel you were a valued partner in the research process?

- Never
- Sometimes
- Usually
- Always

Did the research staff respect your cultural background (e.g. language, religion, ethnic group)?

- Never
- Sometimes
- Usually
- Always
- No cultural issues

Did research staff do everything possible to provide assistance with any language differences you might have?

- Never
- Sometimes
- Usually
- Always
- No language differences

Did research staff help with any disabilities you have (e.g., use of wheelchair or walker, use of hearing aid, etc)?

- Never
- Sometimes
- Usually
- Always
- No disabilities

Research Participant Perception Survey - L

Did the research team involve your family as much as you wanted them to?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- No family members were involved

Was important medical information shared with your primary care doctor?

- No
- Yes
- No information to share
- Do not know

If your study divided participants into groups, after the study was over were you told which group you were in?

- No
- Yes
- No groups
- Do not know
- Study not over yet
- Did not complete study

Would you have liked to receive a summary of the results of the study?

- No
- Yes
- Received a summary of the study

Did the research team share a summary of the results of the study?

- No
- Yes
- Study not over yet

Research Participant Perception Survey - L

Was the summary of the results of the study written in a way you could understand?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely
- Did not receive a summary of the results

After the study was over, did you WANT to have more contact with the research team?

- Yes
- No
- Study not over yet
- Did not complete study

After the study was over, did you want to be contacted to be in other research studies?

- Yes
- No
- Study not over yet
- Did not complete study

Which of the following things would be important for you in a future study? Check all that apply.

- Access to computer, internet, and television
- Access to comfortable bed
- Payment/More Payment
- Support groups
- Volunteer appreciation
- Flexible Schedule
- Accessible parking and study location
- Planned discharge and proper goodbye to research team
- Summary of overall research results shared with me
- Results of personal lab tests shared with me or my doctor
- Other - please specify

Other (please specify)

Research Participant Perception Survey - L

Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

If you wanted to leave the study, do you think you would have been allowed to do so?

- No
- Yes

If you considered leaving the study, did you feel pressure from the Research Team to stay?

- No
- Yes, somewhat
- Yes, mostly
- Yes, completely

Were you ever told that you could stop being in the study, at any time, and for any reason?

- No
- Yes

Research Participant Perception Survey - L

Please use the scale below to rate your overall experience in the research study, where 0 is the WORST possible experience and 10 is the BEST possible experience.

- 0 Worst
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 Best

Would you recommend joining a research study to your family and friends?

- Definitely no
- Probably no
- Probably yes
- Definitely yes

Did the study require that you already have a disease or condition in order to enroll?

- Yes
- No

Did the study involve taking a drug or a supplement OR the use of a new medical device OR undergoing a new medical procedure?

- Yes
- No
- Not sure

Research Participant Perception Survey - L

How much did the study demand of you? Pick the answer that most closely describes your experience.

- Simple (for example: a few visits or simple tests or surveys)
- Moderate (for example: multiple visits or short inpatient stay; only a few procedures, not risky or intense)
- Intense (for example: longer or multiple inpatient stays or many visits; procedure(s) that are intense, risky or complex)

How long did you participate in the study from start to finish? If you left the study before it was finished, or are still participating, answer for the total span of time you were/have been in the study.

- Hours
- Days or Weeks
- Months
- Years

In general, how would you rate your overall health?

- Excellent
- Very Good
- Good
- Fair
- Poor

How many studies have you ever joined?

- 1
- 2 to 5
- 6 to 10
- More than 10

What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

Research Participant Perception Survey - L

What is your age?

- 18-34
- 35-44
- 45-54
- 55-64
- 65 and over

What is your race? Please choose one or more.

- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native

Are you of Spanish, Hispanic or Latino origin or descent?

- No, not Spanish/Hispanic/Latino
- Yes, Puerto Rican
- Yes, Mexican, Mexican American, Chicano
- Yes, Cuban
- Yes, other Spanish/Hispanic/Latino

What language do you mainly speak at home?

- English
- Spanish
- Chinese
- Russian
- Vietnamese
- Some other language

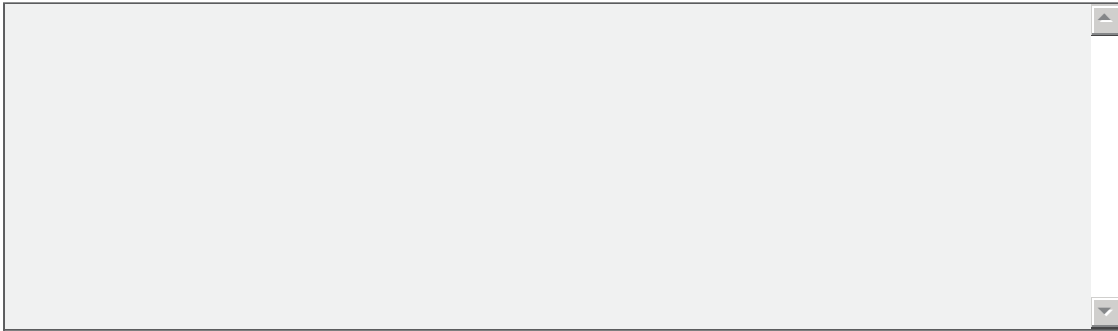
Other (please print)

Research Participant Perception Survey - L

What is your sex/gender?

- Female
- Male
- Transgender or other

Is there anything else you would like to share about your experience in the study you most recently joined?



Research Participant Perception Survey - L

Thank you for completing the survey.

Thank for your interest and the investment of your time. Your responses will help us to improve the research experience for participants.

Por favor, conteste estas preguntas sobre el estudio de investigación más reciente en el que ha participado. En este cuestionario, "lugar/centro de investigación" se refiere a la clínica o universidad en la que tuvo lugar su estudio de investigación.

Reclutamiento...

1. ¿Cómo se enteró del estudio de investigación? (Seleccione la respuesta más importante.)³⁸⁸⁶⁰

- ① Médico de atención primaria
- ② Médico especialista
- ③ Enfermera - no de investigación
- ④ Enfermera o coordinador de investigación
- ⑤ Investigador
- ⑥ Otros profesionales de atención médica
- ⑦ Medios de comunicación - folleto, periódico, tv, radio
- ⑧ Internet, sitios Web, email
- ⑨ Centro de reclutamiento
- ⑩ Por terceros
- ⑪ Otro, especifique, por favor

2. ¿Le resulta fácil a usted encontrar información sobre estudios de investigación en Alpha Hospital?³⁸⁸⁶¹

- ① Nunca
- ② A veces
- ③ Normalmente
- ④ Siempre

3. A continuación encontrará una lista de posibles motivos para participar en un estudio de investigación. Cuando se incorporó a este estudio, ¿cuán importantes eran estos motivos para usted?¹⁶⁶⁰

	1-Muy importante	2-Un poco importante	3-No muy importante	4-Nada importante
a. Para conocer más sobre mi enfermedad ³⁸⁸⁶²	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
b. Porque no había otras opciones médicas disponibles ³⁸⁹⁹⁶	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
c. Para lograr acceso a un nuevo tratamiento o terapia ³⁸⁹⁹⁷	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
d. Para recibir atención médica gratuita ³⁸⁹⁹⁸	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
e. Para ayudar a otras personas ³⁸⁹⁹⁹	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
f. Por la reputación del centro de salud/investigación ³⁹⁰⁰⁰	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
g. Porque me preocupa el tema del estudio ³⁹⁰⁰¹	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
h. Para educarme y aprender ³⁹⁰⁰²	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
i. Por una experiencia positiva que tuve con otro estudio ³⁹⁰⁰³	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
j. Por influencia/participación de la familia ³⁹⁰⁰⁴	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
k. Para recibir dinero/compensación económica ³⁹⁰⁰⁵	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④
l. Porque me animó la persona que me cuida ³⁹⁰⁰⁶	<input type="radio"/> ①	<input type="radio"/> ②	<input type="radio"/> ③	<input type="radio"/> ④



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3. A continuación encontrará una lista de posibles motivos para participar en un estudio de investigación. Cuando se incorporó a este estudio, ¿cuán importantes eran estos motivos para usted?¹⁶⁶⁰

1-Muy importante 2-Un poco importante 3-No muy importante 4-Nada importante

m. Por otros motivos³⁹⁰⁰⁷

① ② ③ ④

En sus discusiones sobre el estudio...

4. ¿Le explicaron el estudio de manera que usted sabía lo que le pedían que hiciera como sujeto de investigación?³⁸⁸⁶³
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente
5. ¿Entendía usted qué pruebas/visitas/procedimientos eran parte regular de la atención médica y cuáles eran para la investigación?³⁹⁸⁸⁰
① No ③ Sí, en general ⑤ No recibí atención médica regular
② Sí, un poco ④ Sí, completamente
6. ¿Alguna persona se tomó el tiempo de contestar a todas sus preguntas sobre el estudio de investigación?³⁸⁸⁶⁴
① No ③ Sí, en general ⑤ No tuve preguntas
② Sí, un poco ④ Sí, completamente ⑥ No me sentía cómodo haciendo preguntas
7. ¿Le describieron los detalles sobre el estudio de investigación de manera que usted pudiera entenderlos?³⁸⁸⁶⁵
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No recuerdo
8. ¿Alguien le explicó los riesgos y beneficios de participar en el estudio de manera que usted pudiera entenderlos?³⁸⁸⁶⁶
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No recuerdo
9. Al explicarle el mismo estudio, ¿los miembros del personal le dieron alguna vez información contradictoria?³⁸⁸⁶⁷
① Nunca ② A veces ③ La mayoría de las veces ④ Siempre ⑤ No recuerdo

Cuando el equipo de investigación repasó los impresos que describían el estudio...

10. ¿Los detalles del estudio estaban incluidos en el documento de consentimiento informado?³⁸⁸⁶⁸
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No recuerdo
11. ¿Los riesgos y beneficios de participar en el estudio estaban incluidos en el documento de consentimiento informado?³⁸⁸⁶⁹
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No recuerdo
12. ¿El documento de consentimiento informado estaba escrito de manera que usted pudiera entenderlo?³⁸⁸⁷⁰
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No recuerdo
13. Al discutir el estudio, ¿sintió usted que el personal de investigación le presionara para participar en el mismo?³⁸⁸⁷¹
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente
14. Cuando le explicaron el estudio, ¿tuvo bastante tiempo para pensar su decisión antes de firmar el documento de consentimiento informado?³⁸⁸⁷²
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente
15. ¿El documento de consentimiento informado le preparó sobre qué esperar durante el estudio?³⁸⁸⁷³
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente

Durante el estudio...

16. ¿Había alguna persona en particular que organizara su participación en el estudio?³⁸⁸⁷⁴
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente
17. ¿Con qué frecuencia estaba listo a tiempo el equipo de investigación en sus visitas?³⁸⁸⁷⁵
① Nunca ② A veces ③ Normalmente ④ Siempre



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18. ¿Alguna vez tuvo que esperar demasiado tiempo para que empezaran sus visitas/procedimientos de estudio?³⁸⁸⁷⁶

- ① Nunca ② A veces ③ Normalmente ④ Siempre

19. ¿Alguna vez tuvo que esperar demasiado tiempo entre procedimientos y pruebas en alguna de sus visitas?³⁸⁸⁷⁷

- ① Nunca ④ Siempre
② A veces ⑤ Sólo me hicieron un procedimiento o prueba en mis visitas
③ La mayoría de las veces

20. ¿Alguna persona le explicó el motivo de las demoras durante el estudio?³⁸⁸⁷⁸

- ① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No hubo demoras

21. ¿Quería recibir usted el resultado de alguna de sus pruebas de rutina?³⁸⁸⁸⁰

- ① No ③ Sí, en general ⑤ No me hicieron pruebas de rutina
② Sí, un poco ④ Sí, completamente

22. ¿Tuvo suficiente privacidad física mientras participó en el estudio?³⁸⁸⁸¹

- ① Nunca ② A veces ③ Normalmente ④ Siempre

23. ¿Sentía usted que manejaban su información personal y la información sobre la investigación de manera protegida?³⁹²⁹³

- ① Nunca ② A veces ③ Normalmente ④ Siempre

24. ¿Se preocupó alguna vez por su seguridad y su salud durante el estudio?³⁸⁸⁸²

- ① Nunca ② A veces ③ Normalmente ④ Siempre

25. Durante el proceso del consentimiento informado, ¿le explicó alguien el dolor o la incomodidad que podría sentir durante el estudio?³⁸⁸⁸⁴

- ① No ③ Sí, en general ⑤ No esperaba sentir dolor
② Sí, un poco ④ Sí, completamente

26. ¿Experimentó usted algún dolor o incomodidad que no esperara en relación con el estudio?³⁸⁸⁸³

- ① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente

27. ¿Le pasó algo durante el estudio para lo que no hubiera estado preparado con antelación?³⁸⁸⁸⁵

- ① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente ⑤ No sé

28. ¿Consideró alguna vez abandonar el estudio?³⁸⁸⁸⁶

- ① No ② Sí, por un tiempo ③ Sí, mucho ④ Sí, abandoné el estudio

29. A continuación encontrará una lista de posibles motivos para abandonar un estudio de investigación. ¿Cuán importantes fueron para usted estos motivos al considerar abandonar el estudio?¹⁶⁴⁵

1-Muy importante 2-Un poco importante 3-No muy importante 4-Nada importante

a. El dolor o la incomodidad relacionados con la participación³⁸⁸⁸⁷

- ① ② ③ ④

b. Riesgos o efectos secundarios de tratamiento³⁹⁰⁰⁸

- ① ② ③ ④

c. Efectos secundarios que surgieron durante el estudio³⁹⁰⁰⁹

- ① ② ③ ④

d. La invasión de la privacidad³⁹⁸⁸¹

- ① ② ③ ④

e. Había que estar esperando demasiado tiempo³⁹⁰¹⁰

- ① ② ③ ④

f. El tiempo de dedicación necesario³⁹⁰¹¹

- ① ② ③ ④

g. Problemas familiares/de trabajo que no estaban relacionados con el estudio³⁹⁰¹²

- ① ② ③ ④



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32. ¿Le trataban con cortesía y respeto el coordinador o la enfermera de la investigación?³⁸⁸⁹⁰

- 1 Nunca 4 Siempre
 2 A veces 5 No había coordinador/enfermera de la investigación
 3 La mayoría de las veces

33. ¿El coordinador o la enfermera de la investigación respondían a sus preguntas de manera que usted pudiera entenderlos?³⁸⁸⁹¹

- 1 Nunca 4 Siempre
 2 A veces 5 No había coordinador/enfermera de la investigación
 3 La mayoría de las veces

34. ¿Tenía confianza en el coordinador o la enfermera de la investigación?³⁸⁸⁹²

- 1 Nunca 4 Siempre
 2 A veces 5 No había coordinador/enfermera de la investigación
 3 La mayoría de las veces

35. Si usted tenía alguna ansiedad o temor sobre su participación en el estudio, ¿hablaron con usted sobre esas cosas el coordinador o la enfermera de la investigación?³⁸⁸⁹³

- 1 Nunca 4 Siempre
 2 A veces 5 No tuve ansiedad ni temores
 3 La mayoría de las veces 6 No había coordinador/enfermera de la investigación

Investigadores/Doctores de la investigación...

36. ¿Le escuchaban con atención el investigador o el doctor de la investigación?³⁸⁸⁹⁴

- 1 Nunca 3 La mayoría de las veces 5 No había investigador/doctor de la investigación
 2 A veces 4 Siempre

37. ¿Le trataban con cortesía y respeto el investigador o el doctor de la investigación?³⁸⁸⁹⁵

- 1 Nunca 3 La mayoría de las veces 5 No había investigador/doctor de la investigación
 2 A veces 4 Siempre

38. ¿El investigador o el doctor de la investigación respondían a sus preguntas de manera que usted pudiera entenderlos?³⁸⁸⁹⁶

- 1 Nunca 3 La mayoría de las veces 5 No había investigador/doctor de la investigación
 2 A veces 4 Siempre

39. ¿Tenía usted confianza en el investigador o el doctor de la investigación que dirigían el estudio?³⁸⁸⁹⁷

- 1 Nunca 3 La mayoría de las veces 5 No había investigador/doctor de la investigación
 2 A veces 4 Siempre

40. Si usted tenía alguna ansiedad o temor sobre su participación en el estudio, ¿hablaron con usted sobre esas cosas el investigador o el doctor de la investigación?³⁸⁸⁹⁸

- 1 Nunca 3 La mayoría de las veces 5 No tuve ansiedad ni temores
 2 A veces 4 Siempre 6 No había investigador/doctor de la investigación

41. ¿Se reunió usted con el investigador o el doctor de la investigación tanto como quería?³⁹⁸⁸³

- 1 No 3 Sí, en general 5 No había investigador/doctor de la investigación
 2 Sí, un poco 4 Sí, completamente

El equipo de investigación en general...

42. Durante el estudio, ¿fue fácil obtener respuestas del equipo de investigación a sus preguntas?³⁸⁸⁹⁹

- 1 Nunca 3 La mayoría de las veces 5 No tuve preguntas durante el estudio
 2 A veces 4 Siempre



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43. Cuando no estaba en el lugar de la investigación, ¿sabía cómo ponerse en contacto con el equipo de investigación si tenía alguna pregunta?³⁹⁸⁸⁴
① No ② Sí, un poco ③ Sí, en general ④ Sí, completamente
44. Cuando no estaba en el lugar de la investigación y necesitaba ponerse en contacto con algún miembro del equipo de investigación, ¿podía hacerlo tan pronto como quería?³⁸⁹⁰⁰
① Nunca
② A veces
③ La mayoría de las veces
④ Siempre
⑤ No necesité al equipo de investigación
⑥ No sabía cómo ponerme en contacto con el equipo de investigación
45. ¿Se sintió valorado como colaborador en el proceso de investigación?³⁸⁹⁰¹
① Nunca ② A veces ③ Normalmente ④ Siempre
46. ¿Respetaba su cultura el equipo de investigación (por ejemplo, su idioma, su religión, su grupo étnico)?³⁸⁹⁰²
① Nunca ③ La mayoría de las veces ⑤ No hubo problemas culturales
② A veces ④ Siempre
47. ¿Hizo todo lo posible para ayudarle el equipo de investigación si tuvo algún problema con el idioma?³⁸⁹⁰³
① Nunca ③ La mayoría de las veces ⑤ No hubo problemas de idioma
② A veces ④ Siempre
48. ¿Le ayudó con sus discapacidades el equipo de investigación (por ejemplo, con el uso de silla de ruedas o andador, aparatos para el oído, etc.)?³⁹²⁹⁴
① Nunca ③ La mayoría de las veces ⑤ No tenía discapacidades
② A veces ④ Siempre
49. ¿El equipo de investigación incluyó a su familia tanto como usted quería?³⁸⁹⁰⁴
① No ③ Sí, en general ⑤ No participaban los familiares
② Sí, un poco ④ Sí, completamente

Sobre su participación en el estudio...

50. ¿Compartían la información médica importante con su médico de atención primaria?³⁸⁹⁰⁵
① No ② Sí ③ No había información que compartir ④ No sé
51. Si el estudio separó a los participantes en grupos, ¿le dijeron a usted en que grupo estaba cuando se completó el estudio?³⁸⁹⁰⁶
① No ② Sí ③ No hubo grupos ④ No sé
52. ¿Le gustaría recibir un resumen de los resultados del estudio?³⁸⁹⁰⁸
① No ② Sí ③ Recibí un resumen del estudio
53. ¿Le dio un resumen de los resultados del estudio el equipo de investigación?³⁸⁹⁰⁷
① No (Vaya al #55) ② Sí (Vaya al #54)
54. ¿El resumen de los resultados del estudio estaba escrito de manera que usted lo pudiera entender? ³⁸⁹⁰⁹
① No ③ Sí, en general ⑤ No recibí un resumen de los resultados
② Sí, un poco ④ Sí, completamente
55. ¿Tuvo más contacto con el equipo de investigación después de que se terminara el estudio?³⁹⁰³⁴
① Sí ② No
56. ¿Quería usted tener más contacto con el equipo de investigación después de que se terminara el estudio?³⁸⁹¹¹
① Sí ② No



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57. ¿Quería que se pusieran en contacto con usted para participar en otros estudios después de que se terminara el estudio?³⁹⁰³⁵

- 1 Sí 2 No

58. ¿Cuál de estos puntos sería importante para usted en un futuro estudio? Marque todos los que correspondan.³⁸⁹¹²

- 1 Acceso a una computadora, Internet y televisión
 2 Acceso a una cama cómoda
 3 Compensación/Más compensación económica
 4 Grupos de apoyo
 5 Apreciación de los voluntarios
 6 Un horario flexible
 7 Accesibilidad de estacionamiento y del lugar del estudio
 8 Alta planeada y despedida adecuada del equipo de investigación
 9 Que compartieran conmigo los resultados generales de la investigación
 10 Que compartieran conmigo o con mi médico los resultados de mis análisis personales
 11 Otro, especifique, por favor _____

En general...

59. La información y las conversaciones que tuvo antes de participar en el estudio de investigación ¿lo prepararon para su experiencia en el estudio?³⁸⁹¹³

- 1 No 2 Sí, un poco 3 Sí, en general 4 Sí, completamente

60. Si hubiera querido abandonar el estudio, ¿cree que se lo hubieran permitido?³⁸⁹¹⁴

- 1 No 2 Sí

61. Si pensó en abandonar el estudio, ¿se sintió presionado por el equipo de investigación para no hacerlo?³⁸⁹¹⁵

- 1 No 2 Sí, un poco 3 Sí, en general 4 Sí, completamente

62. ¿Le dijeron alguna vez que podía dejar de participar en el estudio en cualquier momento y por cualquier motivo?³⁸⁹¹⁶

- 1 No 2 Sí

63. Por favor, califique su experiencia general en este estudio de investigación utilizando la siguiente escala, donde 0 es la peor experiencia posible y 10 la mejor posible.³⁸⁹¹⁷

La peor posible	1	2	3	4	5	6	7	8	9	La mejor posible
<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	<input type="radio"/> 7	<input type="radio"/> 8	<input type="radio"/> 9	<input type="radio"/> 10

64. ¿Recomendaría participar en un estudio de investigación a sus amigos y familiares?³⁸⁹¹⁸

- 1 Definitivamente no 2 Probablemente no 3 Probablemente sí 4 Definitivamente sí

Unas preguntas sobre usted...

65. Para participar en el estudio, ¿era necesario que tuviera una enfermedad o un problema médico?³⁸⁹¹⁹

- 1 Sí 2 No

66. ¿El estudio requería tomar algún medicamento o suplemento O utilizar un nuevo dispositivo médico O someterse a un nuevo procedimiento médico?⁴⁰⁴⁴⁹

- 1 Sí 2 No 3 No estoy seguro(a)



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67. ¿Cuánto exigía el estudio de usted? Seleccione la respuesta que mejor refleje su experiencia.⁴⁰⁴⁵⁰

- ① Poco (por ejemplo: unas cuantas visitas o pruebas sencillas o encuestas)
- ② Moderado (por ejemplo: múltiples visitas o una breve hospitalización; tan sólo unos cuantos procedimientos, nada arriesgado o intenso)
- ③ Mucho (por ejemplo: hospitalización más larga, varias hospitalizaciones o muchas visitas; un procedimiento o procedimientos intensos, arriesgados o complejos)

68. ¿Cuánto tiempo participó en el estudio desde el principio hasta el final? Si abandonó el estudio antes de que terminara o aún está participando, conteste cuánto tiempo participó o ha participado en el estudio.⁴⁰⁴⁵¹

- ① Horas
- ② Días o semanas
- ③ Meses
- ④ Años

69. En general, ¿cómo calificaría su salud?³⁸⁹²⁰

- ① Excelente
- ② Muy Bueno
- ③ Bueno
- ④ Regular
- ⑤ Pobre

70. ¿En cuántos estudios ha participado usted?³⁸⁹²¹

- ① 1
- ② De 2 a 5
- ③ De 6 a 10
- ④ Más de 10

71. ¿Cuál es el nivel escolar más alto que ha completado?³⁸⁹²²

- ① Escuela primaria
- ② Escuela secundaria
- ③ Algunos cursos universitarios
- ④ Título universitario o profesional de 2 años
- ⑤ Título universitario de 4 años
- ⑥ Escuela graduada
- ⑦ Postgrado

72. ¿Cuál es su edad?³⁸⁹²³

- ① 18-40 años
- ② 41-64 años
- ③ 65-74 años
- ④ 75 años o más

73. ¿De qué raza se considera usted? Seleccione todo lo que corresponda.³⁸⁹²⁵

- ① Indígena americano o nativo de Alaska
- ② Asiático
- ③ Negro o afro americano
- ④ Nativo de Hawai o de otras islas del Pacífico
- ⑤ Blanco

74. ¿Es usted español, hispano o de origen o descendencia latina?³⁸⁹²⁴

- ① No, no soy español/hispano/latino
- ② Sí, soy español/hispano/latino

75. ¿Qué idioma habla principalmente en casa con sus familiares y amigos?³⁸⁹²⁶

- ① Inglés
- ② Español
- ③ Chino (cualquier dialecto)
- ④ Otro, especifique, por favor

76. ¿Le gustaría añadir alguna otra cosa sobre el estudio en el que participó más recientemente?



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