

Research Participant Survey

PART A:

Instructions: Below you will find several statements about clinical trials (otherwise known as research studies). Thinking about the trial you just participated in, please read each statement carefully. Then tell us whether you agree with the statement, do not agree with the statement, or you are unsure about the statement by circling the appropriate response. Please respond to each statement as best as you can. We are interested in your opinions.

A1.	When I signed the consent form, I knew I was agreeing to participate in the clinical trial.	Disagree	Unsure	Agree
A2.	The main reason clinical trials are done is to improve the treatment of <u>future</u> patients.	Disagree	Unsure	Agree
A3.	I have been informed how long my participation in this clinical study is likely to last.	Disagree	Unsure	Agree
A4.	All the treatments and procedures in my clinical trial are standard (routinely used) to prevent pneumonia.	Disagree	Unsure	Agree
A5.	One of the main goals of this clinical trial is to compare the effects (good and bad) of 2 or more different ways of treating patients with my disease, in order to see which is better.	Disagree	Unsure	Agree
A6.	The treatment being researched in my clinical trial has been proven to be the best treatment to prevent pneumonia.	Disagree	Unsure	Agree
A7.	After I agreed to participate in my clinical trial, my treatment was chosen randomly (by chance) from two or more possibilities.	Disagree	Unsure	Agree
A8.	Compared with standard treatments for my disease, my clinical trial does not carry any additional risks or discomforts.	Disagree	Unsure	Agree
A9.	I will <u>not</u> directly benefit from participating in this research study.	Disagree	Unsure	Agree
A10.	By participating in this clinical trial, I am helping the researchers learn information that may benefit future patients.	Disagree	Unsure	Agree
A11.	In my clinical trial, each group of patients receives a higher dose of the treatment than the group before, until some patients have serious side effects.	Disagree	Unsure	Agree
A12.	Because I am participating in a clinical trial, it is possible that the study sponsor, various	Disagree	Unsure	Agree

	government agencies, or others who are not directly involved in my care could review my medical records.			
A13.	I was not offered any alternative strategies to prevent pneumonia besides treatment in this clinical trial.	Disagree	Unsure	Agree
A14.	The consent form I signed lists the name of the person (or persons) whom I should to contact if I am injured or become ill as a result of participation in this clinical trial.	Disagree	Unsure	Agree
A15.	The consent form I signed lists the name of the person (or persons) whom I should contact if I have any questions or concerns about the clinical trial.	Disagree	Unsure	Agree
A16.	If I had not wanted to participate in this clinical trial, I could have declined to sign the consent form.	Disagree	Unsure	Agree
A17.	I will have to remain in the clinical trial even if I decide I want to stop participating.	Disagree	Unsure	Agree

PART B:

Instructions: When you signed the consent form to participate in your clinical trial, how well did you understand the following aspects of your clinical trial? *If you didn't understand the item at all, please circle 1. If you understood it very well, please circle 5. If you understand it somewhat, please circle a number between 1 and 5.*

		I Didn't Understand this At All		→		I Understood this Very Well
B1.	The fact that your treatment involves research.	1	2	3	4	5
B2.	How your participation in this clinical trial may benefit <u>future patients</u> .	1	2	3	4	5
B3.	How long you will be in the clinical trial.	1	2	3	4	5
B4.	Which of these treatments and procedures are experimental.	1	2	3	4	5
B5.	What the researchers are trying to find out in the clinical trial.	1	2	3	4	5
B6.	The treatments and procedures you will undergo.	1	2	3	4	5
B7.	The possible risks and discomforts of participating in the clinical trial.	1	2	3	4	5

B8.	The possible benefits to you of participating in the clinical trial.	1	2	3	4	5
B9.	The effect of the clinical trial on the confidentiality of your medical records.	1	2	3	4	5
B10.	The alternatives to participation in the clinical trial.	1	2	3	4	5
B11.	Who will pay for treatment if you are injured or become ill because of participation in this clinical trial.	1	2	3	4	5
B12.	Whom you should contact if you have questions or concerns about the clinical trial.	1	2	3	4	5
B13.	The fact that participation in the clinical trial is voluntary.	1	2	3	4	5
B14.	Overall, how well did you understand your clinical trial when you signed the consent form?	1	2	3	4	5

Part C (Telemedicine patients only):

Instructions: Please respond to the following questions to the best of your ability.

		I Very much DISAGREE with this statement		→		I Very Much AGREE with this statement
C1.	I was concerned that if I didn't participate in the trial that it would change the way my doctor took care of me.	1	2	3	4	5
C2.	I trust the research team to protect my interests completely.	1	2	3	4	5

C3. In what ways did you feel telemedicine affected your ability to decide if you wanted to participate in the study?

C4. In what ways did you feel telemedicine affected the likelihood that you would participate in the study?

C5. Did you like being considered for research by telemedicine? Why or why not?

C6.	Telemedicine (communication between doctors over the iPad) made it more difficult to determine whether I wanted to participate in the clinical trial (if applicable).	1	2	3	4	5	I did not receive telemedicine-based consent.
C7.	Telemedicine made me more likely to participate in this trial than I would have been without telemedicine (if applicable).	1	2	3	4	5	I did not receive telemedicine-based consent.