ı	Research Partici	pant Perception Survey	- SP ID: 29	
This questionnaire is evaluated a Multiple-choice (select all Single-choice (select only	applicable optic	•		ted Undo select
1 Questions				
Welcome! 1. This page provide same questionnaire is being used Voice*). a. The survey that follo The purpose of the research is to follows is part of our quality ass completing the survey. The surve to complete the survey. For yo complete the survey in one sitting understand how to improve country. 4. We will do our best To further minimize the risks to doctors, hospitals, or any diagnot opportunities for improvement. Your publications. 6. There is no can change your mind. Your ans	nationwide to lead we sis part of a result	earn from research particles earch study conducted earch participants' experienced by [INSTIT] ou and your most recent earch you must clicked are no direct benefits to rticipation experience a information, but there is, we do NOT ask for a responses are analyzed aveal any individual survetor completing the survetor.	ipants' feedback (E by [INSERT PI] at iences and enhance UTION] University. Tresearch experience "Done" at the ero you. However, that this research cens always a small rising details about yous as a group to identely responses to states.	mpowering the Participant [INSERT INSTITUTION], them. b. The survey that 2. Participation involves e. It will take 5-7 minutes and of the survey. Plan to e survey results may help ter and others across the k of loss of confidentiality our prior research studies, ify areas of excellence and off or research teams nor in ation is voluntary and you
Please answer the questions below			rolled in within the	past year. If you enrolled
When the survey questions refer study, not this online survey study	to "the study,"	•	r experiences enroll	ed in that clinical research
1.1 Would you recommend joini O Definitely no O Probably no O Probably yes O Definitely yes	ng a research st	udy to your family and	friends?	
1.2 Below is a list of possible important were these reason	s for you?			
To find out more about my disease	Very important	Somewhat important	Not very importai	nt Not important at all
Because no other medical options were available	0	0	0	0
To gain access to new treatment/therapy	0	0	0	0
To obtain free healthcare	0	0	0	0
To help others Because of the	0	0	0	0



 $Research/Health\ Center's$

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	Research Partici	pant Perception Survey	- SP ID: 29	
	Very important	Somewhat important	Not very important	Not important at all
Because I am concerned about the topic of study	0	0	0	0
To obtain education and learning	0	0	0	0
Because of a positive experience in another study	0	0	0	0
Because of family influence/involvement	0	0	0	0
To earn money/payment	0	0	0	0
Because my caregiver encouraged me	0	0	0	0
Other reasons	0	0	0	0
 Yes No 1.4 Did the study involve taking procedure, or a change in Yes No Not sure 1.5 How much did the study of Simple (for example: a few Moderate (for example: m Intense (for example: long complex) 	lifestyle, behavior lemand of you? (v visits or simple ultiple visits or a	or counseling? Pick the answer that motests or surveys) short inpatient stay; on	ost closely describes yo ly a few procedures, n	our experience) ot risky or intense)
 1.6 Before you joined the stud O Mostly through the email O Mostly while physically in O A mix of conversations take O No discussions with the st O I do not remember 1.7 Did the Informed consent 	or video or teleph the same place w king place both pl udy team before j	one conversations ith a member of the stu nysically in the same pla oining the study	dy team ce and over telephone	
NoYes, somewhatYes, mostlyYes, completely				





Research Participant Perception Survey - SP | ID: 29

1.8 Did the information and discussions you had before participating in the research study prepare you for you experience in the study?
O No
O Yes, somewhat
O Yes, mostly
O Yes, completely
1.9 Did the research team members listen carefully to you?
O Never
O Sometimes
O Usually
O Always O No Research Team Member Involved
1.10 Did the research team members treat you with courtesy and respect?
O Never
O Sometimes
O Usually
O Always
O No Research Team Member Involved
1.11 During your discussion about the study, did you feel pressure from the research staff to join the study?
O Never
O Sometimes
O Usually
O Always
1.12 Did the research staff do everything possible to provide assistance with any language difference you might have
O Never
O Sometimes
O Usually
O Always
O No language difference
1.13 When you were not at the research site did you know how to reach the research team if you had a question?
O Never
O Sometimes
O Usually
O Always
O Always
1.14 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?
O Never
O Sometimes
O Usually
O Always
O Did not need to reach the research team





	Research Partici	pant Perception Survey	- SP ID: 29	
1.15 Did you feel you were a	valued partner in t	the research process?		
NeverSometimesUsuallyAlways				
1.16 If you considered leaving	the study, did voi	u feel pressure from the	Research Team to sta	v?
 Never Sometimes Usually Always Did not consider leaving to the consider leaving t		, , , , , , , , , , , , , , , , , , ,		, .
1.17 Did the research staff re	spect your cultura	l background (e.g. langı	uage, religion, ethnic g	group)?
NeverSometimesUsuallyAlwaysNo cultural issues				
1.18 Did you have enough ph	ysical privacy whil	e you were in the study?	?	
O Never O Sometimes O Usually O Always	, , , , , , , , , , , , , , , , , , ,			
1.19 Below is a list of possib considering leaving the s		ving a research study. F	How important were t	hese reasons for you ii
	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	0	0	0	0
Worried about risks of treatment	0	0	0	0
Side effects that occurred during the study	0	0	0	0
Invasion of privacy	0	0	0	0
Too much time spent waiting around	0	0	0	0
Time commitment required	0	0	0	0
Family/work issues unrelated to the study	0	0	0	0
Interactions with research team	0	0	0	0
Not getting test results	0	0	0	0





	Research Partici			
	Very important	Somewhat important	Not very important	Not important at all
Undue pressure to stay in study	0	0	0	0
Problems with study payments	0	0	0	0
Unexpected tests and procedures that occurred during the study	0	0	0	0
Transportation/parking	0	0	0	0
Other reasons	0	0	0	0
1.20 Below is a list of possible staying in the research st		ng in a research study.	How important were t	hese reasons for you in
	Very important	Somewhat important	Not very important	Not important at all
To find out more about my disease	0	0	0	0
Because no other medical options were available	0	0	0	0
To gain access to new treatment/therapy	0	0	0	0
To obtain free healthcare	0	0	0	0
To help others	0	0	0	0
Because of the Research/Health Center's reputation	0	0	0	0
Because I am concerned about the topic of study	0	0	0	0
To obtain education and learning	0	0	0	0
Because of a positive experience in another study	0	0	0	0
Because of family influence/involvement	0	0	0	0
To earn money/payment	0	0	0	0
Because my caregiver encouraged me	0	0	0	0
Because of my relationship with the research team	0	0	0	0
Feeling valued as a research participant	0	0	0	0





	Research Partici	pant Perception Survey	- SP ID: 29	
	Very important	Somewhat important	Not very important	Not important at all
Improved health or quality of life	0	0	0	0
Other reasons	0	0	0	0
1.21 Which of the following the Access to computer, interned Access to comfortable bed Payment/More Payment Support groups Volunteer appreciation Flexible Schedule Accessible parking and stue Planned discharge and produced Summary of overall research Results of personal lab tested Other (please specify)	net, and television dy location oper goodbye to re ch results shared	esearch team with me	ure study?	
1.22 Please specify other impo	ortant things:			
1.23 Please use the scale beloexperience, and 10 is the O 0 worst O 1 O 2 O 3 O 4 O 5 O 6 O 7 O 8 O 9 O 10 best	=	· · · · · · · · · · · · · · · · · · ·	research study, where	U is the worst possible
1.24 What is the highest grad O 8th grade or less O Some high school, did not O High school graduate or G O Some college or 2-year deg O 4-year college graduate O More than 4-year college or	graduate IED gree	ol that you have comple	ted?	
1.25 What is your age? ○ 18-34 ○ 35-44 ○ 45-54 ○ 55-64 ○ 65-74 ○ 75 and over				





Research Participant Perception Survey - SP ID: 29	
1.26 What is your race? (Please choose one or more)	
☐ American Indian or Alaska Native ☐ Asian	
Black or African American	
□ Native Hawaiian or other Pacific Islander□ White	
1.27 Are you of Spanish or Hispanic or Latino/a/x origin or descent?	
○ No - not Spanish/Hispanic/Latino/a/x ○ Yes - Puerto Rican	
O Yes - Mexican/Mexican American/Chicano	
○ Yes - Cuban○ Yes - other Spanish/Hispanic/Latino/a/x	
1.28 What is your sex?	
O Female O Male	
O Intersex	
1.29 How would you describe your gender identity?	
O Female (including transgender women)	
Male (including transgender men)Non-binary/gender-fluid/agender	
O Prefer not to say	
1.30 Is there anything else you would like to share about your experience in the study you most recently joined	4 7
1.00 is there anything else you would like to share about your experience in the study you most recently joined	J.

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

Empowering the Participant Voice is supported in part by a grant from the National Center for Accelerating Translational Science U01TR003026 to The Rockefeller University, and Clinical Translational Science Awards UL1TR002553 (Duke University), UL1TR003098 (Johns Hopkins University), UL1TR002001 (University of Rochester), UL1TR001866 (Rockefeller University), UL1TR002243 (Vanderbilt), and UL1TR001420 (Wake Forest University Health Sciences).





Re	esearch Partic	ipant Perception Survey	- SP ID: 30		
This questionnaire is evaluated au	tomatically. F	Please use a pen to fill in	vour answers	as follows:	
Multiple-choice (select all a O Single-choice (select only or	pplicable opti	•		Selected Selected	Undo select Undo select
1 Questions					
Welcome! 1. This page provides same questionnaire is being used n Voice*). a. The survey that follow The purpose of the research is to use follows is part of our quality assured to complete the survey. The survey to complete the survey. For your complete the survey in one sitting us understand how to improve the country. 4. We will do our best to To further minimize the risks to doctors, hospitals, or any diagnose opportunities for improvement. Wo our publications. 6. There is no can change your mind. Your answer.	ationwide to less is part of a restand restand restand restance programmasks about years asks about years. 3. There are research particularly confidentialityes. 5. Survey fe will NOT restance ompensation	earn from research particles arch study conducted be conducted by [INSTIT ou and your most recent of saved, you must clicare no direct benefits to articipation experience a information, but there is you we do NOT ask for a responses are analyzed eveal any individual surverse for completing the surverse.	cipants' feedback I by [INSERT Pariences and enhances and enhances I UTION] Universe It research expenses I this research I salways a small I salways a smal	ck (Empower 2 2 2 2 2 2 2 2 2	ering the Participant RT INSTITUTION]. b. The survey that articipation involves will take 5-7 minutes the survey. Plan to ey results may help d others across the ss of confidentiality or research studies as of excellence and search teams nor in such as voluntary and your
Please answer the questions below in more than one study, answer fo	v regarding th	e research study you en			
When the survey questions refer to study, not this online survey study	-	we are asking about you	ır experiences (enrolled in t	hat clinical research
1.1 Would you recommend joining O Definitely no O Probably no O Probably yes O Definitely yes	g a research s	tudy to your family and	friends?		
1.2 Below is a list of possible re important were these reasons	for you?		-	_	
To find out more about my disease	ery important	Somewhat important	O	oortant ivo	ot important at all
Because no other medical options were available	0	0	0		0
To gain access to new treatment/therapy	0	0	0		0
To obtain free healthcare To help others	0	0	0		0
Recourse of the	O	O	0		0



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	Research Partici	pant Perception Survey	- SP ID: 30	
	Very important	Somewhat important	Not very important	Not important at all
Because I am concerned about the topic of study	0	0	0	0
To obtain education and learning	0	0	0	0
Because of a positive experience in another study	0	0	0	0
Because of family influence/involvement	0	0	0	0
To earn money/payment	0	0	0	0
Because my caregiver encouraged me	0	0	0	0
Other reasons	0	0	0	0
 No 1.4 Did the study involve taking procedure, or a change in Yes No Not sure 1.5 How much did the study of 	lifestyle, behavior,	, or counseling? Pick the answer that ma		
Simple (for example: a fevolutionModerate (for example: mIntense (for example: lon complex)	nultiple visits or a	short inpatient stay; on		
1.6 Before you joined the stud	ly, how did the stu	udy team discuss the de	tails of the study with	you?
O Mostly through the email O Mostly while physically in O A mix of conversations tal O No discussions with the st O I do not remember	the same place w king place both pl	ith a member of the stunysically in the same pla	=	/video/computer)
1.7 Did the Informed consent	form prepare you	for what to expect duri	ng the study?	
O NoO Yes, somewhatO Yes, mostlyO Yes, completely				





Research Participant Perception Survey - SP | ID: 30

 1.8 Did the information and discussions you had before participating in the research study prepare you for your experience in the study? O No O Yes, somewhat O Yes, mostly O Yes, completely
 1.9 Did the research team members listen carefully to you? O Never O Sometimes O Usually O Always O No Research Team Member Involved
 1.10 Did the research team members treat you with courtesy and respect? O Never O Sometimes O Usually O Always O No Research Team Member Involved
 1.11 During your discussion about the study, did you feel pressure from the research staff to join the study? O Never O Sometimes O Usually O Always
 1.12 Did the research staff do everything possible to provide assistance with any language difference you might have? O Never O Sometimes O Usually O Always O No language difference
1.13 When you were not at the research site did you know how to reach the research team if you had a question? O Never O Sometimes O Usually O Always
 1.14 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? O Never O Sometimes O Usually O Always O Did not need to reach the research team





	Research Partici	pant Perception Survey	- SP ID: 30	
1.15 Did you feel you were a	valued partner in t	the research process?		
NeverSometimesUsuallyAlways				
1.16 If you considered leaving	the study, did you	u feel pressure from the	Research Team to sta	y?
NeverSometimesUsuallyAlwaysDid not consider leaving to	he study			
1.17 Did the research staff res	spect your cultura	l background (e.g. langu	uage, religion, ethnic g	group)?
NeverSometimesUsuallyAlwaysNo cultural issues	,	3		
1.18 Did you have enough ph	ysical privacy whil	e you were in the study?	?	
NeverSometimesUsuallyAlways				
1.19 Below is a list of possib considering leaving the s		ving a research study. F	How important were the	hese reasons for you ir
	Very important	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	0	0	0	0
Worried about risks of treatment	0	0	0	0
Side effects that occurred during the study	0	0	0	0
Invasion of privacy	0	0	0	0
Too much time spent waiting around	0	0	0	0
Time commitment required	0	0	0	0
Family/work issues unrelated to the study	0	0	0	0
Interactions with research team	0	0	0	0
Not getting test results	\circ		\circ	\circ





	Research Participant Perception Survey - SP ID: 30				
	Very important	Somewhat important	Not very important	Not important at all	
Undue pressure to stay in study	0	0	0	0	
Problems with study payments	0	0	0	0	
Unexpected tests and procedures that occurred during the study	0	0	0	0	
Transportation/parking	0	0	0	0	
Other reasons	0	0	0	0	
1.20 Below is a list of possible staying in the research staying		ng in a research study.	How important were t	chese reasons for you in	
	Very important	Somewhat important	Not very important	Not important at all	
To find out more about my disease	0	0	0	0	
Because no other medical options were available	0	0	0	0	
To gain access to new treatment/therapy	0	0	0	0	
To obtain free healthcare	0	0	0	0	
To help others	0	0	0	0	
Because of the Research/Health Center's reputation	0	0	0	0	
Because I am concerned about the topic of study	0	0	0	0	
To obtain education and learning	0	0	0	0	
Because of a positive experience in another study	0	0	0	0	
Because of family influence/involvement	0	0	0	0	
To earn money/payment	0	0	0	0	
Because my caregiver encouraged me	0	0	0	0	
Because of my relationship with the research team	0	0	0	0	
Feeling valued as a research participant	0	0	0	0	





	Research Partici	pant Perception Survey	- SP ID: 30	
	Very important	Somewhat important	Not very important	Not important at all
Improved health or quality of life	0	0	0	0
Other reasons	0	0	0	0
1.21 Which of the following th	nings would be im	portant for you in a fut	ure study?	
☐ Access to computer, interr☐ Access to comfortable bed☐ Payment/More Payment☐ Support groups☐ Volunteer appreciation☐ Flexible Schedule☐ Accessible parking and stu☐ Planned discharge and pro☐ Summary of overall researe☐ Results of personal lab tes☐ Other (please specify)	dy location per goodbye to re ch results shared	esearch team with me		
1.22 Please specify other impo	ortant things:			
1.23 Please use the scale belowexperience, and 10 is the O worst O 1 O 2 O 3 O 4 O 5 O 6 O 7 O 8 O 9 O 10 best	best possible exp	perience.		0 is the worst possible
1.24 What is the highest grade O 8th grade or less O Some high school, did not O High school graduate or G O Some college or 2-year deg O 4-year college graduate O More than 4-year college or	graduate ED gree	ol that you have comple	ted?	
1.25 What is your age?				
○ 18-34 ○ 35-44 ○ 45-54 ○ 55-64 ○ 65-74 ○ 75 and over				

Research Participant Perception Survey - SP ID: 30	
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☐ American Indian or Alaska Native ☐ Asian	
Black or African American	
□ Native Hawaiian or other Pacific Islander□ White	
1.27 Are you of Spanish or Hispanic or Latino/a/x origin or descent?	
○ No - not Spanish/Hispanic/Latino/a/x ○ Yes - Puerto Rican	
O Yes - Mexican/Mexican American/Chicano	
○ Yes - Cuban○ Yes - other Spanish/Hispanic/Latino/a/x	
1.28 What is your sex?	
O Female O Male	
O Intersex	
1.29 How would you describe your gender identity?	
O Female (including transgender women)	
Male (including transgender men)Non-binary/gender-fluid/agender	
O Prefer not to say	
1.30 Is there anything else you would like to share about your experience in the study you most recently joined	۹۶
1.00 is there anything else you would like to share about your experience in the study you most resembly joined	<u>. </u>

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

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