	Research	Participant Perce	otion Survey - SP	ID: 1	1	
This questionnal	re is evaluated automati	cally. Please use a	pen to fill in your	answe	ers as follows:	
	hoice (select all applicab ice (select only one optic	. ,		×	Selected Selected	Undo select Undo select
1 Questions						
The same quest Participant Voic INSTITUTION]. b. The survey t Participation inv It will take 5-7 of the survey. F survey results m and others acros of loss of confide prior research st areas of excellen research teams r	This page provides information ionnaire is being used in the eta). a. The survey that the purpose of the reservation of the reservation of the surpose completing the surpose complete the surpose that complete the surpose the country. 4. We wantiality. To further miniculates, doctors, hospitals, the country of the countr	rationwide to learn follows is part of a carch is to understant quality assurance vey. The survey as survey. For your vey in one sitting, ow to improve the ill do our best to part to	from research para research study cound research particle program conducts about you and answers to be savour. There are no research participal protect your information on fidentiality, we could be savour.	articipal onductipants ited by your of direction end on NO sees are y individual of the properties of	ents' feedback ted by [INSER] experiences as [INSTITUTIO] most recent result benefits to you perience at the but there is a pridual survey result the survey. 7. "	(Empowering the T PI] at [INSERT nd enhance them. ON] University. 2. search experience. Done" at the end ou. However, the is research center Iways a small risk details about your group to identify sponses to staff or Your participation
	ne questions below regard e study, answer for the n	_	tudy you enrolled	in with	nin the past yea	ar. If you enrolled
_	questions refer to "the s nline survey study.	tudy," we are askin	g about your expe	riences	s enrolled in tha	at clinical research
O Definitely no O Probably no O Probably ye O Definitely ye	5 2S					
	ist of possible reasons fere these reasons for you		ch study. When y	you cc	onsidered joinin	g the study, how

	Very important	Somewhat important	Not very important	Not important at al
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





Research Participant Perception Survey - SP   ID: 1				
	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
<ul><li>No</li><li>1.4 Did the study involve tak procedure, or a change in</li><li>Yes</li><li>No</li><li>Not sure</li></ul>			ew medical device, un	dergoing a new medica
<ul> <li>1.5 How much did the study</li> <li>Simple (for example: a fee</li> <li>Moderate (for example: o</li> <li>Intense (for example: lor complex)</li> </ul>	ew visits or simple multiple visits or a	tests or surveys) short inpatient stay; or	nly a few procedures, i	not risky or intense)
1.6 Before you joined the stu		-	etails of the study wit	h you?
O Mostly through the email O Mostly while physically in O A mix of conversations to O No discussions with the sO I do not remember	n the same place vaking place both p	vith a member of the st physically in the same pl	•	e/video/computer)
1.7 Did the Informed consent	form prepare you	ı for what to expect dur	ing the study?	
<ul><li>No</li><li>Yes, somewhat</li><li>Yes, mostly</li><li>Yes, completely</li></ul>				





## Research Participant Perception Survey - SP | ID: 1 1.8 Did the information and discussions you had before participating in the research study prepare you for your experience in the study?

	experience in the study?
0	No Yes, somewhat Yes, mostly Yes, completely
1.9	Did the research team members listen carefully to you?
0	Never
0	Sometimes
	Usually
	Always No Research Team Member Involved
1.10	Did the research team members treat you with courtesy and respect?
_	Never
	Sometimes
	Usually Always
	No Research Team Member Involved
	During your discussion about the study, did you feel pressure from the research staff to join the study?
_	Never Sometimes
	Usually
_	Always
1.12	2 Did the research staff do everything possible to provide assistance with any language difference you might have?
	Never
_	Sometimes
0	Usually
	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?
0	Never
	Sometimes
	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?
0	Never
	Sometimes
_	Usually
	Always  Did not need to reach the research team





	Research Partio	cipant Perception Survey	y - SP   ID: 1	
1.15 Did you feel you were a	valued partner in	the research process?		
<ul><li>Never</li><li>Sometimes</li><li>Usually</li><li>Always</li></ul>				
1.16 If you considered leaving	g the study, did vo	ou feel pressure from the	e Research Team to st	av?
O Never O Sometimes O Usually O Always O Did not consider leaving		, , , , , , , , , , , , , , , , , , ,		- <b>,</b> .
1.17 Did the research staff re	espect your cultura	al background (e.g. lang	guage, religion, ethnic	group)?
<ul><li>Never</li><li>Sometimes</li><li>Usually</li><li>Always</li><li>No cultural issues</li></ul>				
1.18 Did you have enough pl	nysical privacy wh	ile you were in the study	/?	
O Never O Sometimes O Usually O Always				
1.19 Below is a list of possib	ole reasons for lea	ving a research study. I	How important were t	hese reasons for you ir
considering leaving the	•	Somewhat important	Not very important	Not important at all
Pain or discomfort related to participation	O O	O	O O	O
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 Participant Perception Survey - SP   ID: 1					
	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 s		ing in a research study.	How important were t	these reasons for you in	
		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 Participant Perception Survey - SP   ID: 1					
	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 t	things would be in	nportant for you in a fu	ture study?		
☐ Access to computer, inter ☐ Access to comfortable be ☐ Payment/More Payment ☐ Support groups ☐ Volunteer appreciation ☐ Flexible Schedule ☐ Accessible parking and st ☐ Planned discharge and pr ☐ Summary of overall resea ☐ Results of personal lab te ☐ Other (please specify)	d udy location oper goodbye to rch results shared	research team with me			
1.22 Please specify other imp	oortant things:				
1.23 Please use the scale bel experience, and 10 is th  O 0 worst O 1 O 2 O 3 O 4 O 5 O 6 O 7 O 8 O 9 O 10 best	e best possible ex	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 O Some college or 2-year decorption of the Argument o	t graduate GED egree	ool that you have comple	eted?		
<ul><li>○ 55-64</li><li>○ 65-74</li><li>○ 75 and over</li></ul>					





Research Participant Perception Survey - SP   ID: 1	
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?  O No - not Spanish/Hispanic/Latino/a/x O Yes - Puerto Rican O Yes - Mexican/Mexican American/Chicano O Yes - Cuban O Yes - other Spanish/Hispanic/Latino/a/x	
1.28 What is your sex?  O Female O Male O Intersex	
<ul> <li>1.29 How would you describe your gender identity?</li> <li>O Female (including transgender women)</li> <li>O Male (including transgender men)</li> <li>O Non-binary/gender-fluid/agender</li> <li>O Prefer not to say</li> <li>1.30 Is there anything else you would like to share about your experience in the study you most recently joined?</li> </ul>	?
The state drything case you would like to shall about your experience in the state, you most recently joint	

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).





	Research Part	icipant Perception Surve	ey - SP   ID: 2	
This questionnaire is evaluated	automatically.	Please use a pen to fill	in your answers as fo	ollows:
<ul><li>Multiple-choice (select all</li><li>Single-choice (select only</li></ul>	applicable opt	-	Select	ed 📜 Undo select
1 Questions				
Welcome! 1. This page prov The same questionnaire is bein Participant Voice*). a. The sur INSTITUTION]. The purpose of b. The survey that follows is p Participation involves completin It will take 5-7 minutes to com of the survey. Plan to complet survey results may help us under and others across the country. of loss of confidentiality. To fur prior research studies, doctors, I areas of excellence and opportunities research teams nor in our public is voluntary and you can change	g used nation rvey that follow f the research part of our quart of the survey in the survey in the survey of the minimize the mospitals, or an inties for improvations. 6. The	wide to learn from reserve is part of a research is to understand research ality assurance program. The survey asks about yey. For your answers to none sitting. 3. There improve the research pour best to protect you the risks to confidential my diagnoses. 5. Survey yement. We will NOT refer is no compensation for	earch participants' feature study conducted by harticipants' experion conducted by [INST] you and your most report are no direct beneficanticipation experient information, but the responses are analyzeveal any individual super completing the surresponses.	edback (Empowering the INSERT PI] at [INSERT ences and enhance them. ITUTION] University. 2. cent research experience. click "Done" at the end its to you. However, the ce at this research center ere is always a small risk for any details about your red as a group to identify livey responses to staff or vey. 7. Your participation
Please answer the questions belin more than one study answer			nrolled in within the	past year. If you enrolled
in more than one study, answer When the survey questions refer study, not this online survey stu	to "the study,	-	our experiences enrolle	ed in that clinical research
1.1 Would you recommend join  O Definitely no O Probably no O Probably yes O Definitely yes	ing a research	study to your family an	d friends?	
1.2 Below is a list of possible important were these reason			-	
To find out more about my disease	O	O	O	O
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	$\circ$	0	$\circ$	0

reputation





Research Participant Perception Survey - SP   ID: 2				
	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
<ul><li>No</li><li>1.4 Did the study involve tak procedure, or a change in</li><li>Yes</li><li>No</li><li>Not sure</li></ul>			ew medical device, un	dergoing a new medica
<ul> <li>1.5 How much did the study</li> <li>Simple (for example: a fe</li> <li>Moderate (for example: o</li> <li>Intense (for example: lor complex)</li> </ul>	ew visits or simple multiple visits or a ng or multiple inp	tests or surveys) short inpatient stay; or atient stays or many vis	nly a few procedures, i sits; procedure(s) that	not risky or intense) are intense, risky, or
1.6 Before you joined the stu	-	•	etails of the study with	h you?
O Mostly through the email O Mostly while physically in O A mix of conversations to O No discussions with the sO I do not remember	n the same place vaking place both p	vith a member of the st physically in the same pl	•	e/video/computer)
1.7 Did the Informed consent	t form prepare you	ı for what to expect dur	ing the study?	
<ul><li>No</li><li>Yes, somewhat</li><li>Yes, mostly</li><li>Yes, completely</li></ul>				





## Research Participant Perception Survey - SP | ID: 2 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
<ul><li>○ Always</li><li>○ No Research Team Member Involved</li></ul>
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
<ul> <li>1.11 During your discussion about the study, did you feel pressure from the research staff to join the study?</li> <li>O Never</li> <li>O Sometimes</li> <li>O Usually</li> <li>O Always</li> </ul>
<ul> <li>1.12 Did the research staff do everything possible to provide assistance with any language difference you might have?</li> <li>O Never</li> <li>O Sometimes</li> <li>O Usually</li> <li>O Always</li> <li>O No language difference</li> </ul>
1.13 When you were not at the research site did you know how to reach the research team if you had a question? <ul> <li>O Never</li> <li>O Sometimes</li> <li>O Usually</li> <li>O Always</li> </ul>
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 Partic	cipant Perception Survey	v - SP   ID: 2	
1.15 Did you feel you were a	valued partner in	the research process?		
O Never O Sometimes O Usually O Always				
1.16 If you considered leavin	σ the study did vo	ou feel pressure from the	Research Team to st	av?
O Never O Sometimes O Usually O Always O Did not consider leaving		va reer pressure from the	research reall to st	ay:
1.17 Did the research staff re	espect your cultura	al background (e.g. lang	guage, religion, ethnic	group)?
O Never O Sometimes O Usually O Always O No cultural issues  1.18 Did you have enough p O Never O Sometimes O Usually O Always	hysical privacy whi	ile you were in the study	ı?	
1.19 Below is a list of possil		ving a research study. I	How important were t	hese reasons for you in
considering leaving the	=	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	$\circ$			





	Research Participant Perception Survey - SP   ID: 2					
	Very important	Somewhat important	Not very important	Not important at all		
Undue pressure to stay in study	0	0	0	Ο		
Problems with study payments	0	0	0	0		
Unexpected tests and procedures that occurred during the study	0	0	0	0		
${\sf Transportation/parking}$	0	0	0	0		
Other reasons	0	0	0	0		
1.20 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?						
	=	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	Ο		





Research Participant Perception Survey - SP   ID: 2						
	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 to Access to computer, interpolar Access to comfortable be Payment/More Payment Support groups Volunteer appreciation Flexible Schedule Accessible parking and sto Planned discharge and promotion Summary of overall resear Results of personal lab to Other (please specify)	rnet, and television  d  udy location  oper goodbye to  rch results shared	research team with me	ture study?			
1.22 Please specify other imp	portant things:					
1.23 Please use the scale bel experience, and 10 is th  O 0 worst  O 1  O 2  O 3  O 4  O 5  O 6  O 7  O 8  O 9  O 10 best	e best possible ex	perience.		0 is the worst possible		
<ul> <li>1.24 What is the highest grade</li> <li>Sth grade or less</li> <li>Some high school, did not</li> <li>High school graduate or</li> <li>Some college or 2-year de</li> <li>4-year college graduate</li> <li>More than 4-year college</li> </ul>	ot graduate GED egree	ool that you have comple	eted?			
1.25 What is your age?  \( \text{\ti}\text{\texitex{\text{\text{\text{\texi}\text{\text{\texi{\texi{\text{\texi}\text{\texit{\text{\text{\texi\tinte\tint{\tintet{\text{\tet						





Research Participant Perception Survey - SP   ID: 2	
1.26 What is your race? (Please choose one or more)	
☐ American Indian or Alaska Native ☐ Asian	
<ul><li>□ Black or African American</li><li>□ Native Hawaiian or other Pacific Islander</li><li>□ White</li></ul>	
1.27 Are you of Spanish or Hispanic or Latino/ $a/x$ origin or descent?	
O No - not Spanish/Hispanic/Latino/a/x O Yes - Puerto Rican	
O Yes - Mexican/Mexican American/Chicano O Yes - Cuban	
$\bigcirc$ 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?	
<ul> <li>Female (including transgender women)</li> <li>Male (including transgender men)</li> <li>Non-binary/gender-fluid/agender</li> <li>Prefer not to say</li> </ul>	
1.30 Is there anything else you would like to share about your experience in the study you most recently joined?	

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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