

Decentralized clinical trials: Perspectives from research staff and participants within an urban, underserved clinical research network

Appendix A

Staff - Decentralized Clinical Trials Survey

Disclaimer & Consent

You are invited to participate in a survey about decentralized clinical trials (DCTs). This survey has been cleared by IRB as a quality improvement project and should take about 10 minutes to complete.

The goal of this survey is to find out the perspectives of clinical research staff and participants on decentralizing clinical trials. Participation in this study is voluntary. The information you share with us if you participate in this study will be kept completely anonymous. Your responses will help us learn about the benefits and challenges of DCTs, as well as which factors are most important in designing DCTs.

☐ Yes, I volunteer to take this survey.

Background on Decentralized Clinical Trials (DCTs)

How familiar are you with decentralized (also known as site-less, direct-to-patient, hybrid, remote, or virtual) clinical trials?

- ☐ I've never heard of decentralized clinical trials before.
- ☐ I have heard of decentralized clinical trials before, but do not know much about them.
- ☐ I know a lot about decentralized clinical trials.

The following link provides a general overview of what defines a decentralized clinical trial.

[Decentralized Clinical Trials](#)



(Drag page to the right to select fullscreen option on mobile)

Decentralized Clinical Trials (DCTs) are clinical trials where some or all of the trial-related activities occur at locations other than traditional hospital settings.

In full DCTs, all activities take place at locations other than

traditional hospital settings.

In hybrid DCTs, some trial activities involve in-person visits by trial participants to traditional hospital settings, and some activities are conducted at other locations.

Examples of DCT activities are: laboratory tests conducted by remote clinical laboratory facilities (e.g. LabCorp/Quest), telehealth, home visits from providers, digital health technologies (e.g. wearables), using local HCPs for research-related activities

For more information, please visit the FDA guidance released in May 2023: [“Decentralized Clinical Trials for Drugs, Biological Products, and Devices Guidance for Industry, Investigators, and Other Stakeholders”](#)

☐ I have watched or read the above information regarding decentralized clinical trials.

Demographics

What categories describe you? (Select all that apply).

- ☐ American Indian or Alaska Native (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
- ☐ Black or African American (For example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc)
- ☐ Asian (For example: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)

- ☐ Hispanic, Latino, or Spanish (For example: Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran, etc.)
- ☐ Middle Eastern or North African (For example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.)
- ☐ Native Hawaiian or other Pacific Islander (For example: Chamorro, Fijian, Marshallese, Native Hawaiian, Tongan, etc.)
- ☐ White (For example: English, European, French, German, Irish, Italian, Polish, etc.)

What detailed American Indian or Alaska Native category describes you? (Select all that apply).

- ☐ American Indian (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
- ☐ Alaska Native (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
- ☐ Central or South American Indian (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
- ☐ None of these fully describe me. Please Specify:

What detailed Black or African American categories describe you? (Select all that apply).

- ☐ South African
- ☐ Somali
- ☐ Nigerian
- ☐ Liberian
- ☐ Jamaican
- ☐ Haitian

- ☐ Ghanaian
- ☐ Ethiopian
- ☐ Caribbean
- ☐ African American
- ☐ Barbadian
- ☐ None of these fully describe me. Please specify:

What detailed Asian categories describe you? (Select all that apply).

- ☐ Asian Indian
- ☐ Vietnamese
- ☐ Pakistani
- ☐ Korean
- ☐ Japanese
- ☐ Hmong
- ☐ Filipino
- ☐ Chinese
- ☐ Cambodian
- ☐ None of these fully describe me. Please specify:

What detailed Hispanic, Latino, or Spanish category describes you?
(Select all that apply).

- ☐ Colombian
- ☐ Cuban
- ☐ Dominican
- ☐ Ecuadorian
- ☐ Honduran

- ☐ Mexican or Mexican American
- ☐ Puerto Rican
- ☐ Salvadoran
- ☐ Spanish
- ☐ None of these fully describe me. Please specify:

What detailed Middle Eastern or North African categories describe you? (Select all that apply).

- ☐ Afghan
- ☐ Algerian
- ☐ Egyptian
- ☐ Iranian
- ☐ Iraqi
- ☐ Israeli
- ☐ Lebanese
- ☐ Moroccan
- ☐ Syrian
- ☐ Tunisian
- ☐ None of these fully describe me. Please specify:

What detailed Native Hawaiian or other Pacific Islander categories describe you? (Select all that apply).

- ☐ Chamorro
- ☐ Chuukese
- ☐ Fijian

- ☐ Marshallese
- ☐ Native Hawaiian
- ☐ Palauan
- ☐ Samoan
- ☐ Tahitian
- ☐ Tongan
- ☐ None of these fully describe me. Please specify:

What detailed White categories describe you? (Select all that apply).

- ☐ Dutch
- ☐ English
- ☐ European
- ☐ French
- ☐ German
- ☐ Irish
- ☐ Italian
- ☐ Norwegian
- ☐ Polish
- ☐ Scottish
- ☐ Spanish
- ☐ None of these fully describe me. Please specify:

What terms best express how you describe your gender identity?
(Select all that apply).

- ☐ Man
- ☐ Woman

- ☐ Nonbinary
- ☐ Transgender
- ☐ None of these describe me (please specify):
- ☐ Prefer not to answer

What is your age?

- ☐ under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65 or older

What languages do you speak? (Please specify which language if you speak a language other than English).

- ☐ English only
- ☐ English and another language

Research Background

What is your role within clinical research?

- ☐ CTSI research nurse
- ☐ CTSI research coordinator
- ☐ Non-CTSI research nurse
- ☐ Non-CTSI research coordinator
- ☐ Pharmacy team member
- ☐ Principal investigator
- ☐ Other

What clinical research department have you been involved with?
(Select all that apply).

- ☐ Cardiology
- ☐ Infectious Disease
- ☐ Pulmonary and Critical Care
- ☐ Endocrinology
- ☐ Nephrology
- ☐ Gastroenterology
- ☐ Rheumatology
- ☐ General Medicine
- ☐ Pediatrics
- ☐ Other
- ☐ I don't know

How long have you been involved in clinical research?

- ☐ 0-1 year
- ☐ 1-2 years
- ☐ 3-5 years

☐ 5+ years

Which NYU location are you primarily located at?

- ☐ Manhattan
- ☐ Brooklyn
- ☐ Long Island

Concerns

Use this video link on [Decentralized Clinical Trials](#) for reference throughout the survey. NOTE: Decentralized Clinical Trials (DCTs) are clinical trials where some or all of the trial-related activities occur at locations other than traditional hospital settings.

Which of the following safety concerns (if any) do you have about decentralized clinical trials? (Select all that apply). If none, please explain why.

- ☐ Adverse effects
- ☐ Appropriate drug storage
- ☐ Appropriate drug transportation
- ☐ Appropriate dosage
- ☐ Appropriate drug administration
- ☐ Patient privacy

- ☐ Adequate patient monitoring
- ☐ I don't know
- ☐ Other
- ☐ None

Which of the following quality concerns (if any) do you have about decentralized clinical trials? (Select all that apply). If none, please explain why.

- ☐ Accurate data monitoring
- ☐ Study procedure documentation
- ☐ Specimen quality
- ☐ Protocol adherence
- ☐ Patient experience
- ☐ Patient recruitment
- ☐ Staff communication with patient
- ☐ I don't know
- ☐ Other
- ☐ None

Which of the following financial concerns (if any) do you have about decentralized clinical trials? (Select all that apply). If none, please explain why.

- ☐ Additional resources

- ☐ Additional trainings
- ☐ Third party contracts
- ☐ Patient reimbursement
- ☐ I don't know
- ☐ Other
- ☐ None

Barriers

Use this video link on [Decentralized Clinical Trials](#) for reference throughout the survey. NOTE: Decentralized Clinical Trials (DCTs) are clinical trials where some or all of the trial-related activities occur at locations other than traditional hospital settings.

Which patient populations do you think **stand to gain the most from decentralization**? (Select all that apply). If none, please explain why.

- ☐ Immunocompromised/Chronically ill
- ☐ Geriatric
- ☐ Pediatric
- ☐ Urban population
- ☐ Rural population
- ☐ Minority demographics (e.g. LGBTQ, Black, low income)

- ☐ Majority demographics (e.g. middle/high socioeconomic class, white)
- ☐ Lower income populations
- ☐ Middle class populations
- ☐ Wealthy populations
- ☐ I don't know.

☐ Other

☐ None

What barriers do you foresee preventing patient enrollment ***in fully on-site research studies***? (Select all that apply). If none, please explain why.

- ☐ Finances/cost
- ☐ Transportation
- ☐ Technological proficiency
- ☐ Technological access
- ☐ Language/interpreter availability
- ☐ Location
- ☐ Time spent for participation
- ☐ Support System
- ☐ Medical Mistrust
- ☐ I don't know

☐ Other

☐ None

What barriers do you foresee preventing patient enrollment in **decentralized research studies (including hybrid DCT)**? (Select all that apply). If none, please explain why.

- ☐ Finances/cost
- ☐ Transportation
- ☐ Technological proficiency
- ☐ Technological access
- ☐ Language/interpreter availability
- ☐ Location
- ☐ Time spent for participation
- ☐ Support System
- ☐ Medical Mistrust
- ☐ Other
- ☐ None
- ☐ I don't know

Feasibility

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Which processes do you think would take **more time in decentralized clinical trials**, compared to fully centralized trials? (Select all that apply). If none, please explain why.

- ☐ Regulatory approval
- ☐ Recruitment
- ☐ Informed Consent
- ☐ Initial Intake encounter
- ☐ Intervention (e.g. drug, survey instrument, device)
- ☐ Data Collection
- ☐ I don't know
- ☐ Other
- ☐ None

Which of these DCT options do you think are the most feasible to implement? (Drag to rank the below options, with 1 being the most feasible and 5 being the least feasible).

Laboratory Tests: conducted by clinical laboratory facilities at locations remote from traditional hospital settings (e.g. LabCorp/Quest)

Telehealth/Home Visits: interactions with trial participants in different locations allow for fewer in-person visits to clinical trial sites

Digital Health Technologies (DHTs): collection of trial-related data remotely (e.g. wearables)

Local Health Care Providers (HCPs): using local HCPs for research-related activities

Other

Thoughts & Concerns

Do you have any other thoughts or concerns?

Appendix B

Participant - Decentralized Clinical Trials Survey

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☐ Yes, I volunteer to take this survey.

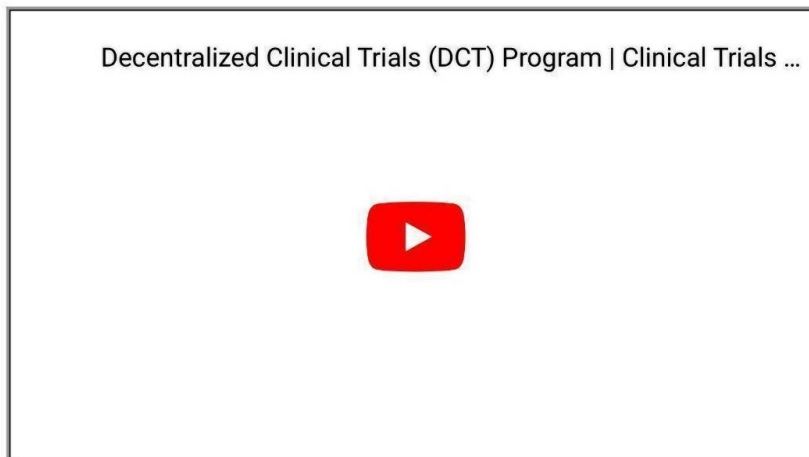
Background on Decentralized Clinical Trials DCTs

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- ☐ Black or African American (For example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc)
- ☐ Asian (For example: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)

- ☐ Hispanic, Latino, or Spanish (For example: Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran, etc.)
- ☐ Middle Eastern or North African (For example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.)
- ☐ Native Hawaiian or other Pacific Islander (For example: Chamorro, Fijian, Marshallese, Native Hawaiian, Tongan, etc.)
- ☐ White (For example: English, European, French, German, Irish, Italian, Polish, etc.)

What detailed American Indian or Alaska Native category describes you? (Select all that apply).

- ☐ American Indian (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
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- ☐ Central or South American Indian (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation, Native Village of Barrow (Utqiagvik) Inupiat Traditional Government, Nome Eskimo Community, etc.)
- ☐ None of these fully describe me. Please Specify:

What detailed Black or African American categories describe you? (Select all that apply).

- ☐ South African
- ☐ Somali
- ☐ Nigerian
- ☐ Liberian
- ☐ Jamaican
- ☐ Haitian

- ☐ Ghanaian
- ☐ Ethiopian
- ☐ Caribbean
- ☐ African American
- ☐ Barbadian
- ☐ None of these fully describe me. Please specify:

What detailed Asian categories describe you? (Select all that apply).

- ☐ Asian Indian
- ☐ Vietnamese
- ☐ Pakistani
- ☐ Korean
- ☐ Japanese
- ☐ Hmong
- ☐ Filipino
- ☐ Chinese
- ☐ Cambodian
- ☐ None of these fully describe me. Please specify:

What detailed Hispanic, Latino, or Spanish category describes you?
(Select all that apply).

- ☐ Colombian
- ☐ Cuban
- ☐ Dominican
- ☐ Ecuadorian
- ☐ Honduran

- ☐ Mexican or Mexican American
- ☐ Puerto Rican
- ☐ Salvadoran
- ☐ Spanish
- ☐ None of these fully describe me. Please specify:

What detailed Middle Eastern or North African categories describe you? (Select all that apply).

- ☐ Afghan
- ☐ Algerian
- ☐ Egyptian
- ☐ Iranian
- ☐ Iraqi
- ☐ Israeli
- ☐ Lebanese
- ☐ Moroccan
- ☐ Syrian
- ☐ Tunisian
- ☐ None of these fully describe me. Please specify:

What detailed Native Hawaiian or other Pacific Islander categories describe you? (Select all that apply).

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- ☐ Chuukese
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- ☐ Marshallese
- ☐ Native Hawaiian
- ☐ Palauan
- ☐ Samoan
- ☐ Tahitian
- ☐ Tongan
- ☐ None of these fully describe me. Please specify:

What detailed White categories describe you? (Select all that apply).

- ☐ Dutch
- ☐ English
- ☐ European
- ☐ French
- ☐ German
- ☐ Irish
- ☐ Italian
- ☐ Norwegian
- ☐ Polish
- ☐ Scottish
- ☐ Spanish
- ☐ None of these fully describe me. Please specify:

What terms best express how you describe your gender identity?
(Select all that apply).

- ☐ Man
- ☐ Woman

- ☐ Nonbinary
- ☐ Transgender
- ☐ None of these describe me (please specify):
- ☐ Prefer not to answer

What is your age?

- ☐ under 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65 or older

What languages do you speak? (Please specify which language if you speak a language other than English).

- ☐ English only
- ☐ English and another language

What is your zip code?

Research Background

What is your role within clinical research? (Note: patient caregivers should answer according to their own experiences, not on the patient's behalf).

- ☐ Patient
- ☐ Patient caregiver
- ☐ Other

What type of clinical research have you participated in? (Select all that apply).

- ☐ Cardiology
- ☐ Infectious Disease
- ☐ Pulmonary and Critical Care
- ☐ Endocrinology
- ☐ Nephrology
- ☐ Gastroenterology
- ☐ Rheumatology
- ☐ General Medicine
- ☐ Pediatrics
- ☐ Other
- ☐ I don't know

How long have you been participating in clinical research?

- ☐ 0-1 year
- ☐ 1-2 years
- ☐ 3-5 years
- ☐ 5+ years

Which NYU location are you primarily located at?

- ☐ Manhattan
- ☐ Brooklyn
- ☐ Long Island

Concerns

Use this video link on [Decentralized Clinical Trials](#) for reference throughout the survey. NOTE: Decentralized Clinical Trials (DCTs) are clinical trials where some or all of the trial-related activities occur at locations other than traditional hospital settings.

Which of the following safety concerns (if any) do you have about decentralized clinical trials? (Select all that apply). If none, please

explain why.

- ☐ Experiencing undesired drug effects
- ☐ Being able to store the drug (eg. at specific temperatures, in a safe location)
- ☐ Receiving the drug in a safe and timely manner
- ☐ Taking the drug by yourself
- ☐ Maintaining privacy of your health information
- ☐ I don't know
- ☐ Other
- ☐ None

Which of the following quality concerns (if any) do you have about decentralized clinical trials? (Select all that apply). If none, please explain why.

- ☐ Collecting and reporting data by yourself (eg. blood pressure, sleep schedule, steps)
- ☐ Sample quality (eg. blood, urine, saliva)
- ☐ Being able to follow research instructions by yourself
- ☐ Your personal experience
- ☐ Getting enough patients to participate
- ☐ Communicating with staff
- ☐ I don't know
- ☐ Other
- ☐ None

Which of the following financial concerns (if any) do you have about decentralized clinical trials? (Select all that apply). If none, please explain why.

- ☐ Having to attend additional trainings (e.g. to administer the drug at home)
- ☐ Buying the necessary equipment (e.g. what you need for wi-fi, specific technological devices)
- ☐ Traveling to off-site locations
- ☐ Change in compensation
- ☐ Liability (e.g. damage to trial equipment, injury to home visit staff)
- ☐ Using additional security measures (e.g. getting malware protection or an encrypted patient portal)
- ☐ I don't know
- ☐ Other
- ☐ None

Barriers

Use this video link on [Decentralized Clinical Trials](#) for reference throughout the survey. NOTE: Decentralized Clinical Trials (DCTs) are clinical trials where some or all of the trial-related activities occur at locations other than traditional hospital settings.

Which patient populations do you think **stand to gain the most from decentralization**? (Select all that apply). If none, please explain why.

- ☐ Immunocompromised/Chronically ill
- ☐ Elderly
- ☐ Children
- ☐ Urban population
- ☐ Rural population
- ☐ Minority demographics (e.g. LGBTQ, Black, low income)
- ☐ Majority demographics (e.g. middle/high socioeconomic class, white)
- ☐ Lower income populations
- ☐ Middle class populations
- ☐ Wealthy populations
- ☐ I don't know
- ☐ Other
- ☐ None

What barriers do you foresee preventing patient enrollment **in fully onsite research studies**? (Select all that apply). If none, please explain why.

- ☐ Finances/cost
- ☐ Transportation
- ☐ Technological proficiency
- ☐ Technological access
- ☐ Language/interpreter availability
- ☐ Location
- ☐ Time spent for participation

- ☐ Support System
- ☐ Medical Mistrust
- ☐ I don't know
- ☐ Other
- ☐ None

What barriers do you foresee preventing patient enrollment in **decentralized research studies (including hybrid DCT)**? (Select all that apply). If none, please explain why.

- ☐ Finances/cost
- ☐ Transportation
- ☐ Technological proficiency
- ☐ Technological access
- ☐ Language/interpreter availability
- ☐ Location
- ☐ Time spent for participation
- ☐ Support System
- ☐ Medical Mistrust
- ☐ I don't know
- ☐ Other
- ☐ None

Feasibility

Use this video link on [Decentralized Clinical Trials](#) for reference throughout the survey. NOTE: Decentralized Clinical Trials (DCTs) are clinical trials where some or all of the trial-related activities occur at locations other than traditional hospital settings.

Which processes do you think would take **more time in decentralized clinical trials**, compared to fully centralized trials? (Select all that apply). If none, please explain why.

- ☐ Enrolling in the study
- ☐ Going over the consent form (e.g. e-consent, consent by phone)
- ☐ Initial trial visit
- ☐ Follow up trial visits
- ☐ Performing the intervention (e.g. drug, survey instrument, device)
- ☐ Collecting and recording data
- ☐ I don't know
- ☐ Other
- ☐ None

Which of these DCT options is most feasible for you to participate in? (Drag to rank the below options, with 1 being the most feasible and 5 being the least feasible).

Laboratory Tests: conducted by clinical laboratory facilities at locations remote from traditional hospital settings (e.g. LabCorp/Quest)

Telehealth/Home Visits: interactions with trial participants in different locations allow for fewer in-person visits to clinical trial sites

Digital Health Technologies (DHTs): collection of trial-related data remotely (e.g. wearables)

Local Health Care Providers (HCPs): using local HCPs for research-related activities

Other

Thoughts & Concerns

Do you have any other thoughts or concerns?

Appendix C

Staff Respondent Demographics

Staff Respondent Demographics		
	Number of Respondents	Percentage of Total
Race/Ethnicity		
American Indian or Alaska Native	0	0.00%
Asian	10	31.25%
<i>Asian Indian</i>	2	6.25%
<i>Vietnamese</i>	0	0.00%
<i>Pakistani</i>	0	0.00%
<i>Korean</i>	0	0.00%
<i>Japanese</i>	0	0.00%
<i>Hmong</i>	0	0.00%
<i>Filipino</i>	6	18.75%
<i>Chinese</i>	1	3.13%
<i>Cambodian</i>	0	0.00%
<i>None of these fully describe me</i>	2	6.25%
Black or African American	0	0.00%
Hispanic, Latino, or Spanish	4	12.50%
<i>Colombian</i>	0	0.00%
<i>Cuban</i>	1	3.13%
<i>Dominican</i>	0	0.00%
<i>Ecuadorian</i>	0	0.00%
<i>Honduran</i>	0	0.00%
<i>Mexican or Mexican American</i>	0	0.00%
<i>Puerto Rican</i>	0	0.00%
<i>Salvadoran</i>	1	3.13%
<i>Spanish</i>	0	0.00%
<i>None of these fully describe me</i>	2	6.25%
<i>Multiethnic</i>	1	3.13%
Middle Eastern or North African	2	6.25%
<i>Afghan</i>	0	0.00%
<i>Algerian</i>	0	0.00%
<i>Egyptian</i>	0	0.00%
<i>Iranian</i>	0	0.00%
<i>Iraqi</i>	0	0.00%
<i>Israeli</i>	1	3.13%

<i>Lebanese</i>	0	0.00%
<i>Moroccan</i>	0	0.00%
<i>Syrian</i>	0	0.00%
<i>Tunisian</i>	0	0.00%
<i>None of these fully describe me</i>	1	3.13%
Native Hawaiian or other Pacific Islander	0	0.00%
White	13	40.63%
<i>Dutch</i>	0	0.00%
<i>English</i>	0	0.00%
<i>European</i>	3	9.38%
<i>French</i>	0	0.00%
<i>German</i>	1	3.13%
<i>Irish</i>	1	3.13%
<i>Italian</i>	2	6.25%
<i>Norwegian</i>	0	0.00%
<i>Polish</i>	0	0.00%
<i>Scottish</i>	0	0.00%
<i>Spanish</i>	1	3.13%
<i>None of these fully describe me</i>	1	3.13%
<i>Multiethnic</i>	4	12.50%
Multiracial	3	9.38%
Gender		
Man	7	21.88%
Woman	24	75.00%
Nonbinary	0	0.00%
Transgender	0	0.00%
None of these describe me	0	0.00%
Prefer not to answer	1	3.12%
Age		
Under 18	0	0.00%
18-24	2	6.25%
25-34	10	31.25%
35-44	7	21.88%
45-54	5	15.62%
55-64	6	18.75%
65 or older	2	6.25%
Languages		
English only	16	50.00%
English and another language	16	50.00%

<i>Spanish</i>	3	9.38%
<i>Hebrew</i>	1	3.13%
<i>Filipino</i>	2	6.25%
<i>Tagalog</i>	1	3.13%
<i>Russian</i>	1	3.13%
<i>2+ languages</i>	3	9.38%
Role in Clinical Research		
CTSI research nurse	8	25.00%
CTSI research coordinator	3	9.38%
Non-CTSI research nurse	1	3.13%
Non-CTSI research coordinator	6	18.75%
Pharmacy team member	1	3.13%
Principal investigator	7	21.88%
Other	6	18.75%
Research Department Experience		
Cardiology	14	43.75%
Infectious Disease	15	46.88%
Pulmonary and Critical Care	11	34.38%
Endocrinology	9	28.13%
Nephrology	8	25.00%
Gastroenterology	8	25.00%
Rheumatology	8	25.00%
General Medicine	14	43.75%
Pediatrics	17	53.13%
Other	14	43.75%
I don't know	0	0.00%
Length of Research Experience		
0-1 year	2	6.25%
1-2 years	7	21.88%
3-5 years	5	15.63%
5+ years	18	56.25%
Primary NYU Location		
Manhattan	16	50.00%
Brooklyn	6	18.75%
Long Island	10	31.25%

Appendix D

Participant Respondent Demographics

Participant Respondent Demographics		
	Number of Respondents	Percentage of Total
Race/Ethnicity		
American Indian or Alaska Native	0	0.00%
Asian	2	3.45%
<i>Asian Indian</i>	<i>1</i>	<i>1.72%</i>
<i>Vietnamese</i>	<i>0</i>	<i>0.00%</i>
<i>Pakistani</i>	<i>0</i>	<i>0.00%</i>
<i>Korean</i>	<i>0</i>	<i>0.00%</i>
<i>Japanese</i>	<i>0</i>	<i>0.00%</i>
<i>Hmong</i>	<i>0</i>	<i>0.00%</i>
<i>Filipino</i>	<i>1</i>	<i>1.72%</i>
<i>Chinese</i>	<i>0</i>	<i>0.00%</i>
<i>Cambodian</i>	<i>0</i>	<i>0.00%</i>
<i>None of these fully describe me</i>	<i>0</i>	<i>0.00%</i>
Black or African American	7	12.07%
<i>South African</i>	<i>0</i>	<i>0.00%</i>
<i>Somali</i>	<i>0</i>	<i>0.00%</i>
<i>Nigerian</i>	<i>1</i>	<i>1.72%</i>
<i>Liberian</i>	<i>0</i>	<i>0.00%</i>
<i>Jamaican</i>	<i>0</i>	<i>0.00%</i>
<i>Haitian</i>	<i>0</i>	<i>0.00%</i>
<i>Ghanaian</i>	<i>0</i>	<i>0.00%</i>
<i>Ethiopian</i>	<i>0</i>	<i>0.00%</i>
<i>Caribbean</i>	<i>1</i>	<i>1.72%</i>
<i>African American</i>	<i>4</i>	<i>6.90%</i>
<i>Barbadian</i>	<i>0</i>	<i>0.00%</i>
<i>None of these fully describe me</i>	<i>0</i>	<i>0.00%</i>
<i>Multiethnic</i>	<i>1</i>	<i>1.72%</i>
Hispanic, Latino, or Spanish	2	3.45%
<i>Colombian</i>	<i>0</i>	<i>0.00%</i>
<i>Cuban</i>	<i>0</i>	<i>0.00%</i>

<i>Dominican</i>	0	0.00%
<i>Ecuadorian</i>	0	0.00%
<i>Honduran</i>	0	0.00%
<i>Mexican or Mexican American</i>	0	0.00%
<i>Puerto Rican</i>	1	1.72%
<i>Salvadoran</i>	0	0.00%
<i>Spanish</i>	0	0.00%
<i>None of these fully describe me</i>	1	1.72%
Middle Eastern or North African	1	1.72%
<i>Afghan</i>	0	0.00%
<i>Algerian</i>	0	0.00%
<i>Egyptian</i>	0	0.00%
<i>Iranian</i>	0	0.00%
<i>Iraqi</i>	0	0.00%
<i>Israeli</i>	0	0.00%
<i>Lebanese</i>	0	0.00%
<i>Moroccan</i>	0	0.00%
<i>Syrian</i>	0	0.00%
<i>Tunisian</i>	0	0.00%
<i>None of these fully describe me</i>	1	1.72%
Native Hawaiian or other Pacific Islander	0	0.00%
White	44	75.86%
<i>Dutch</i>	0	0.00%
<i>English</i>	4	6.90%
<i>European</i>	7	12.07%
<i>French</i>	1	1.72%
<i>German</i>	2	3.45%
<i>Irish</i>	2	3.45%
<i>Italian</i>	6	10.34%
<i>Norwegian</i>	0	0.00%
<i>Polish</i>	1	1.72%
<i>Scottish</i>	0	0.00%
<i>Spanish</i>	0	0.00%
<i>None of these fully describe me</i>	3	5.17%
<i>Multiethnic</i>	18	31.03%

Multiracial	2	3.45%
Gender		
Man	30	47.62%
Woman	27	42.86%
Nonbinary	1	1.59%
Transgender	0	0.00%
None of these describe me	0	0.00%
Prefer not to answer	0	0.00%
Age		
Under 18	0	0.00%
18-24	1	1.72%
25-34	5	8.62%
35-44	7	12.07%
45-54	8	13.79%
55-64	20	34.48%
65 or older	17	29.31%
Languages		
English only	41	68.25%
English and another language	17	31.75%
<i>Spanish</i>	3	9.52%
<i>Greek</i>	2	3.17%
<i>Yoruba</i>	1	1.59%
<i>German</i>	1	1.59%
<i>Hebrew</i>	1	1.59%
<i>Russian</i>	1	1.59%
<i>Italian</i>	1	1.59%
<i>2+ languages</i>	2	3.17%
Home Zip Code		
Queens	7	12.07%
Manhattan	5	8.62%
Brooklyn	5	8.62%
Outside NYC	41	70.69%
Role in Clinical Research		

participant	51	87.93%
participant caregiver	5	8.62%
Other	2	3.45%
Research Department Experience		
Cardiology	6	10.34%
Infectious Disease	27	46.55%
Pulmonary and Critical Care	1	1.72%
Endocrinology	1	1.72%
Nephrology	2	3.45%
Gastroenterology	0	0.00%
Rheumatology	0	0.00%
General Medicine	2	3.45%
Pediatrics	0	0.00%
Other	24	41.38%
I don't know	0	0.00%
Length of Research Experience		
0-1 year	16	27.59%
1-2 years	27	46.55%
3-5 years	11	18.97%
5+ years	4	6.90%
Primary NYU Location		
Manhattan	21	36.21%
Brooklyn	0	0.00%
Long Island	37	63.79%