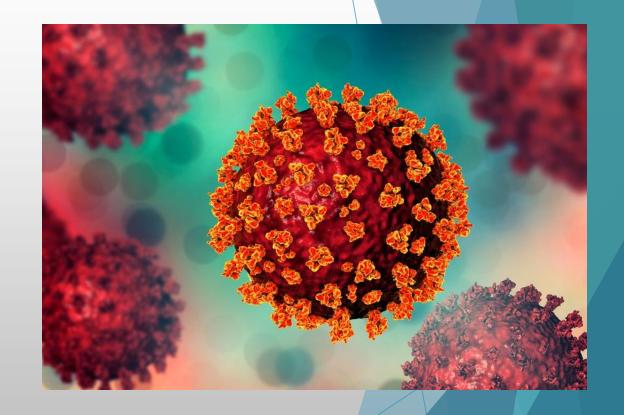
Understanding Long COVID in the Community:
A Exploratory Survey Project

Westchester County Department of Health



# Westchester County Department of Health



George Latimer, County Executive Sherlita Amler, MD, Commissioner Department of Health



Office of Minority Health and Health Disparities Prevention

# Westchester County Department of Health

givo of a study of a verb survey. verb examine examina







# **Learning Objectives:**

- ▶ Upon completion attendees will be able to recognize and restate key considerations in formulating and structuring culturally relevant survey questionnaires to gather data and information for effective public health program planning and outreach. A sample checklist will be provided to guide the steps involved in designing a community survey.
- ▶ Upon conclusion attendees will be able to compare and contrast the advantages/limitations of each data collection approach and the importance of diverse channels for maximizing participation rates. Participants will explore various collection methods in the distribution of the long COVID survey to reach and engage underserved communities effectively.

# **Project Background**

### What is long COVID?

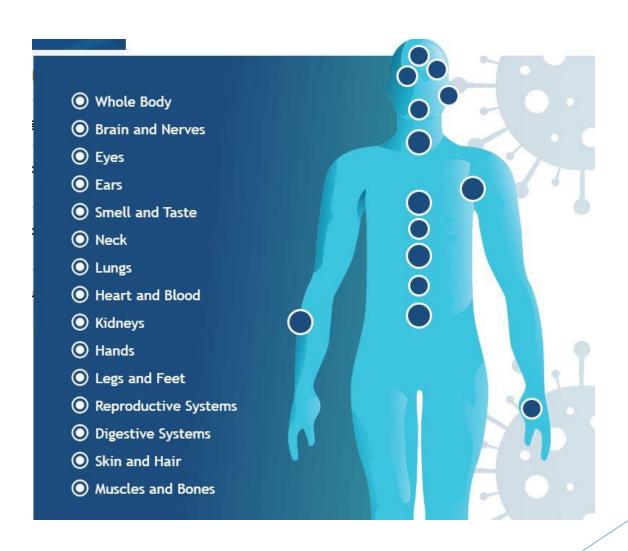
Long COVID, long-haul COVID, post-COVID-19 conditions, chronic COVID, and post-acute sequelae of SARS-CoV-2 (PASC) are all names for the health problems that some people experience within a few months of a COVID-19 diagnosis.

Long COVID | NIH COVID-19 Research

#### Definition:

Long COVID is broadly defined as signs, symptoms, and conditions that continue or develop after acute COVID-19 infection. This definition of Long COVID was developed by the Department of Health and Human Services (HHS) in collaboration with CDC and other partners.

# Symptoms of Long COVID



### What You Need to Know

- ► Long COVID can include a wide range of ongoing health problems; these conditions can last weeks, months, or years.
- ▶ Long COVID occurs more often in people who had severe COVID-19 illness, but anyone who has been infected with the virus that causes COVID-19 can experience it.
- ▶ People who are not vaccinated against COVID-19 and become infected may have a higher risk of developing Long COVID compared to people who have been vaccinated.
- ▶ People can be reinfected with SARS-CoV-2, the virus that causes COVID-19, multiple times. Each time a person is infected or reinfected with SARS-CoV-2, they have a risk of developing Long COVID.
- ▶ While most people with Long COVID have evidence of infection or COVID-19 illness, in some cases, a person with Long COVID may not have tested positive for the virus or known they were infected.

CDC and partners are working to understand more about who experiences Long COVID and why, including whether groups disproportionately impacted by COVID-19 are at higher risk.

### WHY IS THIS IMPORTANT?

► <u>Health inequities</u> may also increase the risk of Long COVID for some racial or ethnic minority groups and some people with disabilities.



### The RFP Process

- ► "A request for proposal, or RFP, is a document that describes a project's needs and asks for proposed solutions from qualified vendors
- Organizations typically use RFPs when they need outside help to complete a specific project.



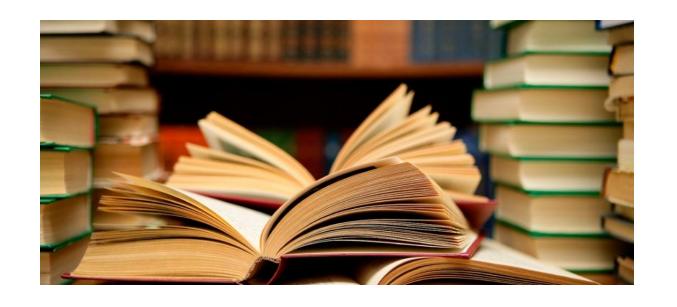
# Work Plan Development

- ► Step 1: Set goals
- Step 2: Lay out objectives and deliverables
- Step 3: List resources
- Step 4: Identify obstacles
- Step 5: Create a step-by-step plan
- Step 6: Execute and evaluate



# **Work Plan Development**

OBJECTIVE	BUDGET CATEGORY/ DELIVERABLE (if applicable)	TASKS	PERFORMANCE MEASURES
By June 30, 2023 identify and/or design post COVID survey to distribute in Greenburgh, Mount Kisco, Mount Vernon, New Rochelle, Ossining, Peekskill, Rye, White Plains and Yonkers.  1A. Identify study participants from Westchester County Department of Health (WCDH) pre-existing data		A. Research and identify Institution Review Board (IRB) entity to determine exemption criteria or apply for expedited or full IRB to conduct research study	<ul> <li>i. IRB process researched and determination made regarding whether exemption applicable or preparation for application of expedited or full IRB.</li> </ul>
base of confirmed cases between March 2020 and September 2022.			ii IRB application completed and submitted (if needed)
			iii. IRB application approved or exemption requirements satisfied
		B. EPI/Clinical team will meet to review and decide on best instrument to use for survey.	i. a clear concise purpose statement will be established
			ii. a clear research question will be established
			iii. Culturally relevant survey with appropriate permission developed and ready for distribution in targeted areas.
		C. Develop methodology for random selection of survey participants to filter participants from WCDH database	<ul> <li>i. Established statement for how participants will be selected and randomly assigned.</li> </ul>
			ii. Excel file containing filtered data
			iii Established statistics that will be used for analysis

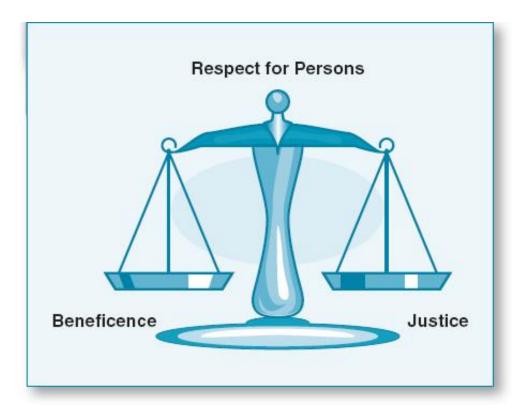


Literature Review on Long COVID Comparable Surveys
Survey Editing
Multilingual Surveys

**Survey Development** 

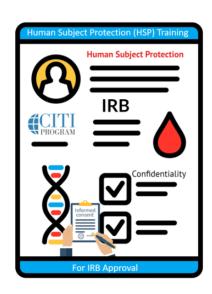
"Good judgment comes from experience and experience comes from poor judgment."
- An Aphorism

Guiding principles (the Belmont Report):



### IRB's & CFR's

IRB: Institutional Review Board committees that make sure researchers follow the HHS rules and ethical guidelines as they carry out their studies.



The Common Rule 45CFR46

CFR: code of federal regulations

Administrative law that defines what constitutes "research" as well as defines "human subject"

# The Revised Common Rule (2018)

Identifies four types of activities as <u>not</u> being "research" as defined in the Rule. In other words, the revised Common Rule does not apply to the following types of activities because they do not meet the regulatory definition of *research*:

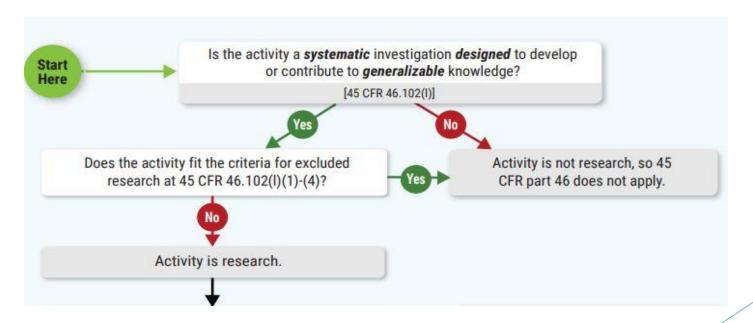
- Certain scholarly and journalistic activities;
- 2) Certain public health surveillance activities;
- 3) Collection and analysis of information, specimens, or records, by or for a criminal justice agency for certain criminal justice or investigative purposes; and,
- 4) Certain authorized operational activities for national security purposes.

### **EXEMPT OR NO?**

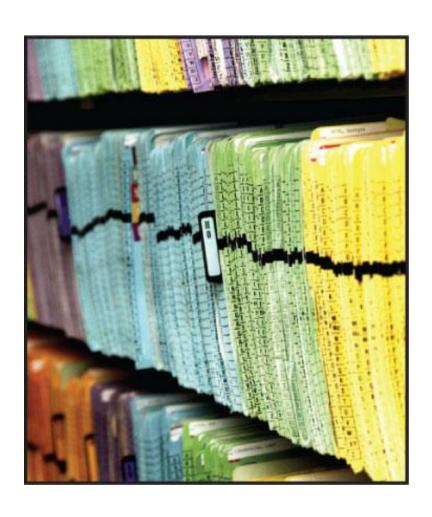
#### Revised Common Rule Categories of Exemption

<u>Category 2</u>: Research involving the use of educational tests, surveys, interviews, or observation.

Revised to allow for collection of potentially sensitive or harmful identifiable information from adults if the IRB makes a determination that adequate provisions for protecting privacy and maintaining confidentiality are in place.



# **Data Management**



# PRE-EXISTING DATABASE 300,00 (+) Contacts

815	43 K = 3	Gr.										
a 4			ь в		F.		H	I Long				M
in min	- Itel Beer	Maritime .	Drantment	Referented	- Test	- El Thomas	Loren	Historia III	Armed Science	Resolve County	City II	Told Dairy
Money.	HTM/ DAYS	or Monger	IT	Research & Deve in places.	PRODES.	Risch.	- 45	4/9/2000	\$341,694	12% united states	teactie	10/16/2001
£64005	Theodore Gren	Technical Architect	II .	Variationing	Male:	Asies:	-59	13/28/1997	599,575	PS Over	Chonge in g	
£ \$655.15	Long Sanders	Discours	Fine to:	Speciality Products	Fernée	Concesion	. 56	10/28/2986	SM0,099	28% United States	Chicopo	
BOURTS.	reactine andm	Computer Systems Manager	T.	Mendacturing.	Persole:	Caucasan	- 29	9/25/2009	\$80,901	- This contest trades	chesego	
DOLLER.	Austr. va	ir. Analyst	Firence	Manufacturing 1	Maria.	Value -	25	41/06/1985	\$10,489	PS (inted literal	Phoenix	
7 D00044	Apphys Gupto	Associat Representative.	Selso	Corporate	Male	Asien	57	1/04/1907	539,594	Ph. China	Change in g.	
8 800300	Diving Berner	Monager	п	Corporate	Nerade	Connector	27	7/3/2920	5115,746	19% United States	Pioente	
100000	Cube Hartin	Analysi	Finance	Manufacturing	MAKE	misch:	15	5/10/2003	Sealing	1% United States	Missel	5/08/0901
0 po4530	Conton Bailey	Monogor	Accounting	Manufacturing	Male	Courselan	29	1/05/0909	\$113,527	PS United States	Aartin	
1 015038	Madeline Walter	St. Analyst	Finence .	Speciality Products	Persele :	Concessor	34	6/15/2908	\$77,293	Pik United States	Chicago	
E ROOMS	besamble of	hr. Manger	HUTSE RESOURCE:	Manufacturing	Person	AURI	38	3/10/2009	\$227,104	15% united states	50490	
2 301044	Carriela Rogert	Controls Engineer	Eng nowing	Speciality Products	Formula	Couranten	- 20	10023/2001	\$309,060	4% Unred States	Scottle	
4 000030	28 Junes	Monager	Human Resources	Manufacturing	Male	Caucattan	59	3/14/1999	5305,086	5% United States	Agrim	
1 104733	the deigh big	N. Wanger	Program.	Lesenth & Development	Person	Asian		0/10/2021	\$346,763	10% chan	Marghar	
n accepto	Robert Yang	te analyst	Accounting	Speciality Products	500	Austr	- 40	10/4/1907	297,076	- 1% subted states	Reitin .	3/5/2018
7 000645	Liebella 30	Vice President	Workeling	Research & Devis legisters.	Formula	Appea	40	3/12/1903	\$349,276	36% United States	Scattle	
il cooper	tie la fowell	Oscillar	Finesce.	Recent & Development	femile.	Bledi	45	5/4/2907	5175,657	28% United States	Phoenix	
W RECORDS	caretanius	36 Blanger	Mintering	Special by Products.	persole	Limbo	10	13/3/2001	\$656,828	18th Juneed horses	textle	
D \$64536	David Earnes	Seption	O. H. Strander	Corporate	Sidelle	Caucaster	164	31/5/1903	\$265,563	265 United States	Columbus	
S 864825	Adam Dong	District	Selec	Research & Development	Male	Apien	45	7/5/1982	\$364,200	18% Chies	Storageing:	
of severe	Olai Ahairdo	Tr. Manger	TT .	Membersing	Male	Terro:		1/4/1003	\$148,16E	18% 2650	Maries	
0.0692	Sys Sivera	0 (10/00)	5090	Manufacturing	Female	Linters:	- 26	4/2/2003	\$20,794	22% United States	Miami	
4 D03454	Lopen Rivers	District	· II	Recent & Development	Male	Lettre	.55	5/04/1982	\$172,787	28'9 Ordel	Rito do Janesto	
3. 800031	Les sando Discore	Andre	Sales	Speciality Products	Male.	Caucedan	307	9/5/2009	543,998	I'm United States	Seattle	
D. MICHIGAN	PARTIES IN RET	rice Precident	Sales	Special by Products	Male:	MATER TO	.08	0/2/2008	\$307,173	Artiches	chorgoing.	
7 002206	Vose Hendelsen	Depoter	Hymor Resources	Special by Products	Male	B lack	40	4/13/1980	\$252,236	22% United States	Columbus	
5 104545	Alogad Victor	Quel to Displaces	Drig scening	Corporate	Fertile .	Lette:	5.88	2/5/2985	\$14,041	Eli Deci	Nade Investo	0
N BESEING	SAVARE SCHOOL	rise medient	anglassing	Special by modulos	Mile	4.031	- 46	0/1/1000	\$266,281	10% saved to see	Septie	
0 D00045	Cerson by	Engineering Monager	Engineering	Speciality Products	Male	Ares	- 64	12/4/1996	\$99,154	12% Other	Beijing	
S 50000A	Dylan Choi	Vice President	II.	Corporate	Mele	Acces	65	5/10/2802	5210,141	36% Ohre	Belling	
or recessor	Park of Curtar	If Court water	it .	Research & Development	Male	4564	38	1/20/2007	\$14,775	6% January States	Columbus	

### **DATA COLLECTION**

#### TARGET DEMOGRAPHIC

- 9 minority AREAS OF WESTCHESTER County
- Greenburgh
- Mt. Kisco
- Mt. Vernon
- New Rochelle
- Ossining
- Peekskill
- Rye
- White Plains
- Yonkers

### 2020 Census [edit]

#### Westchester County Racial Composition<sup>[23]</sup>

Race	Num.	Perc.
White (NH)	497,684	49.55%
Black or African American (NH)	131,010	13.04%
Native American (NH)	1,017	0.1%
Asian (NH)	64,907	6.5%
Pacific Islander (NH)	150	.01%
Other/Mixed (NH)	40,355	4.02%
Hispanic or Latino	269,334	26.81%

# SURVEY DISTRIBUTION

E-MAILS

COMMUNITY OUTREACH

FLYERS w/ QR CODES

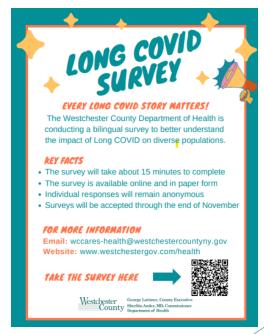
PHONE CALLS

MAILINGS









### DATA COLLECTION

#### mixed methods

- convenience sampling involves stopping people at random, which means that not everyone has an equal chance of being selected depending on the place, time, or day you are collecting your data.
- ► Random sampling or <u>probability sampling</u> is based on random selection. This means that each unit has an equal chance (i.e., equal probability) of being included in the sample.

# **Convenience Sampling**

### pros

- Save time, money, and effort
- Data is available immediately
- ► Limited rules and more freedom
- Secure a wealth of information
- Acknowledging shortcomings improves the validity

#### cons

- Difficulty replicating results
- Inaccurate representation
- Researcher bias
- Producing False Data

# Random Sampling

### pros

- Easy to implement
- This method is very efficient and can be used to select a sample from a large population quickly.
- The data collected using simple random is typically representative of the entire population.
- ► Each member of the population has an equal chance of being chosen.
- Free from bias.

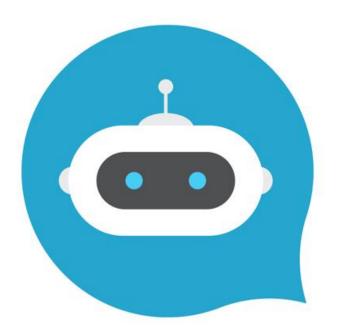
#### cons

- There is a slight chance that the sample selected may not represent the population.
- Minority subgroups within the population may not be present in sample.
- If the sampling frame is large random sampling may be impractical.
- ► Time Consuming.
- ► A complete list of the population may not be available.

# **Bot Management**

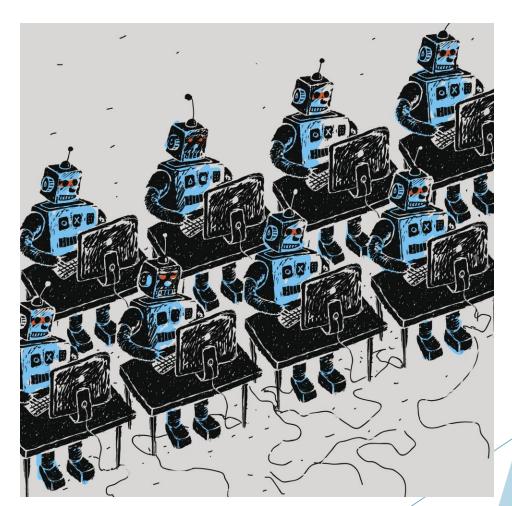
### What are bots?

In online surveys, when we talk about "bots," we mean scripts or programs that fill in fake value on a survey and keeps submitting it over and over. The aim is to get the promised reward multiple times.



# Fields for Identifying Fraudulent Records

- Timestamps
- Branching logic and "impossible" fields
- Attention items
- Repeated items
- Open ended questions



# Fields for Identifying Fraudulent Records

4	Α	В	С	D	Е	F	G	н	1	J	K
1	Responde	Collector ID	Start Date	End Date	IP Address	Email Add	First Nam	Last Nam	Custom [	Name (optional)	The electronic gift card will arrive in your inbox. At
2										Open-Ended Response	Open-Ended Response
89	1.18E+11	452718898	2023-10-11 10:09:34	2023-10-11 10:12:44	191.96.227.94					Caddock Mercado	hannahherty587@gmail.com
90	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:44	66.108.209.87					Bhoja Queen	zciuew@gmail.com
91	1.18E+11	452718898	2023-10-11 10:09:34	2023-10-11 10:12:44	64.145.79.106					Dmitry Otto	ferrylmwuxc@gmail.com
92	1.18E+11	452718898	2023-10-11 10:09:34	2023-10-11 10:12:44	151.202.50.250					Pazel Lam	wyattaaron77@gmail.com
93	1.18E+11	452718898	2023-10-11 10:09:34	2023-10-11 10:12:44	98.14.163.86					Loletta Oliphant	CapShauot@gmail.com
94	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:44	108.6.188.234					Bretton Peak	ncebroav@gmail.com
95	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:44	68.161.182.135					Acelin Hutcheson	Bairdxht@gmail.com
96	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:44	68.197.19.100					Felice Muniz	umsgcp@gmail.com
97	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:44	69.124.228.195					Shanese Sims	candicewatt267@gmail.com
98	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:44	24.90.11.241					Ashaunta Early	caiwang2864@gmail.com
99	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:43	47.230.115.118					Natanya Garland	Mildredpsu@gmail.com
100	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:43	47.230.112.52					Christey Shumaker	merr5950@gmail.com
101	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:43	24.46.119.109					Gennara Rousseau	ClayDorisy@gmail.com
102	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:43	156.238.158.203					Treasha Monk	BragErmic@gmail.com
103	1.18E+11	452718898	2023-10-11 10:09:34	2023-10-11 10:12:43	108.15.28.110					Johna Stephens	buckjudy05@gmail.com
104	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:43	100.12.173.42					Jehovah Westfall	spenderwerner@gmail.com
105	1.18E+11	452718898	2023-10-11 10:09:33	2023-10-11 10:12:43	74.101.145.84					Orion Bryson	zthang876@gmail.com

# **Outsmarting Bots**

#### **Long COVID Survey**

I. FREQUENCY

\* 1. To verify you are not a computer, please identify what you see in the picture below:



#### **Encuesta de COVID Persistente**

I. FRECUENCIA

\* 1. Para fines de verificación, identifique lo que ve en la imagen a continuación.



### **Incentives**



### pros

- Boosting Response Rates
- Targeting Hard-to-Reach People
- Reattempting to Gain Participation
- Encouraging Response on Lengthy Surveys
- Building Goodwill

#### cons

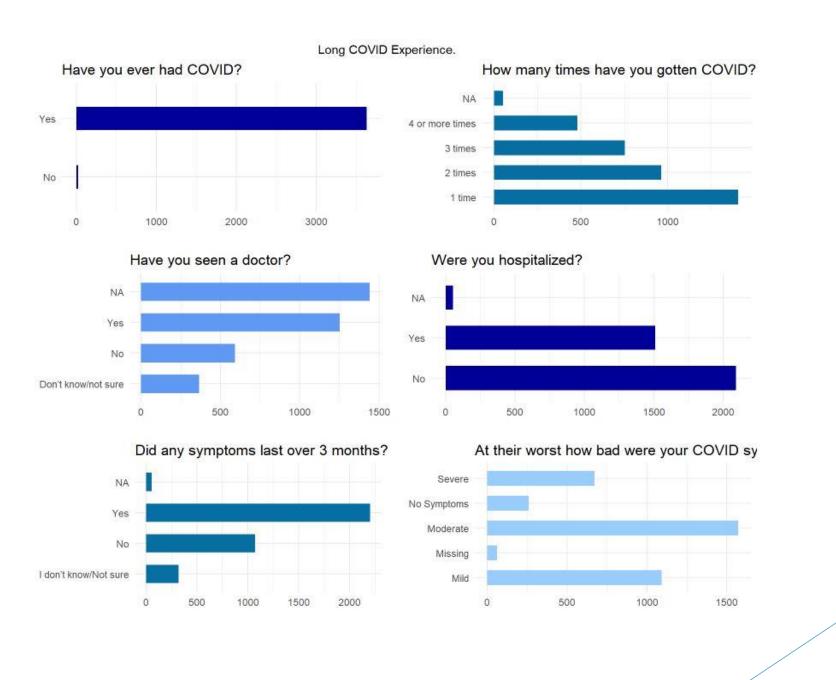
- Attracting Reward-Seekers
- Introducing Survey Bias
- Hurting Your Budget
- Disappointing Participants
- Offering Biased Rewards



# Data Analysis Table One: Exploratory Data Analysis

Gender					
Woman	1824 (49.9%)				
Man	1713 (46.9%)				
Non-binar y	6 (0.2%)				
Transgender Man	4 (0.1%)				
Transgender Woman	1 (0.0%)				
Missing	107 (2.9%)				
Race					
Black or African-American	753 (20.6%)				
White	2385 (65.3%)				
Other (please specify)	4 (0.1%)				
Native Hawaiian or Pacific Islander	32 (0.9%)				
Asian	16 (0.4%)				
American Indian	349 (9.5%)				
Two or more races	16 (0.4%)				
I prefer not to answer	4 (0.1%)				
Missing	96 (2.6%)				
Hispanic					
No	3337 (91.3%)				
Yes	183 (5.0%)				
I prefer not to answer	6 (0.2%)				
Not sur e	27 (0.7%)				
Missing	102 (2.8%)				
Age					
35-54 years old	1882 (51.5%)				
65+ years old	18 (0.5%)				
18-34 years old	1233 (33.7%)				
55-64 years old	433 (11.8%)				
Missing	89 (2.4%)				

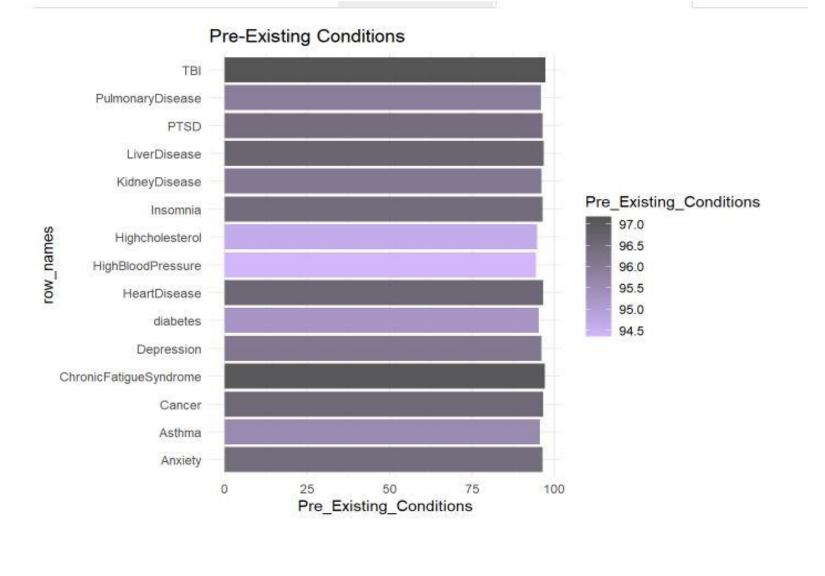
Education	
High School graduate/GED	549 (15.0%)
Advanced or professional degree	590 (16.1%)
College graduate	1003 (27.4%)
Less than high school	225 (6.2%)
Some college or technical school	1172 (32.1%)
Missing	116 (3.2%)
Employment	
Employed	1950 (53.4%)
Employed part-time	897 (24.5%)
Unemployed	273 (7.5%)
Self-employed	418 (11.4%)
Disabled	8 (0.2%)
Retired	3 (0.1%)
Other (please specify)	2 (0.1%)
Missing	104 (2.8%)
Vaccinated	
Yes	2881 (78.8%)
No	691 (18.9%)
Missing	83 (2.3%)
Insurance	
Private or Employer Provided	1164 (31.8%)
Medicare	969 (26.5%)
Uninsur ed	608 (16.6%)
Medicaid	818 (22.4%)
Missing	96 (2.6%)

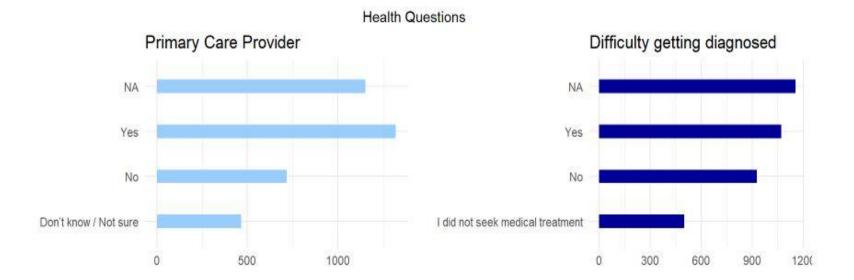


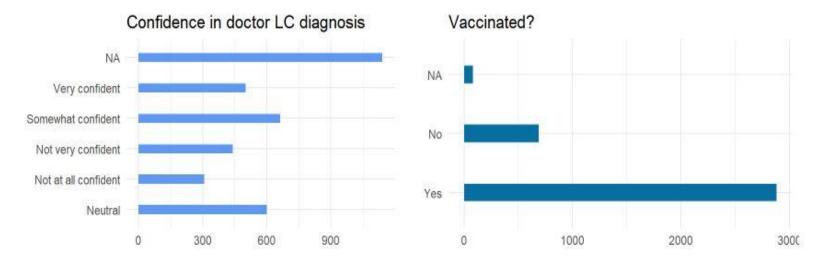
#### Financial impacts of Long COVID illness (Percentage selecting each condition) 20. I have NOT had a financial impact 19. I have lost my medical insurance 18. I have lost or I am about to lose my car 17. I have lost or I am about to lose my home. 16. Single parent with or providing care for family with Long COVID 15. I have a family / members of my household who lost income due to Long COVID 14. I do not know about the available assistance programs/resources FinancialImpacts 13. I do not qualify for the assistance programs that would help my situation 12. The assistance programs I was relying on have ended 11. I have filed or am about to file for disability 10 10. I have accumulated debt 9. I have medical bills I am unable to pay 8. I had a delayed return to work due to ongoing symptoms. 7. No Paid Sick Time 6. Family caregiver changes affected our household income. 5. Host significant wages due to medical appointments/hospitalizations 4. I couldnt continue working for myself because of my ongoing symptoms. 3. I was fearful of getting COVID again or another illness and preferred to stay home. 2. My work hours or shifts were reduced because of my ongoing symptoms. 1. I lost my job because my symptoms made it difficult for me to work full time.

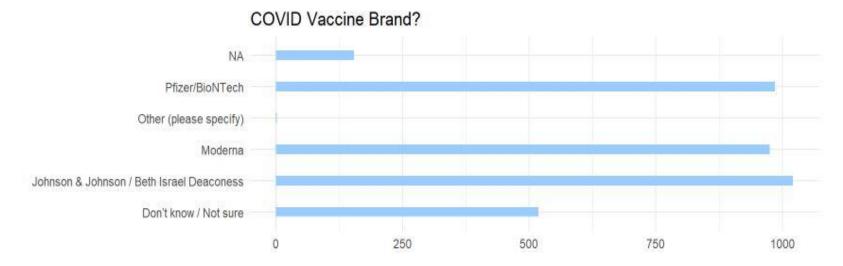
This question was only asked to persons who answered they had long COVID (??).

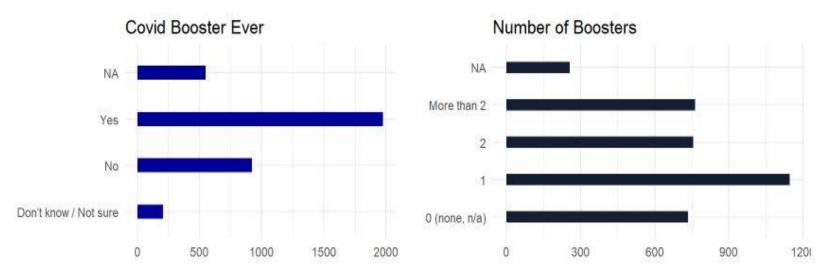
15

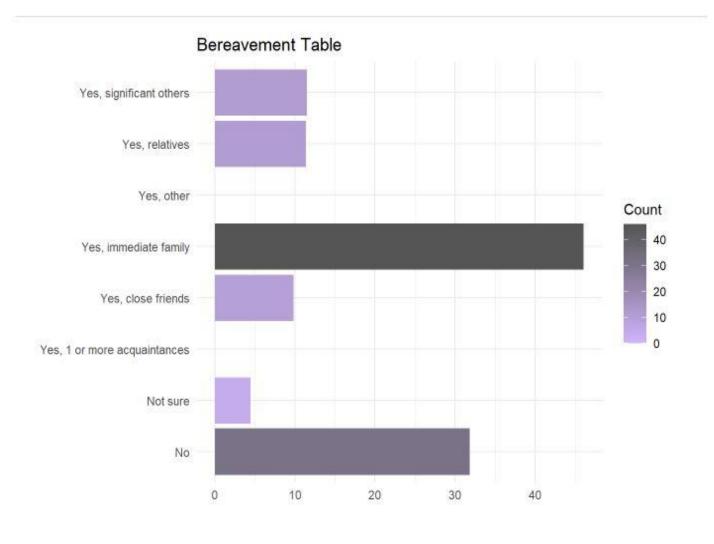














### **Presenters**

Karrée-Lyn Gordon, Ed.D, MHS

Yunilda Perez, MPH

NYSPHC FELLOWSHIP
WESTCHESTER COUNTY DEPARTMENT OF HEALTH



### References:

- ► Long COVID | NIH COVID-19 Research
- What is the difference between random sampling and convenience sampling? (scribbr.com)
- Revised Common Rule Q&As | HHS.gov
- University of Kansas Lisa Hallberg (2022)

