

Introduction: My Health Story (MHS) is a public health surveillance survey administered to residents in the Finger Lakes region of New York State. The primary focus of the My Health Story effort is to gather information on social drivers of health and health outcomes that is more nuanced and detailed than what is typically included in publicly available secondary data sources. My Health Story is a recurring survey first administered during the summer of 2018. My Health Story 2022 is the second version. With each iteration, the My Health Story research team shapes the survey guided by the expertise and lived experiences of Common Ground Health’s extensive community-embedded network. This includes gathering input and feedback from a variety of stakeholders in the design, administration, interpretation, and dissemination of the survey data. Each iteration also includes updated or new context-specific topics relevant to the current public health landscape.

New to the survey in 2022, we added questions on perceived discrimination in health care settings, housing mobility and quality, children’s health and well-being, and language access needs. Additionally, the MHS 2022 survey team prioritized improving accessibility and inclusion of the perspectives of community members living outside of Monroe County, of those with Indigenous backgrounds, and of individuals for whom English is not their primary language. We also refreshed digital accessibility tools embedded in the data collection process. The 2022 survey included a text-to-speech reader in English and Spanish, buttons to increase font size, and survey links in three different languages: English, Spanish, and American Sign Language.

The resulting My Health Story 2022 reached 3,747 people in the 9-county Finger Lakes region and an additional 114 people in three additional counties adjacent to the Finger Lakes region, Genesee, Orleans, and Wyoming. The 9-county region includes the following counties: Monroe, Chemung, Livingston, Ontario, Schuyler, Seneca, Steuben, Wayne, and Yates. The following sections describe the MHS 2022 survey design, data collection procedures, and the data management and sharing process. The project adheres to the oversight rules governed by the Institutional Review Board (IRB) at the Biomedical Research Alliance of New York (BRANY).

Survey Design: MHS 2022 survey questions were written and pilot tested with people ranging in age, lifestyle, racial and ethnic identity, and geographic residence. From August 2021 through June 2022, the MHS research team edited the 2018 version of the survey based on feedback from over 150 individuals including residents and staff from approximately 25 organizations. Feedback was incorporated and multiple drafts of specific sections of the survey were returned for a second and third review as needed. Community members continued to reflect and

provide feedback as we incorporated changes that led to the final version of the survey.

We entered the MHS 2022 survey into REDCap, the online survey administration tool used to collect responses. Multiple internal and external stakeholders tested the online survey and additional edits were made to improve upon inclusion and accessibility of the survey-taking experience. Skip logic was also tested numerous times as MHS 2022 research staff took the survey as though they were representing individuals with varying lifestyles and answer patterns. After internal testing, additional community members tested skip logic and provided feedback on survey questions and answer choices. Finally, four live, virtual feedback sessions were held with groups of people who took the survey online, most of whom did not see a prior version of the My Health Story survey.

Beginning in May 2022, Empire Justice Center also worked with the MHS 2022 survey design team to edit and incorporate the Language Access Needs section of the MHS 2022 survey. The entire survey was then translated into Spanish and into American Sign Language. Lastly, additional REDCap survey links were created for the Spanish language version and American Sign Language version of the MHS 2022 Survey. These were pilot tested by 2-4 language speakers in each group and additional edits were made to the language translations.

The Spanish and English versions of the survey went live during the first week of July 2022 while the ASL version of the survey went live a few months later.

Survey Recruitment and Data Collection: All language versions of the survey links were tracked to specific recruitment materials using TinyURL links and QR codes created and managed by the Common Ground Health communications team. The English and Spanish versions of the survey received a large amount of spam responses. After an 8-month cleaning period, the spam entries were identified and removed from the dataset. If you have questions about process taken to identify and remove spam survey responses, please reach out to Dr. Sarah Farash, Senior Research Associate, at sarah.farash@commongroundhealth.org.

Data Set Description: There are 3,861 survey responses from the 12 counties in the final dataset. In the 9-county Finger Lakes region, there are a total of 3,747 responses. The 9-county region includes the following counties: Monroe, Chemung, Livingston, Ontario, Schuyler, Seneca, Steuben, Wayne, and Yates. The dataset is unweighted, meaning, the data in the dataset represents only the people who took the survey. Results cannot be generalized to the population as a whole.

Here is a breakdown of the total number of survey responses collected by county:

County	MHS Sample		2022 Population Estimates Age 18+	
	Frequency	Percent	Count	Percent
Chemung	195	5%	64456	6%
Genesee	57	1%	46019	4%
Livingston	122	3%	50735	5%
Monroe	2371	61%	601049	54%
Ontario	298	8%	91416	8%
Orleans	43	1%	31898	3%
Schuyler	62	2%	14362	1%
Seneca	80	2%	26182	2%
Steuben	183	5%	73029	7%
Wayne	348	9%	72198	6%
Wyoming	14	0%	32444	3%
Yates	88	2%	19056	2%
Total	3861	100%	1122844	100%

Here is a table for Monroe County and the outlying 8-county Finger Lakes region, which includes Chemung, Livingston, Ontario, Schuyler, Seneca, Steuben, Wayne, and Yates, that shows the demographic breakdown by age range, sex, race and ethnicity, education, income, and household type of the people who submitted survey responses for MHS 2022 compared to the demographics of the total population of each geographic area:

		Monroe County				8-County Finger Lakes Region			
		MHS Sample N = 2,371		2022 Population Estimates Age 18+		MHS Sample N = 1,376		2022 Population Estimates Age 18+	
Segmentation	Segment	Count	Percent	Count	Percent	Count	Percent	Count	Percent
Age	18 - 34	572	27%	178,289	30%	269	20%	104,416	25%
	35 - 44	324	15%	94,042	16%	248	19%	60,262	15%
	45 - 64	743	35%	186,579	31%	535	41%	136,818	33%
	65 and Up	512	24%	142,139	24%	263	20%	109,938	27%
	Prefer Not to Say	220	N/A	N/A	N/A	61	N/A	N/A	N/A
Sex	Female	1,591	68%	312,401	52%	1,093	80%	207,315	50%

	Male	761	32%	288,648	48%	276	20%	204,119	50%
	Intersex	*	N/A	N/A	N/A	*	N/A	N/A	N/A
	Prefer Not to Say	*	N/A	N/A	N/A	*	N/A	N/A	N/A
Race & Ethnicity	Latino	397	17%	50,771	8%	73	5%	13,359	3%
	Black non-Latino	964	42%	80,895	13%	74	5%	10,977	3%
	White non-Latino	850	37%	436,090	73%	1,171	87%	375,446	91%
	Additional non-Latino Races	93	4%	33,293	6%	33	2%	11,652	3%
	Prefer Not to Say	67	N/A	N/A	N/A	25	N/A	N/A	N/A
Educational Attainment	High School Diploma or Less	728	33%	195,024	32%	191	14%	172,372	42%
	Some College, Trade, and Associates	638	29%	182,122	30%	490	36%	133,743	32%
	Bachelor's or higher	868	39%	224,291	37%	674	50%	107,444	26%
	Missing	137	N/A	N/A	N/A	21	N/A	N/A	N/A
Household Income	Low (<\$50K)	1,245	58%	113,302	36%	487	37%	77,131	36%
	Middle (\$50K-\$100K)	573	27%	92,215	29%	468	36%	68,587	32%
	High (>\$100K)	319	15%	109,840	35%	349	27%	66,909	31%
	Prefer Not to Say	234	N/A	N/A	N/A	72	N/A	N/A	N/A
Household Type	Adult living alone	831	36%	101,697	32%	274	20%	64,495	30%
	Couple without children	520	22%	103,706	33%	448	33%	80,408	38%
	Single adult with children	262	11%	23,446	7%	107	8%	10,781	5%
	Couple with children	349	15%	53,427	17%	366	27%	40,756	19%
	Multigenerational or	292	13%	22,813	7%	125	9%	12,543	6%

	extended family								
	Unrelated adults in private residence or group setting	81	3%	9,638	3%	30	2%	3,818	2%
	Other housing situation	36	N/A	N/A	N/A	26	N/A	N/A	N/A

Note: Percentage calculations exclude prefer not to say, missing, and other data. Population estimates for household income and household type represent the number of households.

* Count does not meet reporting threshold and is suppressed.

Due to the large number of respondents in Monroe County, we are also able to provide a breakdown of demographics within the City of Rochester who submitted survey responses compared to the total City of Rochester population:

		City of Rochester			
		MHS Sample N = 1,208		2022 Population Estimates Age 18+	
Segmentation	Segment	Count	Percent	Count	Percent
Age	18 - 34	296	27%	48,538	35%
	35 - 44	151	14%	24,788	18%
	45 - 64	350	32%	38,671	28%
	65 and Up	286	26%	25,119	18%
	Prefer Not to Say	125	N/A	N/A	N/A
Sex	Female	788	66%	71,139	52%
	Male	412	34%	65,978	48%
	Intersex	*	N/A	N/A	N/A
	Prefer Not to Say	*	N/A	N/A	N/A
Race & Ethnicity	Latino	242	21%	22,307	16%
	Black non-Latino	602	51%	46,724	34%
	White non-Latino	284	24%	58,550	43%
	Additional non-Latino Races	47	4%	9,536	7%
	Prefer Not to Say	33	N/A	N/A	N/A

Educational Attainment	High School Diploma or Less	488	44%	59,723	41%
	Some College, Trade, and Associates	334	30%	42,895	29%
	Bachelor's or higher	298	27%	43,518	30%
	Missing	88	N/A	N/A	N/A
Household Income	Low (<\$50K)	781	73%	43,945	54%
	Middle (\$50K-\$100K)	217	20%	21,987	27%
	High (>\$100K)	70	7%	15,287	19%
	Prefer Not to Say	140	N/A	N/A	N/A
Household Type	Adult living alone	567	48%	34,913	43%
	Couple without children	186	16%	17,025	21%
	Single adult with children	148	12%	9,172	11%
	Couple with children	104	9%	8,068	10%
	Multigenerational or extended family	140	12%	7,706	9%
	Unrelated adults in private residence or group setting	45	4%	4,306	5%
	Other housing situation	18	N/A	N/A	N/A

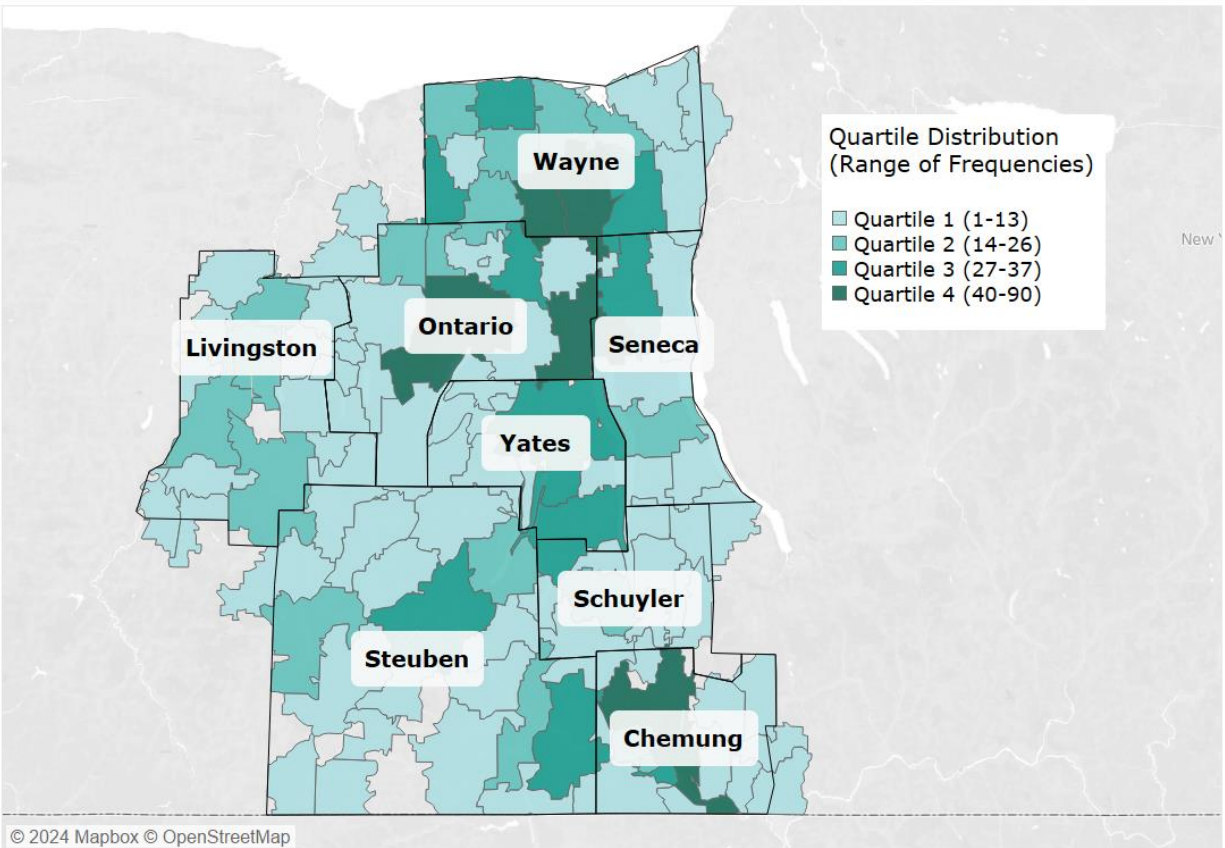
Note: Percentage calculations exclude prefer not to say, missing, and other data. Population estimates for household income and household type represent the number of households.

Urban Monroe County includes the following ZIP Codes: 14604, 14605, 14607, 14608, 14610, 14611, 14613, 14614, 14615, 14619, 14620, 14621, 14627, 14642

* Count does not meet reporting threshold and is suppressed.

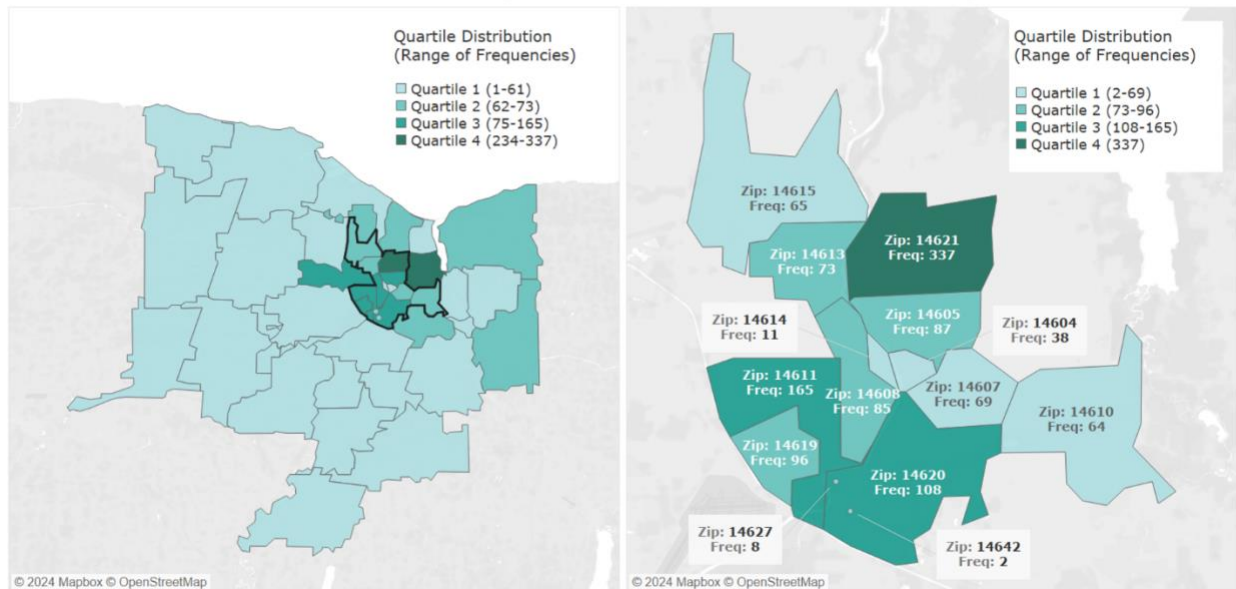
Here is a heat map showing the number of people who took the survey by ZIP Code in the 8-county Finger Lakes region outside of Monroe:

Responses to My Health Story 2022 Survey by ZIP Code Finger Lakes Region (excl. Monroe County)



Here is a map showing the number of people who took the survey by ZIP Code within Monroe County with the City of Rochester boundary line identified:

Responses to My Health Story 2022 Survey By ZIP Code Monroe County and Urban Monroe County



Note: Two Monroe County respondents did not have valid ZIP Code data and are not included on the map.

Data Analysis Methods:

Quantitative Data. The close-ended survey questions are analyzed using descriptive statistics, for example looking at the total count of people who answered “yes” or “no” to a particular question. We also look at percentages of people who reported specific responses to particular questions. When it makes sense to do so, we add up answers that can be grouped together. For example, we might add up all of the responses of people who said they have either good, very good, or excellent physical health status and compare the numbers to those who said they have fair or poor physical health status. We have an internal dashboard that we have created that helps us to look at patterns in the responses counts by race and ethnicity, age, income level, socioeconomic status, gender, county, and poverty rate. We can also look to see what the demographics are of people who answered a specific question. There are many ways to look at the data and we will be analyzing the close-ended questions for many years to come. Sometimes we also use statistical techniques like correlation tests or regression tests to look at patterns in the data. In order to do that we use a statistical testing software like SAS or SPSS.

Qualitative Data. In order to analyze the answers to open-ended questions asked of everyone who took the survey, like “What is the biggest concern for your own health and well-being?”, we entered all the data into a software called Dedoose. Then, we reviewed every answer and tagged them with a short, paraphrased code that remained true to participants’ original language. This step is called “close coding”. Each response could have multiple codes attached to it, if more than one concern was reported. Starting with the framework from the 2018 survey, we then

identified themes and sub-themes among those codes, adding or subtracting from the 2018 framework as needed in an iterative and reflective fashion. A code dictionary was simultaneously created to define each code, inclusion and exclusion criteria, as well as examples of responses that would fit into each. This qualitative data analysis technique is also known as Summative Content Analysis. If you would like to see a copy of the code tree that has definitions of each branch summarized, [please click here.](#)

Other open-ended response questions that were not asked of every respondent are read through and coded using close coding or content analysis using other software like Microsoft Access or Microsoft Excel.

Data Checking and Quality Assurance Review. Both the quantitative and qualitative data analyses and any written products or images that are created from MHS 2022 data are checked by independent team members. We have a list of data equity principles that we use to make sure that our review process is consistent and tells the complete story of the data with accuracy and transparency.

For qualitative data with a large number of responses, we sometimes use other quantitative survey questions to help place codes into the appropriate themes and sub-themes. For example, a quantitative question on the survey asked respondents whether or not they had diagnoses of various chronic conditions, one of which was obesity or overweight. For people who stated in their write-in answer that they had concerns about weight, we were able to code those into people who listed the concern and had checked that they had a chronic condition issue related to weight separately from those who checked that they were concerned about their weight but did not check that they have a chronic condition. Those who did not have a chronic condition checked were listed as having a lifestyle concern related to weight management.

The overall code dictionary created for the “What is the biggest concern for your health?” question was checked for consistency and to ensure that drift had been corrected. Additionally, the theme of *Chronic Conditions* in the code dictionary was reviewed by a medical expert to determine accurate and appropriate placement of codes within that theme. If you would like to see a copy of the code tree that has definitions of each branch summarized, [please click here.](#)

Data Sharing: Agencies, organizations, and individuals who have a secure place to store data are eligible to receive survey records from this dataset for their own use in health equity related projects or advocacy efforts.

A Data Use Agreement (DUA) is necessary if you are requesting access to record-level survey data. MHS survey questions and answer items [are available here.](#) Once you have reviewed the survey questions and have a general idea of the data you would like to request, please reach out to Sarah Farash, Senior Research Associate, at sarah.farash@commongroundhealth.org. Please include in your email a list of the questions you would like to see the data for and how you plan to use

the data. After reviewing your email, a meeting will be set up with you to talk through the request process in more detail.

Alternatively, if you would like to know the percentage of people who responded with a specific answer to a question, but don't need the individual survey response data, please indicate that in your email. In general, it takes approximately four to eight weeks to process MHS 2022 data requests. The timeframe to process the request begins after the meeting occurs where your request is clarified and the scope of work to process the request established.