## New York City Department of Health and Mental Hygiene

# World Trade Center Health Registry Wave 5 Survey (2020): Adults



## Data File User's Manual

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## **Chapter 1: Introduction**

#### 1. Overview

## 1.1 Overview of the World Trade Center Health Registry

Immediately following the World Trade Center (WTC) terrorist attacks of September 11, 2001, the New York City Department of Health and Mental Hygiene (NYC DOHMH) and other environmental health experts became concerned about potential health effects of the disaster on the exposed populations. It was not immediately known what environmental toxins were released from the collapsed buildings and ensuing fires, or how such toxins or irritants would affect the short- and long-term health of residents, school children and staff, building workers and passersby in the vicinity, and first responders, including rescue/recovery workers and volunteers. There was also concern about the mental health effects of the disaster on both the affected population in lower Manhattan and those responding to the disaster. Additionally, the injuries suffered by survivors and responders were an important concern.

The World Trade Center Health Registry (WTCHR) was launched as a joint effort of the NYC DOHMH and the federal Agency for Toxic Substances and Disease Registry. Since April 2009, WTCHR activities, including this Wave 5 Survey, have been supported by the National Institute for Occupational Safety and Health.

The WTCHR's mission is to:

- Identify and track the long-term physical and mental health effects of 9/11.
- Share findings and recommendations with enrollees, others affected, the public, and policymakers.
- Respond to health concerns and assess gaps in care for 9/11-related health problems.
- Offer guidance to public health professionals in planning for potential future emergencies.

The initial enrollment phase (Wave 1 Survey) was completed in November 2004 with 71,431 persons enrolling and completing a 30-minute interview over the telephone (~94.5%) or in person (~5.5%). Eligibility at the Wave 1 Survey was defined according to specific criteria. Individuals could be eligible for one or more of the following four eligibility groups:

- Workers and volunteers involved in rescue, recovery, cleanup, or other activities for at least one shift at the WTC site anytime from September 11, 2001 through June 30, 2002, or in debris handling at the Staten Island Landfill or on the barges transporting debris, anytime from September 12, 2001 through June 30, 2002;
- **Residents** at addresses located south of Canal Street on September 11, 2001;
- **Students and school staff** enrolled/employed in schools or day cares south of Canal Street on September 11, 2001; and
- Building occupants, people in transit, and pedestrians, including employees, visitors, and passersby present south of Chambers Street between the time of the first plane impact and noon on September 11, 2001.

Note that residents, and students and school staff, did not need to be present in lower Manhattan on September 11, 2001. A second survey, the Wave 2 Survey, was completed in 2006–2007. A total of 47,624 enrollees (46,602 adults and 1,022 children) completed the Wave 2 Survey. A total of 43,712 enrollees (43,134 adults and 578 adolescents) completed the Wave 3 Survey in 2011-2012. A total of 36,348 adult enrollees completed the Wave 4 Survey in 2015-2016.

### 1.2 Objectives and Design of the Wave 5 Survey

The overall objective for the 2020 Health Survey (henceforth referred to as the Wave 5 Survey) was to collect updated physical and mental health information for monitoring the health status of the WTCHR enrollees 19 years after 9/11. The frame for the Wave 5 Survey included all WTCHR enrollees who completed at least three wave surveys including Waves 1 and 2 (i.e., completed Waves 1-4, Waves 1-2 & 3 only, or Waves 1-2 & 4 only), and all "new adult" enrollees who were under age 18 years at the time of enrollment and were enrolled in the Registry by a parent or guardian. Enrollees who were deceased or who withdrew from all Registry activities prior to launch were not included in the final sample of 39,711 eligible enrollees.

Data collection for the Wave 5 Survey began on April 6, 2020, with paper surveys that were mailed to enrollees without e-mail addresses. Web survey invitations were sent on May 6, 2020 to participants with email addresses. Web data collection continued through January 25, 2021, while paper surveys were accepted through February 26, 2021.

Many of the Wave 5 Survey questions were similar to questions asked in the Wave 1, 2, 3, and 4 Surveys, while some new questions were added (e.g., oral health, sleep). See *Appendix A* for more details.

## 1.3 Overview of Wave 5 Survey Data File User's Manual

This manual provides documentation to familiarize data users with the design, methodology, data collection, and data processing of the WTCHR Wave 5 Survey, starting with *Chapter 2* which summarizes the instrument development process and content. *Chapter 3* details the pre—data collection activities. *Chapter 4* covers the methods used to collect data from enrollees. *Chapter 5* describes how data were processed. *Chapter 6* describes the results of the data collection. *Chapter 7* details the post-survey activities, and *Chapter 8* guides data users through key elements of using the data file. *Appendix A* provides a comparison of questionnaire content across the Wave 1—Wave 5 Surveys, *Appendix B* provides the Wave 5 questionnaire, and *Appendix C* provides the Wave 5 Survey codebook.

The Wave 5 Survey was a collaboration between NYC DOHMH and RTI International. For the remainder of this document, Wave 5 eligible enrollees will simply be referred to as *enrollees*.

## **Chapter 2: Instrumentation**

#### 2. Instrumentation

### 2.1 Instrument Development

The questionnaire for the Wave 5 Survey was designed to collect data on the physical and mental health status of enrollees and their demographic information and e-mail address. Two modes of self-administration were offered: a web survey (with a consent screen) and a mailed paper form.

The Wave 5 questionnaire was developed through an iterative process in which revisions were made as a result of a formal questionnaire appraisal and cognitive interviewing.

#### 2.1.1 Questionnaire Appraisal

Survey methodologists used RTI's Question Appraisal System (QAS) to evaluate potential problems with the WTCHR Wave 5 questionnaire. The QAS is a structured, standardized instrument review methodology that assists a survey design expert in evaluating questions relative to the tasks they require of enrollees, specifically about how enrollees understand and react to survey questions. The QAS allows the reviewer to evaluate the structure and effectiveness of the questionnaire form itself. It is a coding system (i.e., item taxonomy) that describes the cognitive demands of the questionnaire and documents the question features that are likely to lead to response error. These potential errors include errors related to comprehension, task definition, information retrieval, judgment, and response generation (Willis and Lessler, 1999). The QAS also anticipates errors in translation and cross-cultural administration of a question (Dean et al., 2007).

#### **2.1.1.1** Wave 5 Survey

Appraisal of the Wave 5 Survey using the QAS was conducted in August-September 2019. The questionnaire was revised based on the QAS findings. The questionnaire was then formatted as a self-administered paper instrument to be used in the cognitive interviews.

#### 2.1.2 Cognitive Interviews

The instrumentation process included cognitive interview pilot tests of the WTCHR Wave 5 questionnaire. Cognitive interviewing is a pretest methodology that makes use of *think-aloud interviewing* and other question-probing techniques. A think-aloud interview is one in which the enrollee is instructed to tell the interviewer everything they are thinking about while answering a survey question. Think-aloud techniques are supplemented with *concurrent* (during the interview) or *retrospective* (in a debriefing interview after completing the survey) *probes*. Cognitive interviewing provides detailed information on questionnaire design issues such as the degree to which questions are comprehended, memory search strategies used, the ability of enrollees to make calculations and judgments, sensitivity and social desirability bias associated with questions, and the coverage of the response domain by the response options provided.

#### **2.1.2.1** Wave 5 Survey

In preparation for the cognitive interviews used to assess the Wave 5 Survey, WTCHR staff selected enrollees to participate in cognitive interviews. The goal was to conduct 12-16 interviews. A total of 12 participants were successfully recruited and completed interviews. The breakdown was as follows:

- 4 interviews with rescue and recovery workers;
- 3 interviews with area workers:

- 2 interviews with residents;
- 1 interview with an enrollee who turned 18 years of age since 2016; and
- 2 interviews with enrollees who have an autoimmune disease.

Interviews were conducted in English on October 29 and 30, 2019. The interviews took place at the New York City Department of Health and Mental Hygiene's Manhattan office. During the interviews, participants completed a paper version of the survey, and the trained RTI interviewers asked scripted and spontaneous probes. In half of the interviews, probing was done concurrently as participants completed the survey, and in the other half, it was done retrospectively after participants completed the survey. Interviews lasted about 90 minutes each, and participants were given an \$80 Amazon.com gift card as a token of appreciation.

Findings from the cognitive interviews were reported in a summary report. The report outlined problems with the survey identified during the interviews and provided actionable recommendations to improve the survey. The survey was revised according to this feedback and finalized; the formatted questionnaire was updated accordingly.

#### 2.1.3 Translation of WTCHR Instruments

The Wave 5 questionnaire was translated into both Traditional and Simplified Chinese and Spanish by a translation vendor. The translations were then reviewed by RTI language methodologists and approved by bilingual native speakers of each target language at the WTCHR. The paper surveys were available to enrollees in English, Spanish, Traditional Chinese and Simplified Chinese, while the web survey was available in English only.

#### 2.1.4 TeleForm Paper Survey

Each questionnaire was created as a scannable form using TeleForm. RTI developed the TeleForm data collection and processing system and protocols for receipting and batching the paper surveys at RTI's secured facility, the Research Operations Center.

The scannable forms were used to increase cost-effectiveness and to improve data quality by allowing for data capture through optical scanning. This eliminated the potential for errors associated with manual data entry processes. The scanning process included the initial step of TeleForm interpreting the data on the forms and a verification step that identified and resolved any problems with how the data were interpreted (e.g., marks that were too light or otherwise obscured). Verifiers are staff who were trained to address verification flags. TeleForm flagged data to be reviewed by the verifier, and each flag was recorded in a verification log file.

RTI created form-based scripts to expand on TeleForm's current features. For example, for single-response choice questions, the only permitted answers are blank or one of the choice fields. Selecting multiple responses is not an option. To expand the single-response choice features, when TeleForm detects a multiple-response answer, the form-based script asks the verifier to confirm if the enrollee did check multiple boxes. If confirmed, a data record is written to a verification log with the type of form, question number, etc.

RTI received and scanned all paper surveys and submitted the images to NYC DOHMH. After data were reviewed and all flags were addressed, the data were committed to a data file to be cleaned. A PDF was created for each survey when data were committed to the data file. Raw and cleaned data files, TeleForm PDFs, and the verification log were compressed, encrypted, and transmitted to NYC DOHMH via the secure BISCOM portal.

#### 2.1.5 Web Survey/Mobile Device Design

The Wave 5 web survey was programmed by the Registry's IT staff using *Feedback Server*, a software system used in web survey design, hosting, and survey data collection. The survey was hosted at a NYC Department of

Information Technology & Telecommunications (DoITT)'s central data center with a web server host engine behind firewalls. *Feedback Server* has been vetted by DOHMH Division of Information Technology (DIT) and NYC DoITT and passed the system and application security review; it is compliant with NYC DoITT's information security standards. A separate secure MS SQL database server at DoITT's data center was used for survey data capture through an encrypted internal link between the web survey host server and the Microsoft SQL database server. Registry IT staff conducted user, device, and browser testing of the web survey, and coordinated with DOHMH DIT staff to conduct load testing of the web survey. The survey also underwent multiple rounds of user testing by the Registry's project staff.

The web survey was accessible by standard desktop computers, laptops, and mobile devices including tablets and smartphones. Enrollees could access their web survey using the personalized link and access code sent to them in the e-mail invitation or reminder; for those who did not provide an e-mail address to the Registry and instead received the paper survey, the web survey was accessible through a scannable QR code printed on the cover letter accompanying the mailed paper survey with the enrollee's access code. The personalized link and unique access code provided secure access to the web survey and allowed Registry staff to monitor survey completion status.

## **Chapter 3: Pre-Data Collection Activities**

#### 3. Pre-Data Collection Activities

#### 3.1 Panel Maintenance

On an ongoing basis, enrollees were encouraged to update their contact information using mail, e-mail, web, telephone, or fax. Prior to the launch of the Wave 5 Survey, the Registry sent postcards to enrollees without a valid e-mail address asking them to "Go Green" and provide us with their e-mail address. The goal was to increase the number of enrollees receiving the web version of the survey.

The Registry sent an annual card to all enrollees with a known address, as a thank you for their continued participation in the WTCHR. The Registry also sent quarterly e-newsletters highlighting Registry research, 9/11-related resources, and enrollee stories.

### 3.2 Pre-field Tracing

Tracing of enrollees with an invalid mailing address began in February 2020 and targeted enrollees in the Wave 5 sample. Enrollees without a valid phone number were also targeted for tracing in August 2020, so that reminder phone calls could be conducted. This type of tracing focused on using a private search engine created by Accurint called LexisNexis. LexisNexis has access to information from consumer credit bureaus, Directory Assistance, reverse directories, and other consumer and proprietary databases. Panel Maintenance Unit team members used LexisNexis to do individual searches for enrollees in tracing to update their contact information.

#### 3.3 Notification Letters & Emails

Prior to launching the survey, Registry staff sent all enrollees in the Wave 5 sample a Summary of their Rights as participants in the Registry and a letter signed by the Commissioner of NYC DOHMH and the Director of the WTCHR, encouraging them to complete their Wave 5 Survey. Enrollees for whom the Registry had a valid e-mail address on file also received this letter via e-mail with a link to their Summary of Rights in an electronic format.

All enrollees who provided an e-mail address to the Registry were initially selected to receive a web survey; all other enrollees in the sample were initially sent a paper survey. Enrollees selected for the web survey sample were sent an e-mail invitation that provided information on the purpose, goals, and NYC DOHMH sponsorship of the WTCHR. The invitation included a personalized web link and access code unique to the enrollee that granted access to their Wave 5 web survey, contact information to reach Registry staff, and information about NYC Well, a mental health resource.

Similarly, enrollees selected for the paper sample were mailed a paper survey along with a cover letter that explained the purpose, goals, and NYC DOHMH sponsorship of the WTCHR. The cover letter also included contact information to reach Registry staff and information about NYC Well, a mental health resource. Enrollees with an international address were also mailed a letter with resources in their country of residence that they could contact if the survey caused emotional distress; if no resources were identified, enrollees were encouraged to contact their local crisis hotline or emergency services unit.

## **Chapter 4: Data Collection Activities**

#### 4. Data Collection Activities

### 4.1 Impact of COVID-19

A novel coronavirus called SARS-CoV-2 causing contagious viral illness (COVID-19) in both animals and humans, transmitted through respiratory droplets, began to infect many people worldwide starting in late 2019. On March 11, 2020, COVID-19 was declared a pandemic by the World Health Organization (Ghebreyesus, 2020). Americans saw a sharp increase in infections starting in early 2020. Many states mandated a shelter-in-place ordinance to help decrease the spread of the virus. In addition to these ordinances, many nonessential businesses were forced to temporarily close their doors, and many employees were directed to work from home. These actions had many implications for data collection, including delays in mailings.

## 4.2 Interviewing Methods

The Wave 5 Survey launched on April 6, 2020. Data were collected through two modes: paper and web. Web survey data collection continued through January 25, 2021. To allow for potential delays in delivery of the mail, paper surveys were accepted through February 26, 2021. Of the 27,833<sup>1</sup> full and partially completed Wave 5 Survey interviews, 15,027 (54.0%) were completed by web, and 12,806 (46.0%) were completed by paper.

#### 4.2.1 Paper Interviewing

Paper interviewing attempts began shortly before the release of the web interview. The first set of questionnaires were mailed to 7,429 enrollees on April 6, 2020.

The mailed packet included the questionnaire, a cover letter providing instructions and information for the enrollee, a 9/11-related resources page, a buck slip regarding COVID–19, and a business reply envelope for the enrollee to return a completed survey.

Initial paper questionnaire mailings were sent to enrollees who did not have an e-mail address on file. Other groups of enrollees such as those selected for a web interview who had an invalid e-mail address and those who did not complete the web interview after a given amount of time, also received the paper questionnaire at a later date. Enrollees who did not complete the survey in either mode were included in all mass paper survey mailings starting with the second mailing.

**Table 1** displays information on the target group for paper questionnaire mailed, number of questionnaires mailed, and approximate release dates for the mailings.

Mailing GroupsTotal Number of Paper Questionnaires MailedApproximate Dates of ReleaseMailing #1 — English-speaking enrollees who did not have an e-mail address on file7,4294/6/2020Mailing #1 — Spanish-speaking enrollees4644/29/2020

**Table 1: Paper Questionnaire Mailings for Wave 5 Survey** 

<sup>&</sup>lt;sup>1</sup> The count of completed surveys shown in this text (n=27,833) includes 523 fewer surveys than the count of 28,356 surveys that are included in the survey codebook (Appendix C). The 27,833 surveys in this text reflect surveys that meet the requirement for completion (at least 50% of key items completed) and are used for the response rate calculation. The higher count shown in the survey codebook includes all returned surveys, including those 523 surveys assessed to be "incomplete."

	Total Number of Paper	Approximate Dates
Mailing Groups	Questionnaires Mailed	of Release
Mailing #1A — English-speaking & Spanish-speaking enrollees with	79	6/29/2020
surveys returned with a forwarding address and paper survey requests		
from another mode		
Mailing #1 — Chinese-speaking enrollees	796ª	6/10/2020
Mailing #2 — English-speaking & Spanish-speaking enrollees	29,507	6/24/2020
including enrollees in the web sample who had not yet responded		
Mailing #2 — Chinese-speaking enrollees including enrollees in the	423	9/21/2020
web sample who had not yet responded		
Mailing #2B — All languages, including enrollees with surveys	1,218	9/21/2020
returned with a forwarding address and paper survey requests from		
another mode		
Mailing #3 — All languages, including enrollees in the web sample who	17,715	10/30/2020
had not yet responded		
Mailing #3A — All languages, including enrollees with surveys	570	12/15/2020
returned with a forwarding address and paper survey requests from		
another mode		
Mailing #4 — All languages, including enrollees in the web sample who	13,699	1/5/2021
had not yet responded		
Total	71,900	

<sup>&</sup>lt;sup>a</sup> Mailing #1 for Chinese-speaking enrollees included 409 Simplified Chinese surveys and 387 Traditional Chinese surveys. For all four mailings, Simplified Chinese surveys were mailed to Chinese-speaking enrollees who previously indicated a preference for this Chinese script, and Traditional Chinese surveys were similarly mailed to enrollees with a preference for this script; enrollees with no known preference were mailed a Simplified Chinese survey and a Traditional Chinese survey.

During Wave 5 data collection, if an updated address was identified through tracing efforts or telephone contact, and the enrollee had not yet completed the Wave 5 Survey, the enrollee was added to the paper interviewing sample and sent a questionnaire in the next batch of paper surveys mailed out. If a paper questionnaire had previously been mailed to the enrollee, a new questionnaire was mailed to the new address. Enrollees also received a paper questionnaire upon request, including those initially reached through an e-mail sent with a personalized link to a web survey. Enrollee consent for the paper mode was implied in the return of the paper questionnaire.

#### 4.2.2 Web Interviewing

The web interview was the second mode of data collection made available to enrollees. Wave 5 web interviewing began on May 6, 2020, and continued through January 25, 2021. As previously stated, enrollees were selected to be a part of the web sample if an e-mail address was on file in the enrollee's contact information.

E-mail invitations were released to enrollees in three groups at the beginning of web data collection. *Table 2* displays information on the number of cases and approximate release dates for the web interviewing effort for the Wave 5 Survey. Group A and Group B of the web release included a small proportion of the web sample to test web instrument load before the web interview was released to Group C, the rest of the web sample. Following the initial invitation, web interview reminders were sent to all web sample non-respondents in batches to ensure maximum load capacity was not reached on a given day.

Release Group	Total Number of Cases Released	Approximate Dates of Release
Group A	4	5/6/2020
Group B	200	5/12/2020
Group C	30,602	5/14/2020
Total	30,806	

Table 2: Initial Web Interview Sample Release for Wave 5

Starting with paper mailing #2, the cover letter mailed with the paper survey included an enrollee-specific access code and personalized QR code that opened the web survey when scanned. Enrollees who initially received the paper survey could also contact the Registry and request their personalized link and access code by e-mail. Enrollees in either mode were able to request an e-mail reminder with their link and access code throughout data collection.

During Wave 5 data collection, if an e-mail address was identified through telephone or e-mail contact, and the enrollee had not yet completed the Wave 5 Survey, the enrollee was added to the web interviewing sample and included in all subsequent e-mail reminders sent to the enrollees in this group who had not completed the survey in any mode. The e-mail reminders also included a personalized web link and unique access code for each enrollee.

At the beginning of each web interview, enrollees were provided with informed consent information and asked to confirm their year of birth, prior to starting the interview. If the year of birth provided by the enrollee did not match the year of birth in the WTCHR's records, the enrollee was prohibited from continuing the web survey and instructed to contact WTCHR staff.

## 4.3 Proxy Interviews

Interviews could be conducted by a proxy (a legal guardian, family member, or another knowledgeable person completing the interview on behalf of the enrollee) for a variety of reasons including the enrollee being mentally or physically unable to complete the survey, a language barrier, or other reasons.

*Table 3* displays the number of interviews completed by a proxy for both mode types and by the reasons a proxy was needed to complete the interview. Out of full and partially completed interviews, 441<sup>2</sup> interviews were completed by a proxy across both mode types. For the paper interview, some of the reasons noted for a proxy included the enrollee dealing with the impacts of the COVID-19 pandemic, the survey was too difficult for the enrollee to read, the enrollee did not have time to do a survey, or the enrollee was out of the country.

**Number of Proxy Interviews Reason for Proxy** Web **Paper** Enrollee has physical or mental disability 19 72 Enrollee has a language barrier 1 17 Survey was too difficult for the enrollee to read 3 35 27 Other reason 267 50 391 Total

Table 3: Proxy Interviews by Mode and by Reason for Proxy for Wave 5

<sup>&</sup>lt;sup>2</sup> This number includes enrollees who themselves provided an answer to the "Reason for Proxy" survey question and does not include reports of the enrollee being deceased.

## 4.4 Languages of Administration

Due to the prevalence of persons enrolled in the WTCHR who speak Spanish, Mandarin, or Cantonese, paper surveys were translated into Spanish and Chinese (Traditional and Simplified), and enrollees who indicated their preference (in the previous Wave 1, Wave 2, Wave 3, Wave 4 Surveys, or via personal communications with the WTCHR) for a Spanish or Chinese survey were sent a paper survey in their preferred language. The web survey was only available in English.

*Table 4* displays the number of full and partially completed interviews in each language for the Wave 5 Survey.

	Number of Fully or Partially Completed Interviews				
Languages	Paper	Web			
English	12,316	15,027			
Spanish	265				
Simplified Chinese	114				
Traditional Chinese	111				
Total	12,806	15,027			

Table 4: Interviews by Language and Mode

## 4.5 Methods for Increasing Response Rates

#### 4.5.1 Reminder Postcards, E-mails, & Surveys

For enrollees selected for the web interview mode, reminders to complete the web interview were sent periodically through both e-mail and postal mail. Up to 23 reminder prompts were sent to enrollees in this initial web interview group; these prompts included 18 e-mail reminders, four postcard reminders, and one additional email reminder encouraging enrollees who did not complete a web or paper interview but started a web interview to complete and submit their web interview. Enrollees initially in the web interview mode were also mailed up to three paper questionnaires.

For enrollees selected for the paper interview mode, postcard reminders and subsequent paper questionnaires were sent periodically to enrollees through postal mail. Up to four postcard reminders and up to three additional paper questionnaires were sent to enrollees selected for the paper interview.

Paper questionnaires were also provided on an ad-hoc basis to enrollees who requested a re-send of their paper survey or for those whom we obtained an updated mailing address for in between bulk paper survey mailings.

#### 4.5.2 Outreach Methods for WTCHR

#### 4.5.2.1 Reminder Phone Calls

Enrollees in the sample who had not completed their Wave 5 Survey were contacted by Registry staff by phone between July 2020 and December 2020 and encouraged to complete their survey. An approach with an equity focus was used to increase response rates in sub-groups that have historically been least likely to complete their Registry surveys and who also may have received limited outreach efforts. The Registry's equity-focused outreach for Wave 5 was also a response to a NYC DOHMH-wide strategy to counter institutionalized racism and racial disparities, and to incorporate more equitable practices going forward. This work is informed in part by the agency's participation in the 2017 Government Alliance for Race & Equity (GARE) pilot.

Survey sample members who indicated Mandarin, Cantonese, or Spanish as their preferred language, as well as those with low household income (<\$25,000), were contacted first and with a greater number of attempts than

others in the reminder phone call sample. Fourteen Registry staff members attempted to reach 1,346 enrollees in this equity outreach group between July 27, 2020, and September 4, 2020. Eight native language speakers who were Registry staff reached out to the Spanish, Mandarin, and Cantonese-speaking non-respondents, and six other Registry staff reached out to non-respondents identified as potentially low-income. The staff contacted each enrollee in the equity outreach group with up to three rounds of call attempts until the enrollee was reached or all three rounds of calls were exhausted. A round of call attempts consisted of the caller attempting to reach the enrollee at all available numbers (cell, home, and work) and leaving a message on each line (except the work number), before moving to the next enrollee. Each round of attempts was done on different days of the week and varied by time of day to reach and directly speak with the enrollee. For example, one round of attempts could be made on a weekday during daytime hours (Monday through Friday, 9 AM to 6 PM), another round on a weekday during evening hours (Monday through Friday, 6 PM to 8 PM), and a final round during weekend daytime hours (Saturday and Sunday, 10 AM to 4 PM).

Reminder phone calls were then used to reach out to the remaining Wave 5 Survey non-respondents. These enrollees were contacted in the following pre-defined order based on overall participation rates from the Wave 4 Survey and self-reported demographic characteristics: Non-Hispanic Black, Hispanic, Asian, Multiracial or other race, new adults, adults at least 65 years of age, and all other enrollees in the sample. Enrollees in the equity outreach group were not re-contacted for this round of outreach. Twelve Registry staff members called the 19,288 enrollees in this general reminder call outreach group with one round of call attempts per enrollee between August 3, 2020, and December 15, 2020. Callers attempted to reach the enrollee using all available numbers (cell, home, and work) and left a message on each line (except the work number) before moving on to the next enrollee. The single round of call attempts for this group could be made during any of the three calling periods (daytime, evening, weekend).

Outcomes for call attempts and enrollee interactions were tracked internally for all calls. For both the equity outreach group and the general reminder outreach group, callers were instructed, when speaking to an enrollee, to try to identify the reason(s) that the enrollee had not completed the survey and ask if they would like to receive the paper or web survey again. Contact information was confirmed for enrollees who requested a paper or web survey during the call.

#### 4.5.2.2 Motivational Videos Dissemination

Motivational videos of Registry enrollees encouraging other enrollees to complete their health survey were utilized and included as a video link in the lead e-mail sent to the web group and in the lead letter with instructions on how to access the videos to the paper group.

## 4.6 Incentives for the Wave 5 Survey

A survey design feature with great potential for maximizing response, and thereby potentially reducing non-response bias, is a survey incentive. For the Wave 5 Survey, we offered a small incentive (\$10 per completed/returned survey) to all non-respondents who completed a survey beginning November 3, 2020 (7 months after the survey launch) as a response enhancement activity. After the incentive was offered, all enrollees who completed and returned the paper survey or who submitted the web survey were mailed a \$10 bill along with a thank you letter.

Starting on November 16, 2020, weekly incentive mailings were sent to enrollees who had completed the survey. From an address file that NYC DOHMH provided each week, RTI staff cleaned the addresses (e.g., changed the text from all caps to proper case, dropped extra digits in zip codes) and completed processing, printing, and mailing.

RTI staff tracked the numbers of incentive mailings going out and those coming back in the form of undeliverables and reported these numbers to NYC DOHMH on a weekly basis. Any items that were returned as undeliverable with new forwarding address information provided from the Post Office were also tracked and re-mailed weekly as they came in. The address updates were provided to NYC DOHMH.

## **Chapter 5: Data Preparation and Processing**

## 5. Data Processing of Enrollee Interviews

## 5.1 Data File Preparation for the Wave 5 Survey

Enrollee interviews were collected using a combination of two modes: (1) web interview programmed and maintained by staff at NYC DOHMH, using Microsoft .Net technology and stored in a Microsoft SQL Server database; and (2) paper survey created and scanned using TeleForm software to capture data through optical character recognition. Web data files were delivered by NYC DOHMH to RTI weekly through DOHMH's secure data exchange BISCOM server as zipped CSV files containing responses and tracking information. Summaries of web status were delivered to RTI daily through a secure data exchange SFTP site; these values were imported into RTI's control and tracking system.

Paper surveys were received, scanned, and verified by RTI and delivered to NYC DOHMH weekly as digital image files of the verified TeleForm data. Images of returned surveys were imported into TeleForm where they were evaluated and verified. The evaluation process was the first capture of data performed automatically by TeleForm, and the verification process was the second capture of data performed by trained staff "verifiers." Data were exported to a comma-delimited file, and PDFs of each survey were exported. The raw data file was stored directly in RTI's Enhanced Security Network.

For paper interviews in Spanish and Chinese, responses to open-ended or "other, specify" questions written in Chinese or Spanish were translated by RTI and reviewed by NYC DOHMH. Final translated responses were merged into the clean dataset. Correction files from verification and subsequent QC were added by the cleaning programs. Cleaning processes are described in greater detail below. After data were cleaned, the raw and cleaned datasets were compressed and encrypted with the image PDFs in preparation for data delivery via secure FTP. Data from web and scanned interviews were delivered to NYC DOHMH on a weekly basis.

At the end of data collection, interview data from both modes were combined into a single dataset. The combined files served as the basis for codebook generation (See Chapter 8). Combined files were delivered to DOHMH as a preliminary version for review and again as a final version at the end of the study.

## 5.2 Data Quality Control

Concurrent with the periodic data deliveries and after the completion of data collection, a number of quality control activities were performed on the data. These activities included a review of response frequencies, interitem consistency checks, and the monitoring of daily reports that reflected relationships between case status and the data collected.

#### 5.2.1 Data Editing and Verification for the Wave 5 Survey

The web survey was programmed to route the path through the interview based, as appropriate, on prior responses within the Wave 5 Survey, thereby skipping questions that should not be asked of an enrollee. Additionally, the web surveys were programmed with logical consistency and range checks. To verify the accuracy of the data collected by the programmed instrument and to detect any data anomalies, DOHMH and RTI data analysts scrutinized data for anomalies. Any anomalies detected were reviewed and reconciled as a part of ongoing quality control.

The paper surveys were scanned at RTI International to capture data. Data quality checks that were specific to the Wave 5 Survey were incorporated into the TeleForm program (e.g., range and date checks), and responses

outside of these checks were highlighted by TeleForm. Each survey was reviewed individually in two separate steps, by two separate verifiers. Another review of up to 10% of the surveys was conducted by a senior QC staff person, and final corrections were made if needed.

All fields flagged to be verified were logged into Too Many Marks (TMM), Unrecognizable Character, and Verification logs. The TMM log contained all questions where multiple responses were recorded or detected for a single response question. The Unrecognizable Character log contained a record of each response unrecognizable by the verifier. The Verification log contained all fields flagged by TeleForm to be verified, including TMM and unrecognizable characters. The TMM and Unrecognizable Character logs were used during data cleaning.

#### 5.2.2 Data Review

As described in *Section 5.2.1*, review of web and paper questionnaire data frequencies and related crosstabulations was conducted weekly to ensure that skip patterns were implemented correctly and to identify any questions that contained high item nonresponse rates. Questionnaire items that contained open-ended or "other, specify" verbatim fields were also reviewed for completeness and accuracy in coding. Additionally, any items that were flagged by the data editing system were reviewed so that feedback could be provided to data collection staff, as necessary.

Similarly, review of data from paper questionnaires was conducted to ensure that skip patterns were implemented correctly and to identify questions that contained high item nonresponse rates. Frequency checks were run on all fields, and anomalies were checked, including all questionnaires with high proportions of blank responses. Questionnaires were also examined to identify marks that were not usually captured by TeleForm (e.g., check marks, lines drawn through several answers). In these cases, questionnaire data were typically entered by hand.

In addition, DOHMH and RTI conducted an in-depth review of the definition and implementation of data cleaning rules for the paper survey and their effectiveness in producing a high-quality clean dataset for analysis. This in-depth review consisted of the following steps:

- Review of data cleaning rules and revision as needed after agreement by the joint NYC DOHMH and RTI teams;
- Review of the log file and output of SAS programs that prepared and merged data and/or implemented the rules;
- Review of data frequencies for each rule;
- Review of individual cases for each rule and comparison with scanned originals as needed when questions or concerns arose; and
- Resolution of questions and concerns as needed through joint consideration by the NYC DOHMH and RTI teams.

#### 5.3 Review and Resolution of Discordant Cases

Checks were built into each survey mode to reduce the likelihood of a survey being completed by a non-enrollee or by another enrollee within the same household. Web surveys required a year of birth verification, and the enrollee's full name was printed on the cover letter mailed with the paper survey. However, despite these checks, some surveys were completed by a non-enrollee or another enrollee in the household.

Using the enrollee's demographic information in the WTCHR's database, WTCHR staff used SAS to identify completed surveys that potentially belonged to a non-enrollee or another enrollee. Surveys determined to be completed by someone other than the enrollee were referred to as "discordant" cases and identified with the following variables: gender, year of birth, and the last four digits of the Social Security Number. Over 870 surveys were identified as having at least one piece of discordant information of which 56 required follow-up actions. Among the 56 discordant cases, 18 surveys were completed by a non-enrollee, 3 were completed by another enrollee who was not eligible for the Wave 5 Survey, and 35 were completed by another enrollee in the Wave 5 Survey sample. The 21 surveys completed by a non-enrollee or an enrollee ineligible for this survey were removed from the dataset, while the 35 surveys completed by another enrollee in the sample were reassigned to the correct enrollee.

## 5.4 De-duplication of Multiple Completed Interviews by Different Modes

A major concern of working with multiple data collection modes is the potential for duplication of interview data because the enrollee may complete the survey in more than one mode. For instance, a person may have started the web interview and decided later to fill out and return the paper questionnaire. Because some data in the web interview were already collected, a protocol was needed to determine which interview record to keep at the end of data collection. Another potential source of error arises when a non-enrollee (e.g., a member of the enrollee's household) completes and returns a survey, and the enrollee does too, or the enrollee or proxy completes the paper survey in more than one language, such as in Simplified Chinese and Traditional Chinese. In these cases, the two surveys may initially appear as "duplicate" surveys returned by the same enrollee because each data record is linked to the same control number.

At the end of data collection, all records from the two modes were put together into a single "combined" dataset. If a sample member and/or proxy completed the survey more than once, multiple records existed for that control number and were called "duplicates," although the response values may not match across records.

Survey completeness was used to determine which survey to retain in the final dataset and operationalized by the percentage of selected key questions answered. Surveys containing at least 80% of the selected questions answered were defined as a complete survey; surveys with 50% to 79% of selected questions answered were defined as partially complete; and surveys with less than 50% of selected questions answered were defined as incomplete.

After completeness was defined for each survey in the combined web and paper dataset, the following deduplication rules were used to identify which survey to retain for each enrollee:

- If two (or more) paper surveys were returned for the same enrollee, the survey with the earliest survey completion date was retained. If two or more paper surveys returned for the same enrollee had the same survey completion date, the survey with most complete data (based on the completeness definition) was retained.
- If duplicate surveys were completed for the same enrollee using different survey modes (web and paper), completeness was used as followed:
  - If all duplicate surveys for an enrollee have the same level of completeness, the survey with the earliest survey completion date was retained.
  - o If all duplicate surveys for an enrollee contain various levels of completeness, the survey with the most complete data was retained.

For a handful of enrollees with duplicate surveys that had the same percentage of completion and same survey completion date, a manual review of the duplicates was conducted by NYC DOHMH to identify which survey to retain.

## **Chapter 6: Data Collection Results**

#### 6. Data Collection Results

### **6.1** Summary of Outcome Rates

The standards for calculating outcome rates are provided by the American Association for Public Opinion Research (AAPOR, 2015). Adult enrollees who were deceased or who withdrew from all Registry activities or only from future Registry surveys prior to the launch of the Wave 5 Survey in April 2020 were ineligible for the Wave 5 Survey. Also ineligible for the Wave 5 Survey were any enrollees who did not complete at least three waves including Waves 1 and 2. Out of the original sample of 39,711, 64 additional cases were identified as ineligible due to the Registry member being deceased or having withdrawn from the Registry during data collection. As a result, a total of 39,647 enrollees were eligible for the Wave 5 Survey and included in the outcome rates described in this chapter, including *new adult* enrollees who were under age 18 at the time of enrollment into the Registry. The main outcome rates calculated for the Wave 5 Survey were the contact, cooperation, and response rates.

The *contact rate* measures the proportion of all cases in which an eligible member of the sample was reached by the survey via e-mail or mail. AAPOR offers three alternative contact rate definitions to fit different survey scenarios. Contact Rate 3 does not regard ineligibles in its calculation, and because all enrollees included in the Wave 5 Survey were eligible, this rate was selected for this report. The contact rate is equal to the total eligible enrollees contacted, divided by all eligible enrollees. Note that O (Other) here, and in subsequent rates, includes both Other, contacted non-interview (OC) and Other non-interview, contact probable (OP):

$$CON3 = \frac{(I+P) + R + O}{(I+P) + R + O + NC}$$

where:

I = Complete interview P = Partial interview

R = Refusal, break-off, and incomplete interview

NC = Non-contact

O = Other

The *cooperation rate* is the proportion of all cases contacted who were interviewed. The denominator for the cooperation rate is equal to the numerator of the contact rate — the total number of eligible enrollees contacted, or in the case of Wave 5, the total number of eligible enrollees definitively or probably contacted. AAPOR Cooperation Rate 2 includes partial completes in the numerator and Others in the denominator.

$$COOP2 = \frac{(I+P)}{(I+P)+R+O}$$

The *response rate* is the number of completed and partial interviews, divided by the eligible sample. Its value is equal to the product of the contact and cooperation rates, which, for the Registry, is equivalent to AAPOR Response Rate 6:

$$RR6 = \frac{(I+P)}{(I+P)+(R+NC+O)}$$

Overall, 39,336 (99.2%) of the 39,647 eligible Wave 5 enrollees were definitively or probably contacted during the Wave 5 Survey data collection period. A total of 27,833 agreed to participate and completed or partially completed the interview. *Table 5* provides a breakdown of enrollees by sample type<sup>3</sup> (responders such as rescue and recovery workers, and survivors such as residents and building occupants/passersby) and their contact, cooperation, and response rates for the Wave 5 Survey. Outcome rates are also displayed by enrollee age group, and gender.

			Outcome Rates (%)	
	Enrollees	Contact	Cooperation	Response
All enrollees	39,647°	99.2%	70.7%	70.2%
Eligibility group <sup>a</sup>				
Responders	17,720	99.5%	73.1%	72.8%
Survivors				
-Residents	6,847	98.1%	58.0%	56.9%
-Students & school staff	142	98.6%	57.9%	57.0%
-Area workers	12,786	99.6%	74.6%	74.3%
-Passersby	2,152	98.9%	68.2%	67.5%
Age on 9/11/2001				
Under 18	2,665	96.1%	36.5%	35.1%
18–24	1,773	99.5%	63.0%	62.7%
25–44	19,678	99.6%	71.1%	70.8%
45–64	14,736	99.5%	77.9%	77.5%
65+	795	96.6%	56.0%	54.1%
Gender <sup>b</sup>				
Male	24,022	99.3%	71.3%	70.9%
Female	15,624	99.1%	69.8%	69.2%

**Table 5: Wave 5 Survey Outcome Rates** 

## **6.2** Outcomes by Survey Mode

Table 6 presents the number of completed interviews by mode and device type used for the Wave 5 Survey. Device type was classified using the "user\_agents" python package (Ong, 2020). The user agent string (UAS) for each web respondent was classified into one of four categories: PC (i.e., desktop/laptop), tablet, mobile, or other. It is possible for a UAS to be classified into more than one device type. For the purposes of this report, the hierarchy used was largest to smallest device type. For example, if a device was classified as both PC and tablet, then it would be categorized as PC. If a device was classified as both tablet and mobile, then it would be categorized as tablet. Devices that were not classified into PC, tablet, or mobile were categorized as "other."

<sup>&</sup>lt;sup>a</sup> As during prior waves, enrollees who belonged to more than one eligibility group were classified into a single eligibility group reflecting their greatest potential for exposure. See Murphy (2006) for more information on the eligibility group hierarchy.

<sup>&</sup>lt;sup>b</sup> One enrollee was missing gender at the Wave 1 survey.

<sup>&</sup>lt;sup>c</sup> Excludes 64 ineligible cases from the original sample of 39,711 due to the Registry member being deceased or having withdrawn from the Registry.

<sup>&</sup>lt;sup>3</sup> As during prior waves, enrollees were classified into a single eligibility group reflecting their greatest potential for exposure. See Murphy (2006) for more information on the eligibility group hierarchy.

Table 6: Completed Interviews by Mode and Device Type Used

		Percent of all	Percent of Web
Wave 5 Mode of Completion	Total Respondents	Respondents	Respondents
Web	15,027	54.0%	100.0%
PC (desktop/laptop)	10,866	39.0%	72.3%
Tablet	649	2.3%	4.3%
Mobile	3,511	12.6%	23.4%
Other	1	<0.1%	<0.1%
Mail	12,806	46.0%	_

## **Chapter 7: Post-Survey Activities**

Throughout data collection, the Registry's Treatment Referral Program (TRP) provided appropriate, comprehensive, and timely follow-up to enrollees completing the Wave 5 Survey by addressing their health problems, concerns, and questions. Panel Maintenance staff also followed up with enrollees who experienced emotional distress during Wave 5 or who indicated a need for assistance on their paper or web survey. Follow-up for emotional distress included a phone call to the enrollee to provide them with information or a direct transfer to NYC WELL, a confidential hotline for crisis intervention and mental health referrals.

The TRP plans to conduct targeted outreach with enrollees to ensure eligible enrollees who are not yet enrolled in the World Trade Center Health Program (WTCHP) are able to access this care. TRP will conduct this round of outreach based on updated health information, including a range of self-reported 9/11-related symptoms and conditions and enrollee self-reported engagement with the WTCHP, from Wave 5 participants. This outreach will target, among others, enrollees who endorsed new cancer diagnoses, unmet healthcare needs, and/or new adult participants in the Wave 5 Survey. Additional outreach to enrollees who reported particular health conditions or participated in nested studies will continue to remain a priority.

## **Chapter 8: Data File Contents**

#### 8. Guide to Data File Codebooks

The WTCHR Wave 5 Survey included data collected from web and paper modes of data collection. The data files for both surveys were created for use with SAS analytic software.

## 8.1 Guide to Hardcopy Codebooks

The codebooks in *Appendix C* supply a comprehensive description of the WTCHR Wave 5 data files. For each variable in the WTCHR Wave 5 data files — excluding identifying and contact information — the codebooks provide a summary of the related information, including a brief description, the available responses, and their frequencies and percentages.

While some variables have been assigned special reserve codes to indicate the reason for missing responses, these codes have all been collapsed into one category labeled "Coded Missing," showing the combined frequencies and percentages in the codebook. These special reserved codes are described below:

- *Invalid Data* (-4): Data for the item are invalid (e.g., multiple answers for single question answers on paper survey).
- Out of Range (-5): Data for the item are out of range (e.g., diagnosis year is earlier than birth year).
- *Unrecognized Character* (-6): Data for the item could not be interpreted by TeleForm software or verifiers.
- *Special Missing (-7):* Exact value or category cannot be determined.
- Birth Year Mismatch (-8): Birth year in the data does not match the preloaded birth year.
- Missing Data (-9): Data for the item are missing.

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## **Appendix A:**

**Wave 1-Wave 5 Health Survey Questionnaire Topic Matrix** 

## WTC Health Registry Snapshot of Adult Survey Topics by Wave WAVE 2: 2006-07 WAVE 3: 2011-12 WAVE 4: 2015-16

**WAVE 1:** 2003-04 **WAVE 5:** 2020-21

Topics	Contents	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5
A. Demographics and						
quality of life	Name	Х	X	R	R	R
	Sex	Х	R	X	X	X
	Date of birth	Х	X	X	X	X
	Current age (*age calculated from DOB)	Х	X	R*	x*	x*
	Social security number (†last 4 digits only)	Х	$R^{\dagger}$	$\mathbf{x}^{\dagger}$	${ m x}^{\dagger}$	$\mathbf{x}^{\dagger}$
	E-mail address	Х	R	R	R	R
	Number of current household members				X	X
	Current employment status	X	R	R	R	R
	Marital status	X	X	R	X	R
	Vital status of enrollee	X		X	R	R
	Ethnicity/race	X				
	Household income	X		R	R	R
	Education	X			R	R
	Residence on 9/11/2001	X				
	Eligibility group	X				
	Life satisfaction			X	X	
	General health		X	X	X	
	SF-12					NEW
	Use of assistive devices due to health					NEW
	problems					INE W
	Quality of physical/mental health in last 30		X	v	X	X
	days		Λ	X	Λ	Λ
	Pre-9/11 & current disabilities/medical		X			
	conditions		Λ			
	Height			X	X	
	Weight			X	R	X
	Exercise			X	R	X
	Sleep quality					NEW
	Sleep quantity					NEW
	Cognitive function			X	R	R
B. Physical health						
symptoms	Eye irritation	X				
	Hearing problem or loss	X	R			
	Throat irritation/sore throat	X	R			
	Hoarseness or loss of voice		R			
	Persistent cough	X	R	R	R	R
	Shortness of breath	X	R	R	R	R
	Wheezing	X	R	R	R	R
	Phlegm				X	
	Skin rash or irritation	X	R			
	Frequent severe headaches	X	R	R		
	Heartburn, indigestion, or acid reflux	X	R	R	R	R
	Sinus problems, nose irritation, or postnasal	X	R			
	irritation					
C. Physical health						
conditions	Hypertension or high blood pressure	X	R	R	R	X
	Angina, or angina pectoris	X	R	R	R	X

Topics	Contents	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5
	Heart attack or myocardial infarction	X	R	R	R	X
	Other (coronary) heart disease	X	R	R	R	X
	Stroke	X	R	R	R	X
	Diabetes or sugar diabetes	X	R	R	R	R
	Hay fever or allergic rhinitis		X			
	Asthma	X	R	X	R	R
	Asthma control			X	R	R
	Asthma – attack or episode in last 12 months		X	X	R	R
	Asthma – inhaler use		X	R	R	
	Asthma – spirometry (pulmonary function test)				X	R
	Chronic bronchitis		X	R	R	X
	Emphysema, or COPD	Х	X	R	R	X
	Reactive airways disease syndrome (RADS)		X	R	R	X
	Sarcoidosis		X	R	R	
	Cancer	X	R	R	R	R
	Cancer – family history				X	R
	Cancer – screening				X	R
	Pulmonary fibrosis			Х	R	X
	Asbestosis			X	R	X
	High cholesterol			X	R	X
	Gastroesophageal reflux disease (GERD)			X	R	X
	Sleep apnea			X	R	X
	Multiple sclerosis (MS) or amyotrophic lateral sclerosis (ALS)			X	R	R
	Thyroid disease			X	R	X
	Peripheral neuropathy			A	X	X
	Alzheimer's disease or some other form of				A	
	dementia					NEW
	Multiple chemical sensitivity (MCS)					NEW
	Hearing loss					NEW
	Parkinson's disease					NEW
	Chronic sinusitis					NEW
	Periodontal disease or gum disease					NEW
	Chronic pain					NEW
	Reproductive health problems					NEW
	Rheumatoid arthritis			X	R	R
	Other autoimmune disorders (e.g., lupus,			Α	IX.	IX
	scleroderma, polymyositis, dermatomyositis					
	Sjögren's syndrome, mixed connective tissue disease)			X	R	R
D. Women's health						
(WOMEN ONLY)	Current pregnancy status	X			X	X
	Pregnancy history (number of pregnancies and number of births)					NEW
	Menstrual history			X		NEW
E. Access to health care	Trionoc dur motor y			A		111111
(physical, mental, and/or	Unmet health care needs		X	R	R	R
oral)	Health care access and utilization		X	R	R	R
<i>-</i>	9/11-related health services utilization		X	11	- 1	
	7/11-Totated Hearth Services utilization		Λ			

Topics	Contents	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5
-	World Trade Center health program		••	R	D	R
	utilization		X	K	R	K
	Health insurance coverage			X	R	R
	Usual health care provider			X	X	
	Oral health care utilization					NEW
	Barriers to care at WTCHP clinic					NEW
F. Oral health	Loss of tooth to decay or gum disease					NEW
G. Mental health						
symptoms	PTSD Checklist	X	X	X	R	R
	Functional status			X	R	X
	Self-medication with alcohol				X	X
	Self-medication with opioids					NEW
	Nonspecific psychological distress (Kessler 6				D	
	Scale)	X	X	X	R	X
	Current depression assessment (PHQ-8)			X	X	Х
	Generalized anxiety disorder			Х		
H. Diagnosed mental						
health conditions	Depression	X	R	R	R	R
	PTSD		R	R	R	R
	Other anxiety disorder		R	R	R	R
	Nerves, emotions, or other mental health					
	problems			X	R	R
	Alcohol or drug dependence				X	R
	Mental health medication/treatment		X	R	R	R
I. Traumatic history						
· · · · · · · · · · · · · · · · · · ·	History of traumatic stress, traumatic life					
	events			X	R	R
	Adverse Childhood Experiences (ACE)					NEW
J. Substance use						
	Cigarette use	X	R	R	R	Х
	E-cigarette use (vaping)					NEW
	Alcohol use		x	R	R	X
	Prescription pain reliever use			1	X	R
	Treatment/counseling for alcohol or drug use				X	R
K. Resiliency and social	Treatment counseling for alcohol of drug use					- 10
support	Self-efficacy				X	R
support	Social support		X	R	R	R
L. 9/11 exposures and	Social support		A	- 10	- 1	- 10
injuries	Injuries on 9/11	X				
injuitou	Exposure details	X	R			
	Dust and debris cloud experience, location,	Λ	10			
	time, evacuation, home or workplace	x	R			
	condition, cleaning	^	10			
	Witnessing events	X				
M. 9/11-related loss	Death of family, friends, co-workers	Λ	X			
N. Union membership	Death of failing, friends, co-workers		X			
11. Omon membership			Λ			

x: item is in the survey
NEW: item is new to Wave 5
R: revised or expanded from previous Wave

## Appendix B: Wave 5 Questionnaire

# World Trade Center Health Registry 2020 Health Survey

 $\rightarrow$ 

2982443675

INSTRUCTIONS:

Please fill in circles completely using

	<ul> <li>a black or blue ink pen.</li> <li>Written answers should be printed in -&gt; capital letters.</li> </ul>		Exam	ple: JA12
	Please enter today's date:  M M D D Y Y Y Y			hat is your date of birth?  M D D Y Y Y Y  M D D D Y Y Y Y
2.	Are you the enrollee named on the cover letter?  O Yes → Go to Question 5  O No, but I am completing this survey for the enrollee  As you complete the survey for the enrollee, please provide the responses that fit best for the enrollee. The words "you" and "your" refer to the enrollee.  3. What prevented the enrollee from		7. W	hat is your sex?  Male Female  hat is your current marital status?  Married → Go to Question 9  Widowed  Divorced or separated  Never married
	completing the survey? Please pick the one best option below.  ○ The enrollee is deceased ○ A physical or mental disability ○ A language barrier ○ The survey was too difficult for the enrollee to read ○ Other reason (Please specify):  ☐ Question 5		9. Ho	
	4. If the enrollee has died, please accept our condolences. Complete only the date and place of death below and mail back the survey or call us at 866-692-9827.  Date of death:  M M D D Y Y Y Y  Place of death: Enter the state if the death occurred in the US, or the country if the death occurred outside of the US.  State:  Country:		en 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	hich of the following describe your current inployment status? Select all that apply.  Employed full-time Employed part-time Self-employed Retired On maternity or parental leave Looking for work Unemployed for less than 1 year Unemployed for 1 year or more Unable to work because of health Homemaker Student
		1		2002442675

#### WTC HEALTH REGISTRY

11.	What is the highest level of education you completed?  O Grade 8 or less O Grades 9 through 11 O Grade 12 or GED O Some college, Associate's Degree, or Technical Degree O Bachelor's Degree O Postgraduate Degree	15	During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?  a. Accomplished less than you would like.  O All of the time O Most of the time O Some of the time O A little of the time O None of the time
12.	What was your total <u>household</u> income in 2019 before taxes?  ○ Less than \$25,000 ○ \$25,000 - \$49,999 ○ \$50,000 - \$74,999 ○ \$75,000 - \$99,999 ○ \$100,000 - \$149,999 ○ \$150,000 or more	16	b. Were limited in the kind of work or other activities.  All of the time  Most of the time  Some of the time  A little of the time  None of the time
13.	In general, would you say your health is:  O Excellent O Very good O Good O Fair O Poor	16	have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?  a. Accomplished less than you would like.  O All of the time  O Most of the time
14.	The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?  a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.  O Yes, limited a lot O Yes, limited a little O No, not limited at all  b. Climbing several flights of stairs. O Yes, limited a lot O Yes, limited a little O No, not limited at all	17	O Some of the time O A little of the time None of the time  b. Did work or other activities less carefully than usual. O All of the time O Most of the time O Some of the time O A little of the time O None of the time O None of the time O None and thousework)? O Not at all O A little bit O Moderately O Quite a bit O Extremely

18.	These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.  How much of the time during the past 4 weeks	23. 24.	For how many days did poor physical or menta health keep you from doing your usual activities during the last 30 days?  days  What is your current weight?				
	a. Have you felt calm and peaceful?  O All of the time O Most of the time O Some of the time O A little of the time O None of the time	25.	In general, how physically active are you?  O Very active O Somewhat active O Not very active O Not active at all				
	<ul> <li>b. Did you have a lot of energy?</li> <li>All of the time</li> <li>Most of the time</li> <li>Some of the time</li> <li>A little of the time</li> <li>None of the time</li> </ul>	26.	During the last 30 days, how many hours of actual sleep did you get most nights?  O Less than 4 hours O 4 hours O 5 hours O 6 hours				
	c. Have you felt downhearted and depressed?  O All of the time O Most of the time O Some of the time O A little of the time O None of the time	27.	<ul> <li>○ 7 hours</li> <li>○ 8 hours</li> <li>○ 9 hours</li> <li>○ 10 hours</li> <li>○ 11 or more hours</li> <li>During the last 30 days, how would you rate your sleep quality overall?</li> </ul>				
19.	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?  O All of the time O Most of the time O Some of the time O A little of the time O None of the time	28.	O Very good O Fairly good O Fairly bad O Very bad  During the last 12 months, have you experienced confusion or memory loss, other than occasionally forgetting the name of someone you recently met?  O Yes				
20.	Do you use any assistive devices because of a health condition? Examples include a cane, a wheelchair, an adapted bed, a hearing assistive telephone, and other similar devices.  O Yes  O No		O No → Go to Question 35  29. During the last 12 months, has your confusion or memory loss happened more often or gotten worse?  O Yes O No				
21.	Thinking about your physical health, which includes physical illness and injury, for how many days during the last 30 days was your physical health not good?  days		30. During the <u>last 12 months</u> , as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?				
22.	Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the <u>last 30</u> days was your mental health <u>not</u> good?		O Always O Usually O Sometimes O Rarely O Never				

#### WTC HEALTH REGISTRY

	31.	ONever	Question 33					sistance with th		
		that you need O Always O Usually O Sometimes O Rarely O Never	i? .	nose day to c	ay uouv		, 11011 0110	in are you able t	o get the help	
	33.	During the last 12 in work, volunteer, or O Always O Usually O Sometimes O Rarely O Never						s interfered with	your ability to	
	34.	Have you or anyon OYes ONo	e else discus	sed your con	fusion o	mer	mory loss	s with a health ca	are professiona	ıl?
35.	For each of the following questions in each row.		In the <u>last 30 days</u> , have you experienced this symptom when you did not have a cold, the flu, or seasonal allergies?		In the <u>last 30 days</u> , how many days did you experience this symptom?		0 days, lays did nce	In the <u>last 30 days</u> , have you been awakened during the night by this symptom when you did <u>not</u> have a cold, the flu, or seasonal allergies?		
			No	Yes	Numl	oer o	f days	No	Yes	
	a. S	hortness of breath	0	$\circ \rightarrow$			<u> </u> →	0	0	
	b. W	Vheezing	0	$\circ \rightarrow$			$\rightarrow$	0	0	
	c. P	ersistent cough	0	$\circ \rightarrow$			$\rightarrow$	0	0	
36.	In the		you used a p	rescription in	haler for	any	breathing	g problem?		
37.	<ul> <li>During the <u>last 12 months</u>, on average, how often have you experienced heartburn or acid reflux?</li> <li>○ Never → Go to Question 39</li> <li>○ Less than once a month</li> <li>○ About once a month</li> <li>○ About once a week</li> </ul>									
		least twice a week								
	¥38.	In the last 30 days, OYes ONo	have you tak	en any medic	ations fo	or hea	artburn o	r acid reflux?		

#### 2020 HEALTH SURVEY

39. Have you ever been told by a doctor or other health professional that you had any of the following conditions? If YES, please provide the year you were first told you had that condition. No Yes Year first told 0  $\circ \rightarrow$ Hypertension, or high blood pressure  $\circ \rightarrow$ High cholesterol 0  $\circ \rightarrow$ 0 c. Angina, or angina pectoris  $\circ \rightarrow$ Heart attack, or myocardial infarction 0 0  $\circ \rightarrow$ Coronary heart disease  $\circ \rightarrow$ f. Stroke 0  $\circ \rightarrow$ g. Type 2 diabetes, or sugar diabetes  $\circ$  $\circ \rightarrow$ 0 h. Chronic bronchitis  $\circ \rightarrow$ Emphysema, or COPD  $\bigcirc$ 0  $\circ \rightarrow$ Reactive airways dysfunction syndrome, or RADS 0  $\circ \rightarrow$ Pulmonary fibrosis Asbestosis 0  $\circ \rightarrow$ 0  $\circ \rightarrow$ m. Chronic sinusitis 0  $\circ \rightarrow$ Alzheimer's disease or some other form of dementia  $\circ \rightarrow$ 0 Sleep apnea, or obstructive sleep apnea  $\circ \rightarrow$ 0 Gastroesophageal reflux disease, or GERD  $\circ \rightarrow$ q. Thyroid disease  $\circ \rightarrow$ Peripheral neuropathy  $\circ \rightarrow$ 0 Multiple chemical sensitivity, or MCS 0  $\circ \rightarrow$ Hearing loss t. 0  $0 \rightarrow$ Parkinson's disease 0  $\circ \rightarrow$ Periodontal disease or gum disease w. Chronic pain 0  $\circ \rightarrow$ Reproductive health problem (Please specify): 0  $\circ \rightarrow$  $\circ \rightarrow$ 0 Lung cancer Other cancer 1 (Please specify): 0  $\circ \rightarrow$ aa. Other cancer 2 (Please specify):- $\circ \rightarrow$ bb. Other disease\* (Please specify):- $0 \rightarrow$ 0 \*Note: Asthma, autoimmune diseases, and mental health conditions are covered later in this survey and should not be added here.

·o.	heal O Y	e you <u>ever</u> been told by a doctor or other th professional that you had asthma?  es  o   Go to Question 49		46.	How would you rate your asthma control during the past 4 weeks?  O Not controlled at all O Poorly controlled
	<b>▶</b> 41.	In what year were you <u>first</u> told by a doctor or other health professional that you had asthma?			O Somewhat controlled O Well controlled O Completely controlled
		Year first told:		47.	During the <u>last 12 months</u> , have you had an asthma episode, also known as an asthma attack or an asthma flare-up?
	42.	In the <u>past 4 weeks</u> , how much of the time did your asthma keep you from getting as much done at work, school or at home?			O Yes O No
		<ul><li>All of the time</li><li>Most of the time</li><li>Some of the time</li><li>A little of the time</li><li>None of the time</li></ul>		48.	In the <u>last 12 months</u> , have you had a pulmonary function test (for example, spirometry)? For pulmonary function tests, you breathe into a mouthpiece connected to a machine that measures how much air you breathe out, and how quickly.  O Yes
	43.	During the <u>past 4 weeks</u> , how often have you had shortness of breath?			O No
		O More than once a day O Once a day O 3 to 6 times a week O Once or twice a week O Not at all	49.	heal auto — O Y	e you <u>ever</u> been told by a doctor or other th professional that you had an simmune disease?  es  o → If male, go to Question 59  If female, go to Question 51
	44.	During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?  O 4 or more nights a week O 2 to 3 nights a week O Once a week O Once or twice O Not at all	Ļ	50.	What type(s) of autoimmune disease were you diagnosed with? Select all that apply.  Amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease  Mixed connective tissue disease  Multiple sclerosis (MS)  Myositis (polymyositis or dermatomyositis Or Rheumatoid arthritis (RA)  Scleroderma  Sjögren's syndrome  Systemic lupus erythematosus
	45.	During the past 4 weeks, how often have you used your rescue inhaler or nebulizer medication (such as Albuterol, Ventolin®, Proventil®, or Maxair®)?  O 3 or more times per day O 1 or 2 times per day O 2 or 3 times per week O Once a week or less		IF Y	Other (Please specify): →  OU ARE MALE → Go to Question 59
		O Not at all	IF	YOU	ARE FEMALE $ ightarrow$ Continue to Question 51

prostate cancer. It is also called a prostate- specific antigen test.  O Yes O No → Go to Question 61  60. What was the main reason you had your most recent PSA test? O Part of a routine exam O Because of a problem O Other reason  61. Has your biological father ever had cancer? O Yes O No O Don't know  → Go to Question 63
62. Which of the following type(s) of cancer has your biological father ever had?  Select all that apply.  ○ Colon  ○ Prostate  ○ Other (Please specify):  ○ Yes  ○ No  ○ Don't know  → Go to Question 65   64. Which of the following type(s) of cancer has your biological mother ever had?  Select all that apply.  ○ Breast  ○ Colon  ○ Other (Please specify):  ○ Other (Please specify):
65. Do you have any biological brothers/sisters who have ever had cancer? Include half- brothers/sisters but not step-brothers/sisters.  ○ Yes ○ No ○ Don't know  → Go to Question 67   66. Which of the following type(s) of cancer have any of your biological brothers/sisters ever had? Select all that apply. ○ Breast ○ Colon ○ Prostate ○ Other (Please specify):-

#### WTC HEALTH REGISTRY

67.	Do you currently have any health insurance? Include private health insurance, HMO, managed care, or a government plan such as Medicare or Medicaid.  O Yes O No	74. The World Trade Center Health Program (WTCHP) provides services through the following clinics:  • FDNY WTC clinics  • Mount Sinai – Icahn School of Medicine  • NYU School of Medicine
68.	During the last 12 months, were you without health insurance at any point?  O Yes O No	<ul> <li>Northwell Health (formerly Queens College/North Shore-LIJ Health System)</li> <li>Rutgers University Robert Wood Johnson Medica School (formerly UMDNJ)</li> <li>SUNY-Stony Brook – in Nassau &amp; Suffolk Counties, and formerly in Brooklyn</li> </ul>
69.	About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.  O Within the last 12 months Over a year ago but less than 2 years ago 2 or more years ago but less than 5 years ago 5 or more years ago Never in my life	<ul> <li>NYC Health + Hospitals System WTC         Environmental Health Center – at Bellevue         Hospital, Elmhurst Hospital and Gouverneur         Healthcare Services</li> <li>William Street Clinic</li> <li>The Nationwide Provider Network (formerly the National Responder Program) or Logistics Health Incorporated (LHI)</li> <li>Have you ever received services for a 9/11-related health condition through any of these clinics?</li> </ul>
70.	During the last 12 months, was there ever a time when you needed health care for physical health problems, but were unable to receive it for any reason?  O Yes O No	O Yes O No O Don't know  75. Have you ever been certified for a 9/11-related mental health condition by the WTCHP?  Certification of a 9/11-related health condition
71.	During the last 12 months, was there ever a time when you needed mental health care or counseling, but were unable to receive it for any reason?  O Yes O No	means the federal WTCHP has determined a patient's condition to be eligible for treatment through the WTCHP.  O Yes O No O Pending certification  → Go to Question 78  ▼76. Was there ever a time when you needed
72.	How long has it been since you last visited a dentist or a dental clinic for any reason? Include visits to dental specialists, such as orthodontists.  O Within the last 12 months Over a year ago but less than 2 years ago 2 or more years ago but less than 5 years ago 5 or more years ago Never in my life	mental health care or counseling but were unable to receive it through the WTCHP for any reason?  ○ Yes ○ No ○ Not applicable – did not seek → Go to care through the program  77. Why could you not get the mental health
73.	How many of your permanent teeth have been removed because of tooth decay or gum disease? Include teeth lost to infection, but do not include teeth lost for other reasons, such as injury or orthodontics.  O None O 1 to 5 O 6 or more but not all O All	care or counseling that you needed through the WTCHP? Select all that apply.  O Phone sessions were not available O Live video sessions were not available O There was limited appointment availability O The wait time in the clinic was too long O My schedule was too busy O I had problems with transportation O I could not find a provider I liked O Other reason(s) not listed above

Below is a list of problems that people sometimes have in response to stressful experiences like the events of September 11, 2001. In the last 30 days, how much were you bothered by:

_	int of deptember 11, 2001. In the <u>last 00 a</u>	Not at all			Quite a bit	Extremely
a.	Repeated, disturbing, and unwanted memories of the events of 9/11?	0	0	0	0	0
b.	Repeated, disturbing dreams of the events of 9/11?	0	0	0	0	0
c.	Suddenly feeling or acting as if the events of 9/11 were actually happening again (as if you were actually back there reliving it)?	0	0	0	0	0
d.	Feeling very upset when something reminded you of the events of 9/11?	0	0	0	0	0
e.	Having strong physical reactions when something reminded you of the events of 9/11 (for example, heart pounding, trouble breathing, sweating)?	0	0	0	0	0
f.	Avoiding memories, thoughts, or feelings related to the events of 9/11?	0	0	0	0	0
g.	Avoiding external reminders of the events of 9/11 (for example, people, places, conversations, activities, objects, or situations)?	0	0	0	0	0
h.	Trouble remembering important parts of the events of 9/11?	0	0	0	0	0
i.	Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	0	0	0	0
j.	Blaming yourself or someone else for the events of 9/11 or what happened after it?	0	0	0	0	0
k.	Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	0	0	0	0
l.	Loss of interest in activities that you used to enjoy?	0	0	0	0	0
	Feeling distant or cut off from other people?	0	0	0	0	0
n.	Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	0	0	0	0	0
0.	Irritable behavior, angry outbursts, or acting aggressively?	0	0	0	0	0
p.	Taking too many risks or doing things that could cause you harm?	0	0	0	0	0
q.	Being "superalert" or watchful or on guard?	0	0	0	0	0
r.	Feeling jumpy or easily startled?	0	0	0	0	0
S.	Having difficulty concentrating?	0	0	0	0	0
t.	Trouble falling or staying asleep?	0	0	0	0	0

#### WTC HEALTH REGISTRY

	79. I hinking about the problems in Question 78:							
	<ul> <li>a. How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?</li> <li>○ Not difficult at all</li> <li>○ Somewhat difficult</li> <li>○ Very difficult</li> <li>○ Extremely difficult</li> </ul>							
	<ul> <li>b. During the <u>last 12 months</u> when you were having some of these problems, did you drink alcohol to improve your mood or to make yourself feel better?         <ul> <li>Yes</li> <li>No</li> </ul> </li> </ul>							
	C.	During the last 12 months when you were use an opioid drug to improve your mod killers such as oxycodone, hydrocodone, codrug.  O Yes O No	od or to make	your	self feel	better? C	pioid drugs in	clude pain
80.	Ove	r the <u>last 2 weeks</u> , how often have you be	en bothered	by an	y of the	following	-	
					Not at a	Sever		
	a. Little interest or pleasure in doing things			0	0	0	0	
	b. F	eeling down, depressed, or hopeless			0	0	0	0
	c. T	c. Trouble falling or staying asleep, or sleeping too much			0	0	0	0
	d. F	d. Feeling tired or having little energy				0	0	0
	e. Poor appetite or overeating				0	0	0	0
	f. Feeling bad about yourself, or that you are a failure or have let yourself or your family down				0	0	0	0
		rouble concentrating on things, such as read rwatching television	ing the newsp	aper	0	0	0	0
	h. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual				0	0	0	0
81.	Duri	ng the <u>last 30 days</u> , about how often did y	ou feel:					
			None of the time	A litt		Some of the time	Most of the time	All of the time
	a. S	o sad that nothing could cheer you up?	0		)	0	0	0
	b. N	ervous?	0			0	0	0
	c. R	estless or fidgety?	0			0	0	0
	d. H	opeless?	0			0	0	0
	e. T	hat everything was an effort?	0			0	0	0
	f. W	/orthless?	0			0	0	0

#### 2020 HEALTH SURVEY

h	ave you <u>ever</u> been told by a doctor or other he ealth conditions? If YES, please provide the ye ou last visited a doctor or other health profess	ear you w	ere first t	old you had that co	
_		No	Yes	Year first told	Year of last visit
а	. Depression	0	$\circ \rightarrow$	$\longrightarrow$	
b	. Post-traumatic stress disorder (PTSD)	0	$\circ \rightarrow$	<u> </u>	
С	. An anxiety disorder, other than PTSD	0	$\circ \rightarrow$	$\qquad \longrightarrow \qquad$	
d	. Problems with your use of alcohol or drugs	0	$\circ \rightarrow$	$\qquad \longrightarrow \qquad$	
е	. Other mental health problems, including problems with your nerves or emotions	0	$\circ$	<u> </u>	
→ If yo	u answered "No" to <u>all</u> of the questions above	(Questio	n 82a-e) -	→ Go to Question &	36
8	<ul> <li>During the <u>last 12 months</u>, have you had a longer for any of the conditions listed in the for medication only.</li> <li>Yes</li> <li>No → Go to Question 85</li> </ul>				
	A. The next several questions are about countable.  During the last 12 months, for which of the therapy? Select all that apply.  Depression  PTSD  An anxiety disorder, other than PTSD  Problems with your use of alcohol or drug  Other mental health problems, including posterial that apply.  During the last 12 months, which of the fortherapy? Select all that apply.  Psychiatrist  Psychologist  Other mental health professional, such as or mental health nurse  General practitioner, family doctor, or other health nurse, occupational therapist, or other health nurse, or a process of the pro	e followings suroblems we social ver medical alth profesinister, pri	vith your n rofession vorker, con doctor ssional est, or rab	erves or emotions  als have you seen  unselor, psychothera	for counseling or apist,

#### WTC HEALTH REGISTRY

	<ul> <li>85. During the last 12 months, for which of the following mental health conditions have y prescription medication? Select all that apply.</li> <li>O Depression</li> <li>O PTSD</li> <li>O An anxiety disorder, other than PTSD</li> <li>O Problems with your use of alcohol or drugs</li> <li>O Other mental health problems, including problems with your nerves or emotions</li> <li>O None of the above</li> </ul>	ou tak	en any
86.	During the <u>last 12 months</u> , have you experienced any of the following situations?		.,
	a. Could not pay for food, housing, or other basic necessities for a period of 3 months or longer	No O	Yes
	b. Serious problems at work or lost a job	0	0
	c. Serious legal problems	0	0
	d. Serious family problems involving your spouse or partner, child, or parents	0	0
	e. Took care of a close family member or friend with a serious or life-threatening illness	0	0
	f. The death of a spouse or partner, close family member, or friend	0	0
	sensitive topics and we appreciate your responses.  Since 9/11, has your life been threatened by any of the following situations? Answer "Yes" of physically harmed or thought you would be physically harmed.	only if y	ou were
		No	Yes
	a. A disaster, either natural or human-made	0	_
	b. A serious accident, including a car accident, an accident at work, or another type of accident	0	O
	c. An attack with a gun, knife, or some other weapon		0
	c. An attack with a gun, knile, or some other weapon	0	0
	d. An attack without a weapon, but with the intent to kill or seriously injure you		
		0	0
	<ul> <li>d. An attack <u>without</u> a weapon, but with the intent to kill or seriously injure you</li> <li>e. A situation in which someone used physical force or threat of force to make you have some</li> </ul>	0	0
	<ul> <li>d. An attack <u>without</u> a weapon, but with the intent to kill or seriously injure you</li> <li>e. A situation in which someone used physical force or threat of force to make you have some type of unwanted sexual contact</li> <li>f. Any other situation in which you were seriously injured or feared you might be killed or</li> </ul>	0 0	0 0
	<ul> <li>d. An attack <u>without</u> a weapon, but with the intent to kill or seriously injure you</li> <li>e. A situation in which someone used physical force or threat of force to make you have some type of unwanted sexual contact</li> <li>f. Any other situation in which you were seriously injured or feared you might be killed or seriously injured</li> </ul>	0 0 0	0 0 0

#### 2020 HEALTH SURVEY

96.	The next questions are about drinks of alcoholic beverages. By a "drink," we mean a can or bottle of beer, a glass of wine or a wine cooler, a shot of liquor, or a mixed drink with liquor in it. We are not asking about times when you only had a sip or two from a drink.	97. For the next few questions, please think about prescription pain relievers such as oxycodone (e.g., Percocet, Endocet, OxyContin) or hydrocodone (e.g., Vicodin, Norco, Lortab). Do not include "over the counter" medications.
a.	Have you ever – even once – had a drink of any type of alcoholic beverage? Do not include times when you only had a sip or two.  O Yes	<ul> <li>a. During the <u>last 12 months</u>, has a doctor or other health professional given you a prescription for a pain reliever?</li></ul>
	O No → Go to Question 97	One / de le Question s/u
	<ul> <li>b. How long has it been since you last drank an alcoholic beverage? <ul> <li>○ Within the last 30 days</li> <li>○ More than 30 days ago but within the last 12 months</li> <li>○ More than 12 months ago</li> <li>□ Question 97</li> </ul> </li> <li>c. During the last 30 days, how many days did you have at least 1 drink of any alcoholic beverage? <ul> <li>□ days</li> </ul> </li> </ul>	b. During the last 12 months, have you ever  - even once - taken the pain reliever that you were prescribed?  ○ Yes ○ No → Go to Question 97d  c. During the last 12 months, have you ever  - even once - taken more of the pain reliever than you were prescribed? This includes taking a higher dosage or taking it more often than directed.  ○ Yes ○ No
	<ul> <li>d. On the days when you drank, about how many drinks did you drink on average?</li> <li>drinks</li> <li>e. In the last 30 days, what is the maximum</li> </ul>	d. During the <u>last 12 months</u> , have you <u>ever</u> – even once – taken a prescription pain reliever that was <u>not</u> prescribed to you?  Ores O No → Go to Question 98
	In the last 30 days, what is the maximum number of drinks you have consumed on one single occasion?  drinks  If female, go to Question 96g	e. During the <u>last 12 months</u> , on average, how often have you taken a prescription pain reliever that was <u>not</u> prescribed to you?  O More than once a week
	f. (If male) Considering all types of alcoholic beverages, how many times during the last 30 days did you have 5 or more drinks on one occasion?  times  → If male, go to Question 97  g. (If female) Considering all types of alcoholic beverages, how many times during the last 30 days did you have 4 or	O Once a week O Two or three times a month O Once a month O Less than once a month
	more drinks on one occasion?  times	

#### 2020 HEALTH SURVEY

	f.	Now think about the <u>last time</u> you used a prescription pain reliever in any way a doctor did <u>not</u> direct you to use. What were the reasons you used the prescription pain reliever the last time?									
		Select all that apply.									
		O To relieve physical pain									
		O To relax or relieve tension									
		O To experiment or to see what it's like									
		OTo feel good or get high									
		O To help with my sleep									
		O To help with my feelings or emotions									
		O To increase or decrease the effect(s) of some other	drug								
		O Because I am "hooked" or I have to have it									
		O I used it for some other reason									
98.	Hav you OYe	e you <u>ever</u> stayed overnight or longer at a hospital, re could receive treatment or counseling for alcohol or es	ehabilitation drug use?	facility, or n	nental health	center so					
	ON	o → Go to Question 100									
L	99.	When did your stay(s) occur?									
		O Before 9/11									
		O After 9/11									
		O Both before and after 9/11									
100.		owing is a list of statements. For each statement, pleaut you.	ase indicate	to what exte	ent it is true c	or not true					
			Not at all true	Hardly true	Moderately true	Exactly true					
		can always manage to solve difficult problems if I try ard enough.	0	0	0	0					
		someone opposes me, I can find the means and ways get what I want.	0	0	0	0					
		is easy for me to stick to my aims and accomplish my loals.	0	0	0	0					
		am confident that I could deal efficiently with nexpected events.	0	0	0	0					
		hanks to my resourcefulness, I know how to handle inforeseen situations.	0	0	0	0					
	f. I	can solve most problems if I invest the necessary effort.	0	0	0	0					
		can remain calm when facing difficulties because I can ely on my coping abilities.	0	0	0	0					
		When I am confronted with a problem, I can usually find everal solutions.	0	0	0	0					
	i. If	I am in trouble, I can usually think of a solution.	0	0	0	0					
		lo matter what comes my way, I'm usually able to andle it.	0	0	0	0					

#### WTC HEALTH REGISTRY

101.	. How often is someone available:						
		None of the time	A little of the time	Some of the time	Most of the time	All of the time	
	a. To take you to the doctor if you need to go?	0	0	0	0	0	
	b. To have a good time with?	0	0	0	0	0	
	c. To hug you?	0	0	0	0	0	
	d. To prepare your meals if you are unable to do it yourself?	0	0	0	0	0	
	e. To understand your problems?	0	0	0	0	0	
102.	In the <u>last 30 days</u> , have you visited, O Yes O No	talked, texted	l, or emailed w	vith friends at	least twice?		
103.	In the <u>last 30 days</u> , have you attende O Yes O No	d a religious s	service at leas	t twice?			
104.	In the <u>last 30 days</u> , have you been ac O Yes O No	tively involve	d in a volunte	er organizatio	n or club?		
105.	About how many close friends or relative with about what is on your mind.	atives do you	have now? In	clude people y	ou feel at ease	with and can	
was	ollowing information is requested to l sent to. This information will remain s hone, please call us at 866-692-9827.						
106.	What are the last 4 digits of your Soc	cial Security N	lumber?				
107.	Go Paperless! You can receive Regis	stry communic	cations via em	nail.			
	What is your current email address? PLEASE PRINT IN CAPITAL LETTERS.						
	This is the end of the survey.  For official use only:						
	Thank you for helping us learn about the long-term health effects of 9/11.  We appreciate your input and will keep your answers confidential.						
16.	Please return the completed surv	ey in the pro	ovided envel	ope.			
IT 1	If the envelope was not included or was lost, call us at 866-692-9827.  Visit nyc.gov/911health for the latest information on 9/11-related research and services.						
Г							

## Appendix C: Wave 5 Survey Codebook

## World Trade Center Health Registry Data Set 2020 Health Survey

Number of Observations: 28356 Number of Variables: 336 Organization of file: One record per enrollee identification number

Note: 'Missing' category includes all values that are not available for any of the following reasons:

Missing Value Code	Meaning of Code
-4	Multiple responses provided for a single-response question
-5	Out of range
-6	Unrecognizable character
-7	Exact value or category cannot be determined
-8	Year of birth date mismatch
-9	Missing

Note: All missing values are coded into one group and reported as Coded Missing.

Data set created by: W5\_full\_v2.sas

Codebook created by: WTCHR\_W5\_Codebook.sas

## Unique identifying control number for participant CTRLNO\_W5

Value	Label	Frequency	Percent
	Data present	28356	100.00

### Q2. Are you the enrollee named on the cover letter? ENROLLEE W5

Value	Label	Frequency	Percent
-7	Uncertain	130	0.46
1	Yes	27939	98.53
2	No - proxy for live enrollee	168	0.59
3	No - proxy for deceased enrollee	119	0.42

#### Q3. What prevented the enrollee from completing the survey? PROXY\_WHY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27787	97.99
1	The enrollee is deceased	117	0.41
2	A physical or mental disability	91	0.32
3	A language barrier	19	0.07
4	The survey was too difficult for the enrollee to read	38	0.13
5	Other reason (Please specify)	304	1.07

## $\ensuremath{\mathbf{Q3}}\xspace$ Oth. Please specify the reason preventing the enrollee from completing the survey.

PROXY\_WHY\_OTHER\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	28078	99.02
	Data present	278	0.98

## Q6. What is your sex? GENDER\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	297	1.05
1	Male	17175	60.57
2	Female	10884	38.38

## Q7. What is your current marital status? MARITAL\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	347	1.22
1	Married	18374	64.80
2	Widowed	1367	4.82
3	Divorced or separated	3976	14.02
4	Never married	4292	15.14

## Q8. Do you currently live with a partner? COHABIT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	18022	63.56
1	Yes	2476	8.73
2	No	7858	27.71

### Q9. How many people live in your household, including you? SIZE HOUSEHOLD W5

_	Value	Label	Frequency	Percent
	-94	Coded Missing	472	1.66
	1-99	Valid range	27884	98.34

## Q10. Which of the following describe your current employment status?: Employed full-time EMPLOY FULL W5

Value	Label	Frequency	Percent
0	Not Selected	17140	60.45
1	Selected	11216	39.55

## Q10. Which of the following describe your current employment status?: Employed part-time EMPLOY\_PART\_W5

Value	Label	Frequency	Percent
0	Not Selected	26629	93.91
1	Selected	1727	6.09

## Q10. Which of the following describe your current employment status?: Self-employed

SELFEMPLOYED\_W5

Value	Label	Frequency	Percent
0	Not Selected	26331	92.86
1	Selected	2025	7.14

## Q10. Which of the following describe your current employment status?: Retired

RETIRED\_W5

Value	Label	Frequency	Percent
0	Not Selected	16680	58.82
1	Selected	11676	41.18

### Q10. Which of the following describe your current employment status?: On maternity or parental leave

LEAVE\_W5

_	Value	Label	Frequency	Percent
-	0	Not Selected	28333	99.92
	1	Selected	23	0.08

### Q10. Which of the following describe your current employment status?: Looking for work

LOOK\_WORK\_W5

Value	Label	Frequency	Percent
0	Not Selected	27667	97.57

#### Q10. Which of the following describe your current employment status?: Looking for work LOOK\_WORK\_W5

Value	Label	Frequency	Percent
1	Selected	689	2.43

#### Q10. Which of the following describe your current employment status?: Unemployed for less than 1 year

NOT EMPLOY LTYR W5

Value	Label	Frequency	Percent
0	Not Selected	27485	96.93
1	Selected	871	3.07

#### Q10. Which of the following describe your current employment status?: Unemployed for 1 year or more

NOT\_EMPLOY\_1YR\_W5

Value	Label	Frequency	Percent
0	Not Selected	27939	98.53
1	Selected	417	1.47

#### Q10. Which of the following describe your current employment status?: Unable to work because of health NOT\_EMPLOY\_HLTH\_W5

Value	Label	Frequency	Percent
0	Not Selected	27040	95.36
1	Selected	1316	4.64

#### Q10. Which of the following describe your current employment status?: Homemaker

HOMEMAKER\_W5

Value	Label	Frequency	Percent
0	Not Selected	27883	98.33
1	Selected	473	1.67

#### Q10. Which of the following describe your current employment status?: Student

STUDENT\_W5

Value	Label	Frequency	Percent
0	Not Selected	28025	98.83
1	Selected	331	1.17

#### Q11. What is the highest level of education you completed? EDUCATION\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	431	1.52
1	Grade 8 or less	225	0.79
2	Grades 9 through 11	437	1.54
3	Grade 12 or GED	3436	12.12
4	Some college, Associate's Degree, or Technical Degree	7924	27.94
5	Bachelor's Degree	8226	29.01
6	Postgraduate Degree	7677	27.07

#### Q12. What was your total household income in 2019 before taxes? **INCOME W5**

Value	Label	Frequency	Percent
-94	Coded Missing	1603	5.65
1	Less than \$25,000	1758	6.20
2	\$25,000 - \$49,999	2967	10.46
3	\$50,000 - \$74,999	3688	13.01
4	\$75,000 - \$99,999	3932	13.87
5	\$100,000 - \$149,999	5960	21.02
6	\$150,000 or more	8448	29.79

#### Q13. In general, would you say your health is... SF12 GENHLTH W5

Value	Label	Frequency	Percent
-94	Coded Missing	382	1.35
1	Excellent	2431	8.57
2	Very good	8293	29.25
3	Good	10646	37.54
4	Fair	5382	18.98
5	Poor	1222	4.31

Q14a. The following questions are about activities you might do during a typical day. Does your health now limit you in: Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf? If so, how much?

SF12\_LIMIT\_ACTIVITIES\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	424	1.50
1	Yes, limited a lot	3047	10.75
2	Yes, limited a little	7614	26.85
3	No, not limited at all	17271	60.91

#### Q14b. The following questions are about activities you might do during a typical day. Does your health now limit you in: Climbing several flights of stairs? If so, how much?

SF12 LIMIT STAIRS W5

Value	Label	Frequency	Percent
-94	Coded Missing	482	1.70
1	Yes, limited a lot	4750	16.75
2	Yes, limited a little	9744	34.36
3	No, not limited at all	13380	47.19

Q15a. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?: Accomplished less than you would like.

SF12 PHYS ACCOMPLISH 4WKS W5

		<del>-</del>	
Value	Label	Frequency	Percent
-94	Coded Missing	511	1.80
1	All of the time	1357	4.79
2	Most of the time	3301	11.64
3	Some of the time	6675	23.54

Q15a. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?: Accomplished less than you would like.

SF12 PHYS ACCOMPLISH 4WKS W5

Value	Label	Frequency	Percent
4	A little of the time	6305	22.24
5	None of the time	10207	36.00

Q15b. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?: Were limited in the kind of work or other activities.

SF12\_PHYS\_LIMITED\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	644	2.27
1	All of the time	1392	4.91
2	Most of the time	2821	9.95
3	Some of the time	6012	21.20
4	A little of the time	6054	21.35
5	None of the time	11433	40.32

Q16a. During the past 4 wks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed/anxious)?: Accomplished less than you would like

SF12\_MH\_ACCOMPLISH\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	494	1.74
1	All of the time	972	3.43
2	Most of the time	2675	9.43
3	Some of the time	6424	22.65
4	A little of the time	6608	23.30
5	None of the time	11183	39.44

Q16b. During past 4 wks, how much of the time have you had any of the following problems w/ your work/other regular daily activities as a result of emotional problems (such as feeling depressed/anxious)?: Did work/other activities less carefully than usua

SF12\_MH\_CAREFUL\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	704	2.48
1	All of the time	728	2.57
2	Most of the time	1886	6.65
3	Some of the time	5456	19.24
4	A little of the time	6586	23.23
5	None of the time	12996	45.83

Q17. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? SF12 PAIN 4WKS W5

Value	Label	Frequency	Percent
-94	Coded Missing	465	1.64
1	Not at all	9774	34.47

Q17. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? SF12 PAIN 4WKS W5

Value	Label	Frequency	Percent
2	A little bit	8877	31.31
3	Moderately	5201	18.34
4	Quite a bit	3153	11.12
5	Extremely	886	3.12

Q18a. These questions are about how you feel/how things have been w/ you during the past 4 wks. Please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks: have you felt calm and peaceful?

SF12\_CALM\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	486	1.71
1	All of the time	1731	6.10
2	Most of the time	11448	40.37
3	Some of the time	8799	31.03
4	A little of the time	4610	16.26
5	None of the time	1282	4.52

Q18b. These questions are about how you feel/how things have been w/ you during the past 4 wks. Please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks: did you have a lot of energy?

SF12 ENERGY 4WKS W5

Value	Label	Frequency	Percent
-94	Coded Missing	540	1.90
1	All of the time	962	3.39
2	Most of the time	9151	32.27
3	Some of the time	10428	36.78
4	A little of the time	5545	19.55
5	None of the time	1730	6.10

Q18c. These questions are about how you feel/how things have been w/ you during the past 4 wks. Please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 wks: have you felt downhearted/depressed

SF12\_DOWNHEARTED\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	664	2.34
1	All of the time	557	1.96
2	Most of the time	2471	8.71
3	Some of the time	7798	27.50
4	A little of the time	9629	33.96
5	None of the time	7237	25.52

Q19. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

SF12\_SOCIAL\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	639	2.25

Q19. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

SF12\_SOCIAL\_4WKS\_W5

Value	Label	Frequency	Percent
1	All of the time	1484	5.23
2	Most of the time	2650	9.35
3	Some of the time	5608	19.78
4	A little of the time	5867	20.69
5	None of the time	12108	42.70

Q20. Do you use any assistive devices because of a health condition? Examples include a cane, a wheelchair, an adapted bed, a hearing assistive telephone, and other similar devices.

ASSISTIVE DEVICE W5

Value	Label	Frequency	Percent
-94	Coded Missing	657	2.32
1	Yes	3687	13.00
2	No	24012	84.68

Q21. Thinking about your physical health, which includes physical illness and injury, for how many days during the last 30 days was your physical health not good?

PHYSHLTH W5

Value	Label	Frequency	Percent
-94	Coded Missing	1103	3.89
0	0 days	12661	44.65
1-30	1-30 days	14592	51.46

Q22. Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the last 30 days was your mental health not good?

MENTHLTH\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1149	4.05
0	0 days	10626	37.47
1-30	1-30 days	16581	58.47

## Q23. For how many days did poor physical or mental health keep you from doing your usual activities during the last 30 days?

POORHLTH\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1511	5.33
0	0 days	12920	45.56
1-30	1-30 days	13925	49.11

## Q24. What is your current weight (in pounds)? WEIGHT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1725	6.08
50-600	Valid range	26631	93.92

Value	Label	Frequency	Percent
-94	Coded Missing	638	2.25
1	Very active	5111	18.02
2	Somewhat active	14471	51.03
3	Not very active	6956	24.53
4	Not active at all	1180	4.16

Q26. During the last 30 days, how many hours of actual sleep did you get most nights?

SLEEP\_HRS\_30D\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	613	2.16
1	Less than 4 hours	675	2.38
2	4 hours	1692	5.97
3	5 hours	4480	15.80
4	6 hours	8034	28.33
5	7 hours	7790	27.47
6	8 hours	3960	13.97
7	9 hours	758	2.67
8	10 hours	239	0.84
9	11 or more hours	115	0.41

### Q27. During the last 30 days, how would you rate your sleep quality overall?

SLEEP\_QUALITY\_30D\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	546	1.93
1	Very good	2937	10.36
2	Fairly good	15629	55.12
3	Fairly bad	7816	27.56
4	Very bad	1428	5.04

Q28. During the last 12 months, have you experienced confusion or memory loss, other than occasionally forgetting the name of someone you recently met?

CML\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	557	1.96
1	Yes	8043	28.36
2	No	19756	69.67

Q29. During the last 12 months, has your confusion or memory loss happened more often or gotten worse?

CML\_WORSE\_12M\_W5

 Value	Label	Frequency	Percent
 -94	Coded Missing	20589	72.61
1	Yes	4378	15.44
 2	No	3389	11.95

Q30. During the last 12 months, as a result of confusion or memory loss, how often have you given up day-to-day household activities or chores you used to do, such as cooking, cleaning, taking medications, driving, or paying bills?

CML NOCHORES 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	20370	71.84
1	Always	240	0.85
2	Usually	601	2.12
3	Sometimes	2296	8.10
4	Rarely	2135	7.53
5	Never	2714	9.57

## Q31. As a result of confusion or memory loss, how often do you need assistance with these day-to-day activities?

CML ASSISTANCE W5

Value	Label	Frequency	Percent
-94	Coded Missing	19985	70.48
1	Always	192	0.68
2	Usually	350	1.23
3	Sometimes	1383	4.88
4	Rarely	2316	8.17
5	Never	4130	14.56

### Q32. When you need help with these day-to-day activities, how often are you able to get the help that you need?

CML\_GET\_HELP\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	25867	91.22
1	Always	405	1.43
2	Usually	668	2.36
3	Sometimes	746	2.63
4	Rarely	366	1.29
5	Never	304	1.07

## Q33. During the last 12 months, how often has confusion or memory loss interfered with your ability to work, volunteer, or engage in social activities outside the home?

CML INTERFERE 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	19857	70.03
1	Always	334	1.18
2	Usually	516	1.82
3	Sometimes	1765	6.22
4	Rarely	2227	7.85
5	Never	3657	12.90

### Q34. Have you or anyone else discussed your confusion or memory loss with a health care professional?

CML\_DISCUSS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	20170	71.13

### Q34. Have you or anyone else discussed your confusion or memory loss with a health care professional?

CML DISCUSS W5

Value		Label	Frequency	Percent
1	Yes		2086	7.36
2	No		6100	21.51

## Q35a1. In the last 30 days, have you experienced this symptom when you did not have a cold, the flu, or seasonal allergies?: Shortness of breath

BRTHLESS\_NOFLU\_30D\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	884	3.12
1	Yes	8511	30.01
2	No	18961	66.87

### Q35a2. In the last 30 days, how many days did you experience this symptom? : Shortness of breath

BRTHLESS NOFLU 30D NDAYS W5

_	Value	Label	Frequency	Percent
_	-94	Coded Missing	20195	71.22
	1-30	Valid range	8161	28.78

#### Q35a3. In the last 30 days, have you been awakened during the night by this symptom when you did not have a cold, the flu, or seasonal allergies?: Shortness of breath

BRTHLESS NOFLU 30D AWAKE W5

Value	Label	Frequency	Percent
-94	Coded Missing	17915	63.18
1	Yes	2701	9.53
2	No	7740	27.30

## Q35b1. In the last 30 days, have you experienced this symptom when you did not have a cold, the flu, or seasonal allergies?: Wheezing WHEEZE NOFLU 30D W5

Value	Label	Frequency	Percent
-94	Coded Missing	1387	4.89
1	Yes	4868	17.17
2	No	22101	77.94

### Q35b2. In the last 30 days, how many days did you experience this symptom?: Wheezing

WHEEZE\_NOFLU\_30D\_NDAYS\_W5

 Value	Label	Frequency	Percent
 -94	Coded Missing	23732	83.69
 1-30	Valid range	4624	16.31

## Q35b3. In the last 30 days, have you been awakened during the night by this symptom when you did not have a cold, the flu, or seasonal allergies?: Wheezing

WHEEZE\_NOFLU\_30D\_AWAKE\_W5

 Value	Label	Frequency	Percent
 -94	Coded Missing	21066	74.29
1	Yes	1693	5.97

Q35b3. In the last 30 days, have you been awakened during the night by this symptom when you did not have a cold, the flu, or seasonal allergies?: Wheezing

WHEEZE\_NOFLU\_30D\_AWAKE\_W5

Value		Label	Frequency	Percent
2	No		5597	19.74

## Q35c1. In the last 30 days, have you experienced this symptom when you did not have a cold, the flu, or seasonal allergies? Persistent cough COUGH\_NOFLU\_30D\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1410	4.97
1	Yes	4779	16.85
2	No	22167	78.17

### Q35c2. In the last 30 days, how many days did you experience this symptom?: Persistent cough

COUGH NOFLU 30D NDAYS W5

Value	Label	Frequency	Percent
-94	Coded Missing	23833	84.05
1-30	Valid range	4523	15.95

#### Q35c3. In the last 30 days, have you been awakened during the night by this symptom when you did not have a cold, the flu, or seasonal allergies?: Persistent cough

COUGH\_NOFLU\_30D\_AWAKE\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	20990	74.02
1	Yes	2502	8.82
2	No	4864	17.15

### Q36. In the last 30 days, have you used a prescription inhaler for any breathing problem?

INHALER 30D W5

Value	Label	Frequency	Percent
-94	Coded Missing	820	2.89
1	Yes	5240	18.48
2	No	22296	78.63

### Q37. During the last 12 months, on average, how often have you experienced heartburn or acid reflux?

HTBURN\_12M\_FREQ\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	787	2.78
1	Never	8382	29.56
2	Less than once a month	5867	20.69
3	About once a month	4288	15.12
4	About once a week	3977	14.03
5	At least twice a week	5055	17.83

### Q38. In the last 30 days, have you taken any medications for heartburn or acid reflux?

HTBURN\_30D\_MEDS\_W5

Value	Label	Frequency	Percent	

## Q38. In the last 30 days, have you taken any medications for heartburn or acid reflux?

HTBURN\_30D\_MEDS\_W5

 Value	Label	Frequency	Percent
 -94	Coded Missing	8836	31.16
1	Yes	10537	37.16
2	No	8983	31.68

## Q39a. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Hypertension or high blood pressure

HYPERTENSION\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	898	3.17
1	Yes	12533	44.20
2	No	14925	52.63

## Q39a. If YES, please provide the year you were first told you had that condition.: Hypertension or high blood pressure HYPERTENSION\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	17106	60.33
1900-2021	Valid range	11250	39.67

## Q39b. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: High cholesterol

CHOLESTEROL\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	989	3.49
1	Yes	13993	49.35
2	No	13374	47.16

## Q39b. If YES, please provide the year you were first told you had that condition.: High cholesterol $\,$

CHOLESTEROL\_YR\_W5

_	Value	Label	Frequency	Percent
	-94	Coded Missing	15815	55.77
	1900-2021	Valid range	12541	44.23

## Q39c. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Angina, or angina pectoris

ANGINA W5

Value	Label	Frequency	Percent
-94	Coded Missing	1469	5.18
1	Yes	838	2.96
2	No	26049	91.86

### Q39c. If YES, please provide the year you were first told you had that condition.: Angina, or angina pectoris

ANGINA\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27720	97.76

Q39c. If YES, please provide the year you were first told you had that condition.: Angina, or angina pectoris

ANGINA\_YR\_W5

Value	Label	Frequency	Percent
1900-2021	Valid range	636	2.24

## Q39d. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Heart attack, or myocardial infarction

HEART\_ATTACK\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1325	4.67
1	Yes	1260	4.44
2	No	25771	90.88

## Q39d. If YES, please provide the year you were first told you had that condition.: Heart attack, or myocardial infarction $\,$

HEART ATTACK YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	27287	96.23
1900-2021	Valid range	1069	3.77

## Q39e. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Coronary heart disease

CHD W5

Value	Label	Frequency	Percent
-94	Coded Missing	1336	4.71
1	Yes	2189	7.72
2	No	24831	87.57

## Q39e. If YES, please provide the year you were first told you had that condition.: Coronary heart disease

CHD\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	26467	93.34
1900-2021	Valid range	1889	6.66

## Q39f. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Stroke

STROKE\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1353	4.77
1	Yes	859	3.03
2	No	26144	92.20

### Q39f. If YES, please provide the year you were first told you had that condition.: Stroke

STROKE\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27654	97.52
1900-2021	Valid range	702	2.48

# Q39g. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Type 2 diabetes, or sugar diabetes DIABETES\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1194	4.21
1	Yes	3941	13.90
2	No	23221	81.89

## Q39g. If YES, please provide the year you were first told you had that condition.: Type 2 diabetes, or sugar diabetes

DIABETES YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	24970	88.06
1900-2021	Valid range	3386	11.94

## Q39h. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Chronic bronchitis

CHBRONCH W5

Value	Label	Frequency	Percent
 -94	Coded Missing	1375	4.85
1	Yes	2608	9.20
2	No	24373	85.95

## Q39h. If YES, please provide the year you were first told you had that condition.: Chronic bronchitis

CHBRONCH\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	26172	92.30
1900-2021	Valid range	2184	7.70

## Q39i. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Emphysema, or COPD EMPHYS\_COPD\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1371	4.83
1	Yes	2116	7.46
2	No	24869	87.70

## Q39i. If YES, please provide the year you were first told you had that condition.: Emphysema, or COPD EMPHYS COPD YR W5

 Value
 Label
 Frequency
 Percent

 -9--4
 Coded Missing
 26593
 93.78

 1900-2021
 Valid range
 1763
 6.22

## Q39j. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Reactive airways dysfunction syndrome, or RADS

RADS W5

Value	Label	Frequency	Percent
-94	Coded Missing	1484	5.23
1	Yes	1338	4.72

## Q39j. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Reactive airways dysfunction syndrome, or RADS $\frac{1}{2} \frac{1}{2} \frac{1}{2}$

RADS\_W5

Value		Label	Frequency	Percent
2	No		25534	90.05

## Q39j. If YES, please provide the year you were first told you had that condition.: Reactive airways dysfunction syndrome, or RADS RADS\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27266	96.16
1900-2021	Valid range	1090	3.84

## Q39k. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Pulmonary fibrosis

#### **PULMONARY FIBROSIS W5**

Value	Label	Frequency	Percent
-94	Coded Missing	1460	5.15
1	Yes	367	1.29
2	No	26529	93.56

## Q39k. If YES, please provide the year you were first told you had that condition.: Pulmonary fibrosis

#### PULMONARY FIBROSIS YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	28142	99.25
1900-2021	Valid range	214	0.75

## Q391. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Asbestosis ASBESTOSIS W5

Value	Label	Frequency	Percent
-94	Coded Missing	1468	5.18
1	Yes	296	1.04
2	No	26592	93.78

## Q391. If YES, please provide the year you were first told you had that condition.: Asbestosis

#### ASBESTOSIS\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	28204	99.46
1900-2021	Valid range	152	0.54

## Q39m. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Chronic sinusitis

#### **CHSINUSITIS W5**

Value	Label	Frequency	Percent
-94	Coded Missing	1360	4.80
1	Yes	5524	19.48
2	No	21472	75.72

## ${\bf Q39m.}$ If YES, please provide the year you were first told you had that condition.: Chronic sinusitis

#### CHSINUSITIS\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	23584	83.17
1900-2021	Valid range	4772	16.83

## Q39n. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Alzheimer's disease or some other form of dementia

#### ALZ\_DEMENTIA\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1425	5.03
1	Yes	330	1.16
2	No	26601	93.81

## Q39n. If YES, please provide the year you were first told you had that condition.: Alzheimer's disease or some other form of dementia ALZ DEMENTIA YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	28186	99.40
1900-2021	Valid range	170	0.60

## Q390. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Sleep apnea, or obstructive sleep apnea

#### SLEEP APNEA W5

Value	Label	Frequency	Percent
-94	Coded Missing	1297	4.57
1	Yes	6117	21.57
2	No	20942	73.85

## Q390. If YES, please provide the year you were first told you had that condition.: Sleep apnea, or obstructive sleep apnea

#### SLEEP\_APNEA\_YR\_W5

	Value	Label	Frequency	Percent
-	-94	Coded Missing	22965	80.99
	1900-2021	Valid range	5391	19.01

## Q39p. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Gastroesophageal reflux disease, or GERD

#### GERD\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1213	4.28
1	Yes	8175	28.83
2	No	18968	66.89

## Q39p. If YES, please provide the year you were first told you had that condition.: Gastroesophageal reflux disease, or GERD

#### GERD\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21168	74.65
1900-2021	Valid range	7188	25.35

Q39q. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Thyroid disease

THYROID\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1305	4.60
1	Yes	3167	11.17
2	No	23884	84.23

#### Q39q. If YES, please provide the year you were first told you had that condition.: Thyroid disease

THYROID YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	25609	90.31
1900-2021	Valid range	2747	9.69

#### Q39r. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Peripheral neuropathy

PERIPH\_NEUROP W5

Value	Label	Frequency	Percent
-94	Coded Missing	1503	5.30
1	Yes	1571	5.54
2	No	25282	89.16

#### Q39r. If YES, please provide the year you were first told you had that condition.: Peripheral neuropathy PERIPH NEUROP YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	27046	95.38
1900-2021	Valid range	1310	4.62

#### Q39s. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Multiple chemical sensitivity, or MCS

MCS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1500	5.29
1	Yes	374	1.32
2	No	26482	93.39

#### Q39s. If YES, please provide the year you were first told you had that condition.: Multiple chemical sensitivity, or MCS MCS YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	28156	99.29
1900-2021	Valid range	200	0.71

#### Q39t. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Hearing loss HEARING\_LOSS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1269	4.48
1	Yes	5741	20.25

#### Q39t. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Hearing loss HEARING\_LOSS\_W5

Value		Label	Frequency	Percent
2	No		21346	75.28

#### Q39t. If YES, please provide the year you were first told you had that condition .: Hearing loss

**HEARING LOSS YR W5** 

Value	Label	Frequency	Percent
-94	Coded Missing	23315	82.22
1900-2021	Valid range	5041	17.78

#### Q39u. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Parkinson's disease

PARKINSONS W5

 Value	Label	Frequency	Percent
-94	Coded Missing	1407	4.96
1	Yes	275	0.97
2	No	26674	94.07

#### Q39u. If YES, please provide the year you were first told you had that condition .: Parkinson's disease

PARKINSONS\_YR\_W5

_	Value	Label	Frequency	Percent
	-94	Coded Missing	28221	99.52
	1900-2021	Valid range	135	0.48

#### Q39v. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Periodontal disease or gum disease **GUM DISEASE W5**

Value	Label	Frequency	Percent
-94	Coded Missing	1370	4.83
1	Yes	3840	13.54
2	No	23146	81.63

#### O39v. If YES, please provide the year you were first told you had that condition .: Periodontal disease or gum disease

**GUM DISEASE YR W5** 

Value	Label	Frequency	Percent
-94	Coded Missing	25027	88.26
1900-2021	Valid range	3329	11.74

#### Q39w. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Chronic pain

CHPAIN W5

Value	Label	Frequency	Percent
-94	Coded Missing	1438	5.07
1	Yes	5439	19.18
2	No	21479	75.75

## $\ensuremath{\mathsf{Q39w}}.$ If YES, please provide the year you were first told you had that condition.: Chronic pain

CHPAIN\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	23750	83.76
1900-2021	Valid range	4606	16.24

## Q39x. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Reproductive health problem

REPRODUCTIVE\_PROB\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1782	6.28
1	Yes	2231	7.87
2	No	24343	85.85

## Q39x. If YES, please provide the year you were first told you had that condition.: Reproductive health problem REPRODUCTIVE PROB YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	26540	93.60
1900-2021	Valid range	1816	6.40

## Q39x\_Oth. Specify the reproductive health problem. REPRODUCTIVE\_PROB\_SPECIFY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	26389	93.06
	Data present	1967	6.94

## Q39y. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Lung cancer

**LUNG CANCER W5** 

Value	Label	Frequency	Percent
-94	Coded Missing	1638	5.78
1	Yes	335	1.18
2	No	26383	93.04

### Q39y. If YES, please provide the year you were first told you had that condition.: Lung cancer

LUNG\_CANCER\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	28146	99.26
1900-2021	Valid range	210	0.74

## Q39z. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Other cancer 1

OTHER\_CANCER1\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	2193	7.73
1	Yes	5266	18.57
2	No	20897	73.70

## Q39z. If YES, please provide the year you were first told you had that condition.: Other cancer 1

OTHER CANCER1 YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	23687	83.53
1900-2021	Valid range	4669	16.47

#### Q39z\_Oth. Specify the other type of cancer. OTHER CANCER1 SPECIFY W5

Value	Label	Frequency	Percent
-94	Coded Missing	23238	81.95
	Data present	5118	18.05

## Q39aa. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Other cancer 2

OTHER\_CANCER2\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	3357	11.84
1	Yes	1169	4.12
2	No	23830	84.04

## Q39aa. If YES, please provide the year you were first told you had that condition.: Other cancer 2 OTHER\_CANCER2\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27416	96.69
1900-2021	Valid range	940	3.31

### Q39aa\_Oth. Specify the other type of cancer. OTHER\_CANCER2\_SPECIFY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27312	96.32
	Data present	1044	3.68

## Q39bb. Have you ever been told by a doctor or other health professional that you had any of the following conditions?: Other disease

OTHER DIS W5

_	Value	Label	Frequency	Percent
	-94	Coded Missing	3282	11.57
	1	Yes	4144	14.61
	2	No	20930	73.81

## Q39bb. If YES, please provide the year you were first told you had that condition.: Other disease

OTHER\_DIS\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	24828	87.56
1900-2021	Valid range	3528	12.44

## Q39b\_Oth. Specify the other disease. OTHER\_DIS\_SPECIFY\_W5

Value Label Frequency Perce
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### Q39b\_Oth. Specify the other disease. OTHER\_DIS\_SPECIFY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	24429	86.15
	Data present	3927	13.85

## Q40. Have you ever been told by a doctor or other health professional that you had asthma?

#### ASTHMA\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	759	2.68
1	Yes	6666	23.51
2	No	20931	73.82

### Q41. In what year were you first told by a doctor or other health professional that you had asthma?

#### ASTHMA\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	22534	79.47
1900-2021	Valid range	5822	20.53

## Q42. In the past 4 weeks, how much of the time did your asthma keep you from getting as much done at work, school or at home?

#### ACT\_IMPAIR\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21775	76.79
1	All of the time	147	0.52
2	Most of the time	355	1.25
3	Some of the time	1226	4.32
4	A little of the time	1436	5.06
5	None of the time	3417	12.05

### Q43. During the past 4 weeks, how often have you had shortness of breath?

#### ACT\_BREATHLESS\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21683	76.47
1	More than once a day	794	2.80
2	Once a day	412	1.45
3	3 to 6 times a week	858	3.03
4	Once or twice a week	2222	7.84
5	Not at all	2387	8.42

## Q44. During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

#### ACT\_AWAKEN\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21723	76.61
1	4 or more nights a week	477	1.68
2	2 to 3 nights a week	703	2.48
3	Once a week	479	1.69

## Q44. During the past 4 weeks, how often did your asthma symptoms (wheezing, coughing, shortness of breath, chest tightness or pain) wake you up at night or earlier than usual in the morning?

#### ACT\_AWAKEN\_4WKS\_W5

Value	Label	Frequency	Percent
4	Once or twice	1303	4.60
5	Not at all	3671	12.95

## Q45. During the past 4 weeks, how often have you used your rescue inhaler or nebulizer medication (such as Albuterol, Ventolin®, Proventil®, or Maxair®)?

#### ACT\_INHALER\_4WKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21738	76.66
1	3 or more times per day	1.15	
2	1 or 2 times per day	933	3.29
3	2 or 3 times per week	983	3.47
4	Once a week or less	1326	4.68
5	Not at all	3051	10.76

### Q46. How would you rate your asthma control during the past 4 weeks?

#### ACT CONTROL 4WKS W5

Value	Label	Frequency	Percent
-94	Coded Missing	21920	77.30
1	Not controlled at all	102	0.36
2	Poorly controlled	238	0.84
3	Somewhat controlled	1577	5.56
4	Well controlled	2296	8.10
5	Completely controlled 2223		7.84

## Q47. During the last 12 months, have you had an asthma episode, also known as an asthma attack or an asthma flare-up?

#### ASTHMA EPISODE 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	21840	77.02
1	Yes	2035	7.18
2	No	4481	15.80

### Q48. In the last 12 months, have you had a pulmonary function test (for example, spirometry)?

#### ASTHMA\_PFT\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21755	76.72
1	Yes	2928	10.33
2	No	3673	12.95

### Q49. Have you ever been told by a doctor or other health professional that you had an autoimmune disease?

#### AUTOIMM\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	961	3.39
1	Yes	2674	9.43

#### Q49. Have you ever been told by a doctor or other health professional that you had an autoimmune disease?

#### **AUTOIMM W5**

Value		Label	Frequency	Percent
2	No		24721	87.18

#### Q50a. What type(s) of autoimmune disease were you diagnosed with?: Amyotrophic lateral sclerosis (ALS) or Lou Gehrig's disease

**AUTOIMM ALS W5** 

Value	Label	Frequency	Percent
0	Not Selected	28346	99.96
1	Selected	10	0.04

#### Q50b. What type(s) of autoimmune disease were you diagnosed with?: Mixed connective tissue disease

#### AUTOIMM\_MCTD\_W5

Value	Label	Frequency	Percent
0	Not Selected	28283	99.74
1	Selected	73	0.26

#### Q50c. What type(s) of autoimmune disease were you diagnosed with?: Multiple sclerosis (MS)

#### AUTOIMM\_MS\_W5

Value	Label	Frequency	Percent
0	Not Selected	28247	99.62
1	Selected	109	0.38

#### Q50d. What type(s) of autoimmune disease were you diagnosed with?: Myositis (polymyositis or dermatomyositis)

#### **AUTOIMM MYOSITIS W5**

Value	Label	Frequency	Percent
0	Not Selected	28317	99.86
1	Selected	39	0.14

#### Q50e. What type(s) of autoimmune disease were you diagnosed with?: Rheumatoid arthritis (RA)

#### AUTOIMM\_RA\_W5

Valu	ue	Label	Frequency	Percent
0	Not	Selected	27788	98.00
1	Sele	ected	568	2.00

#### Q50f. What type(s) of autoimmune disease were you diagnosed with?: Scleroderma

#### AUTOIMM\_SCLERODERMA W5

Value	Label	Frequency	Percent
0	Not Selected	28318	99.87
1	Selected	38	0.13

#### Q50g. What type(s) of autoimmune disease were you diagnosed with?: Sjögren's syndrome

#### AUTOIMM\_SJORGENS\_W5

Value	Label	Frequency	Percent
0	Not Selected	28226	99.54
1	Selected	130	0.46

#### Q50h. What type(s) of autoimmune disease were you diagnosed with?: Systemic lupus erythematosus

#### AUTOIMM\_LUPUS\_W5

Value	Label	Frequency	Percent
0	Not Selected	28239	99.59
1	Selected	117	0.41

### Q50i. What type(s) of autoimmune disease were you diagnosed with?:

#### **AUTOIMM OTHER W5**

Value	Label	Frequency	Percent
0	Not Selected	26466	93.33
1	Selected	1890	6.67

#### Q50 Oth. Specify the other type of autoimmune disease that you have. AUTOIMM\_OTHER\_SPECIFY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	26508	93.48
	Data present	1848	6.52

### Q51. (If female) Are you currently pregnant?

#### **CURR PREGNANT W5**

Valu	ie Label	Frequency	Percent
-9	4 Coded Missing	17837	62.90
1	Yes	45	0.16
2	No	10448	36.85
3	Don't know	26	0.09

#### Q52. (If female) How many times have you been pregnant including miscarriages, stillbirths, ectopic or tubal pregnancies, abortions, and live births? If you are pregnant now, please count this pregnancy.

#### NTIMES\_PREGNANT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	18158	64.04
	Data present	10198	35.96

#### Q52. (If female) How many times have you been pregnant including miscarriages, stillbirths, ectopic or tubal pregnancies, abortions, and live births?: None

#### NTIMES\_PREGNANT\_NONE\_W5

 Value	Label	Frequency	Percent
-94	Coded Missing	18211	64.22
0	No	7164	25.26
1	Yes	2981	10.51

#### Q53. How old were you when you became pregnant for the first time? AGE FIRST PREG W5

Value	Label	Frequency	Percent
-94	Coded Missing	21272	75.02
	Data present	7084	24.98

#### Q54. How many children have you given birth to? NCHILDREN W5

Value	Label	Frequency	Percent
-94	Coded Missing	21146	74.57
	Data present	7210	25.43

Q55. (If female) Have you gone through menopause? Menopause is when you have gone for 12 months or more without having a menstrual period, not counting when you were pregnant, breastfeeding, or taking hormonal medication, such as hormonal contraception.

MENOPAUSE\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	17944	63.28
1	Yes	7375	26.01
2	No	3037	10.71

### Q56. How old were you when you went through menopause? MENOPAUSE AGE ONSET W5

Value	Label	Frequency	Percent
-94	Coded Missing	21487	75.78
	Data present	6869	24.22

### Q57. (If female) In the last 12 months, did you have a mammogram? MAMMOGRAM\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	17897	63.12
1	Yes	6864	24.21
2	No	3595	12.68

### Q58. What was the main reason you had your most recent mammogram?

MAMMOGRAM\_REASON\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21633	76.29
1	Part of a routine exam	6130	21.62
2	Because of a problem	426	1.50
3	Other reason	167	0.59

## Q59. (If male) In the last 12 months, did you have a PSA test? A PSA test is a blood test to detect prostate cancer. It is also called a prostate-specific antigen test.

PSA\_TEST\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	11103	39.16
1	Yes	8915	31.44
2	No	8338	29.40

### Q60. What was the main reason you had your most recent PSA test? PSA TEST REASON W5

Value	Label	Frequency	Percent
-94	Coded Missing	19635	69.24
1	Part of a routine exam	7224	25.48
2	Because of a problem	1192	4.20
3	Other reason	305	1.08

### Q61. Has your biological father ever had cancer? CANCER\_FATHER\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	927	3.27
1	Yes	9016	31.80
2	No	15989	56.39
3	Don't know	2424	8.55

## Q62. Which of the following type(s) of cancer has your biological father ever had?: Colon

CANCER\_FATHER\_COLON\_W5

Value	Label	Frequency	Percent
0	Not Selected	27149	95.74
1	Selected	1207	4.26

### Q62. Which of the following type(s) of cancer has your biological father ever had?: Prostate ${\bf q}$

**CANCER FATHER PROSTATE W5** 

Value	Label	Frequency	Percent
0	Not Selected	25562	90.15
1	Selected	2794	9.85

### Q62. Which of the following type(s) of cancer has your biological father ever had?: Other

CANCER\_FATHER\_OTHER\_W5

Value	Label	Frequency	Percent
0	Not Selected	22614	79.75
1	Selected	5742	20.25

### $\ensuremath{\mathbf{Q62}}\xspace$ Oth: Specify the other type of cancer your biological father has had.

**CANCER FATHER SPECIFY W5** 

Value	Label	Frequency	Percent
 -94	Coded Missing	23306	82.19
	Data present	5050	17.81

### Q63. Has your biological mother ever had cancer? CANCER\_MOTHER\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	945	3.33
1	Yes	8621	30.40
2	No	17549	61.89
3	Don't know	1241	4.38

## Q64. Which of the following type(s) of cancer has your biological mother ever had?: Breast

CANCER\_MOTHER\_BREAST\_W5

Value	Label	Frequency	Percent
0	Not Selected	25388	89.53
1	Selected	2968	10.47

#### Q64. Which of the following type(s) of cancer has your biological mother ever had?: Colon

#### CANCER\_MOTHER\_COLON\_W5

Value	Label	Frequency	Percent
0	Not Selected	27417	96.69
1	Selected	939	3.31

#### Q64. Which of the following type(s) of cancer has your biological mother ever had?: Other

#### CANCER\_MOTHER\_OTHER\_W5

Value	Label	Frequency	Percent
0	Not Selected	23083	81.40
1	Selected	5273	18.60

### Q64\_Oth: Specify the other type of cancer your biological mother has

#### CANCER\_MOTHER\_SPECIFY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	23707	83.60
	Data present	4649	16.40

#### Q65. Do you have any biological brothers/sisters who have ever had cancer? Include half-brothers/sisters but not step-brothers/sisters. **CANCER SIB W5**

Value	Label	Frequency	Percent
-94	Coded Missing	951	3.35
1	Yes	6119	21.58
2	No	19927	70.27
3	Don't know	1359	4.79

#### Q66. Which of the following type(s) of cancer have any of your biological brothers/sisters ever had?: Breast

#### CANCER\_SIB\_BREAST\_W5

Value	Label	Frequency	Percent
0	Not Selected	26713	94.21
1	Selected	1643	5.79

#### Q66. Which of the following type(s) of cancer have any of your biological brothers/sisters ever had?: Colon

#### CANCER\_SIB\_COLON\_W5

Value	Label	Frequency	Percent
0	Not Selected	27776	97.95
1	Selected	580	2.05

#### Q66. Which of the following type(s) of cancer have any of your biological brothers/sisters ever had?: Prostate

#### CANCER\_SIB\_PROSTATE\_W5

Value	Label	Frequency	Percent
0	Not Selected	27577	97.25
1	Selected	779	2.75

Q66. Which of the following type(s) of cancer have any of your biological brothers/sisters ever had?: Other CANCER\_SIB\_OTHER\_W5

Value	Label	Frequency	Percent
 0	Not Selected	24594	86.73
1	Selected	3762	13.27

#### Q66 Oth: Specify the other type of cancer your biological brothers/sisters have had.

#### CANCER\_SIB\_SPECIFY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	24752	87.29
	Data present	3604	12.71

#### Q67. Do you currently have any health insurance? Include private health insurance, HMO, managed care, or a government plan such as Medicare or Medicaid.

#### HEALTH\_INSURANCE\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	817	2.88
1	Yes	26932	94.98
2	No	607	2.14

#### Q68. During the last 12 months, were you without health insurance at any point?

#### HEALTH NOINSUR 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	883	3.11
1	Yes	934	3.29
2	No	26539	93.59

#### Q69. About how long has it been since you last visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.

#### **ROUTINE CHECKUP W5**

Value	Label	Frequency	Percent
-94	Coded Missing	783	2.76
1	Within the last 12 months	21442	75.62
2	Over a year ago but less than 2 years ago	4120	14.53
3	2 or more years ago but less than 5 years ago	1324	4.67
4	5 or more years ago	642	2.26
5	Never in my life	45	0.16

#### Q70. During the last 12 months, was there ever a time when you needed health care for physical health problems, but were unable to receive it for any reason?

#### **UNMET NEED PHYS 12M W5**

Value	Label	Frequency	Percent
-94	Coded Missing	844	2.98
1	Yes	2311	8.15
2	No	25201	88.87

#### Q71. During the last 12 months, was there ever a time when you needed mental health care or counseling, but were unable to receive it for any reason?

UNMET NEED MH 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	862	3.04
1	Yes	1789	6.31
2	No	25705	90.65

Q72. How long has it been since you last visited a dentist or a dental clinic for any reason? Include visits to dental specialists, such as orthodontists.

DENTAL LAST VISIT W5

Value	Label	Frequency	Percent
-94	Coded Missing	841	2.97
1	Within the last 12 months	20567	72.53
2	Over a year ago but less than 2 years ago	3449	12.16
3	2 or more years ago but less than 5 years ago	2114	7.46
4	5 or more years ago	1359	4.79
5	Never in my life	26	0.09

Q73. How many of your permanent teeth have been removed because of tooth decay or gum disease? Include teeth lost to infection, but do not include teeth lost for other reasons, such as injury or orthodontics. DENTAL\_TEETH\_RMVD\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	883	3.11
1	None	12989	45.81
2	1 to 5	10570	37.28
3	6 or more but not all	3263	11.51
4	All	651	2.30

## Q74. Have you ever received services for a 9/11-related health condition through any WTCHP clinic? WTCPROG SERVICES W5

Value	Label	Frequency	Percent
-94	Coded Missing	908	3.20
1	Yes	6539	23.06
2	No	19922	70.26
3	Don't know	987	3.48

Q75. Have you ever been certified for a 9/11-related mental health condition by the WTCHP? Certification of a 9/11-related health condition means the federal WTCHP has determined a patient's condition to be eligible for treatment through the WTCHP.

WTCHP\_CERTIFIED\_MH\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1006	3.55
1	Yes	3286	11.59
2	No	23758	83.78
3	Pending certification	306	1.08

Q76. Was there ever a time when you needed mental health care or counseling but were unable to receive it through the WTCHP for any reason?

WTCHP NEED CARE W5

Value	Label	Frequency	Percent
-94	Coded Missing	21236	74.89
1	Yes	910	3.21
2	No	5025	17.72
3	Not applicable did not seek care through the program	1185	4.18

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: Phone sessions were not available NO\_PHONE\_SESSION\_W5

Value	Label	Frequency	Percent
0	Not Selected	28235	99.57
1	Selected	121	0.43

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: Live video sessions were not available

#### NO\_VIDEO\_SESSION\_W5

v	alue	Label	Frequency	Percent
	0	Not Selected	28286	99.75
	1	Selected	70	0.25

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: There was limited appointment availability

#### LIMITED\_APPT\_W5

Value	Label	Frequency	Percent
0	Not Selected	28203	99.46
1	Selected	153	0.54

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: The wait time in the clinic was too long

#### LONG\_WAIT\_TIMES\_W5

Value	Label	Frequency	Percent
0	Not Selected	28285	99.75
1	Selected	71	0.25

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: My schedule was too busy BUSY SCHEDULE W5

Value	Label	Frequency	Percent
 0	Not Selected	28259	99.66
1	Selected	97	0.34

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: I had problems with transportation

#### TRANSPORTATION\_W5

Value	Label	Frequency	Percent
0	Not Selected	28246	99.61
1	Selected	110	0.39

Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: I could not find a provider I liked PROVIDER W5

Value	Label	Frequency	Percent
0	Not Selected	28236	99.58
1	Selected	120	0.42

## Q77. Why could you not get the mental health care or counseling that you needed through the WTCHP?: Other reason(s) not listed above OTHER\_WTCHP\_BARRIER\_W5

Value	Label	Frequency	Percent
0	Not Selected	27771	97.94
1	Selected	585	2.06

## Q78a. In the last 30 days, how much were you bothered by: Repeated, disturbing, and unwanted memories of the events of 9/11? PCL5\_MEMORIES\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	951	3.35
1	Not at all	14154	49.92
2	A little bit	8405	29.64
3	Moderately	3064	10.81
4	Quite a bit	1407	4.96
5	Extremely	375	1.32

## Q78b. In the last 30 days, how much were you bothered by: Repeated, disturbing dreams of the events of 9/11?

#### PCL5\_DREAMS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1023	3.61
1	Not at all	19624	69.21
2	A little bit	4837	17.06
3	Moderately	1853	6.53
4	Quite a bit	779	2.75
5	Extremely	240	0.85

# Q78c. In the last 30 days, how much were you bothered by: Suddenly feeling or acting as if the events of 9/11 were actually happening again (as if you were actually back there reliving it)? PCL5 RELIVE W5

Value	Label	Frequency	Percent
-94	Coded Missing	1034	3.65
1	Not at all	21229	74.87
2	A little bit	3721	13.12
3	Moderately	1442	5.09
4	Quite a bit	699	2.47
5	Extremely	231	0.81

## Q78d. In the last 30 days, how much were you bothered by: Feeling very upset when something reminded you of the events of 9/11? PCL5 UPSET REMIND W5

Value	Label	Frequency	Percent
-94	Coded Missing	1002	3.53

Q78d. In the last 30 days, how much were you bothered by: Feeling very upset when something reminded you of the events of 9/11? PCL5\_UPSET\_REMIND\_W5

 Value	Label	Frequency	Percent
1	Not at all	11405	40.22
2	A little bit	8850	31.21
3	Moderately	3764	13.27
4	Quite a bit	2251	7.94
5	Extremely	1084	3.82

Q78e. In the last 30 days, how much were you bothered by: Having strong physical reactions when something reminded you of the events of 9/11 (for example, heart pounding, trouble breathing, sweating)? PCL5\_PHYSICAL\_REMIND\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	982	3.46
1	Not at all	17973	63.38
2	A little bit	4947	17.45
3	Moderately	2387	8.42
4	Quite a bit	1421	5.01
5	Extremely	646	2.28

Q78f. In the last 30 days, how much were you bothered by: Avoiding memories, thoughts, or feelings related to the events of 9/11? PCL5\_AVOID\_THINK\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	987	3.48
1	Not at all	13884	48.96
2	A little bit	6778	23.90
3	Moderately	3109	10.96
4	Quite a bit	2401	8.47
5	Extremely	1197	4.22

Q78g. In the last 30 days, how much were you bothered by: Avoiding external reminders of the events of 9/11 (for example, people, places, conversations, activities, objects, or situations)?

PCL5\_AVOID\_EXT\_REMINDER\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1028	3.63
1	Not at all	15697	55.36
2	A little bit	5468	19.28
3	Moderately	2732	9.63
4	Quite a bit	2201	7.76
5	Extremely	1230	4.34

## Q78h. In the last 30 days, how much were you bothered by: Trouble remembering important parts of the events of 9/11? PCL5 TROUBLE REMEMBER W5

Va	alue	Label	Frequency	Percent
-9	)4	Coded Missing	1012	3.57
	1	Not at all	21478	75.74
	2	A little bit	3365	11.87

## Q78h. In the last 30 days, how much were you bothered by: Trouble remembering important parts of the events of 9/11?

PCL5\_TROUBLE\_REMEMBER\_W5

Value	Label	Frequency	Percent
3	Moderately	1415	4.99
4	Quite a bit	752	2.65
5	Extremely	334	1.18

Q78i. In the last 30 days, how much were you bothered by: Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, ...)?

PCL5 NEGATIVE BELIEF W5

Value	Label	Frequency	Percent
-94	Coded Missing	1007	3.55
1	Not at all	20244	71.39
2	A little bit	3889	13.71
3	Moderately	1678	5.92
4	Quite a bit	1049	3.70
5	Extremely	489	1.72

Q78j. In the last 30 days, how much were you bothered by: Blaming yourself or someone else for the events of 9/11 or what happened after it?

PCL5\_BLAME\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1029	3.63
1	Not at all	24300	85.70
2	A little bit	1626	5.73
3	Moderately	700	2.47
4	Quite a bit	443	1.56
5	Extremely	258	0.91

Q78k. In the last 30 days, how much were you bothered by: Having strong negative feelings such as fear, horror, anger, guilt, or shame? PCL5\_NEGATIVE\_FEELING\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1045	3.69
1	Not at all	19219	67.78
2	A little bit	4706	16.60
3	Moderately	1848	6.52
4	Quite a bit	1047	3.69
5	Extremely	491	1.73

Q78l. In the last 30 days, how much were you bothered by: Loss of interest in activities that you used to enjoy?

PCL5\_LOSS\_INTEREST\_W5

_			
Value	Label	Frequency	Percent
-94	Coded Missing	1051	3.71
1	Not at all	17050	60.13
2	A little bit	5858	20.66
3	Moderately	2306	8.13

Q781. In the last 30 days, how much were you bothered by: Loss of interest in activities that you used to enjoy?

PCL5\_LOSS\_INTEREST\_W5

Value	Label	Frequency	Percent
4	Quite a bit	1417	5.00
5	Extremely	674	2.38

Q78m. In the last 30 days, how much were you bothered by: Feeling distant or cut off from other people?

PCL5\_FEELING\_DISTANT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1012	3.57
1	Not at all	15922	56.15
2	A little bit	6130	21.62
3	Moderately	2613	9.21
4	Quite a bit	1829	6.45
5	Extremely	850	3.00

Q78n. In the last 30 days, how much were you bothered by: Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?

PCL5 TROUBLE POS FEELING W5

Value	Label	Frequency	Percent
-94	Coded Missing	1009	3.56
1	Not at all	18478	65.16
2	A little bit	5094	17.96
3	Moderately	2079	7.33
4	Quite a bit	1205	4.25
5	Extremely	491	1.73

Q780. In the last 30 days, how much were you bothered by: Irritable behavior, angry outbursts, or acting aggressively?

PCL5\_FEEL\_ANGRY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1006	3.55
1	Not at all	17046	60.11
2	A little bit	6485	22.87
3	Moderately	2251	7.94
4	Quite a bit	1144	4.03
5	Extremely	424	1.50

Q78p. In the last 30 days, how much were you bothered by: Taking too many risks or doing things that could cause you harm?
PCL5\_RISKS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1067	3.76
1	Not at all	23131	81.57
2	A little bit	2703	9.53
3	Moderately	868	3.06
4	Quite a bit	420	1.48
5	Extremely	167	0.59

### Q78q. In the last 30 days, how much were you bothered by: Being "superalert" or watchful or on guard?

PCL5\_SUPERALERT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1051	3.71
1	Not at all	13901	49.02
2	A little bit	6406	22.59
3	Moderately	3179	11.21
4	Quite a bit	2271	8.01
5	Extremely	1548	5.46

## Q78r. In the last 30 days, how much were you bothered by: Feeling jumpy or easily startled?

PCL5\_JUMPY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1032	3.64
1	Not at all	16683	58.83
2	A little bit	5771	20.35
3	Moderately	2453	8.65
4	Quite a bit	1593	5.62
5	Extremely	824	2.91

### Q78s. In the last 30 days, how much were you bothered by: Having difficulty concentrating?

PCL5\_CONCENTRATING\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	998	3.52
1	Not at all	14262	50.30
2	A little bit	7333	25.86
3	Moderately	3047	10.75
4	Quite a bit	1833	6.46
5	Extremely	883	3.11

### Q78t. In the last 30 days, how much were you bothered by: Trouble falling or staying asleep?

PCL5\_TROUBLE\_SLEEP\_W5

rcent
3.44
41.58
24.98
13.04
10.86
6.10

## Q79a. Thinking about the problems in Q78: How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

PCL\_PROBS\_WORKHOME\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	5143	18.14
1	Not difficult at all	14485	51.08
2	Somewhat difficult	7481	26.38

Q79a. Thinking about the problems in Q78: How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

PCL\_PROBS\_WORKHOME\_W5

Va	lue	Label	Frequency	Percent
	3	Very difficult	895	3.16
	4	Extremely difficult	352	1.24

Q79b. Thinking about the problems in Q78: During the last 12 months when you were having some of these problems, did you drink alcohol to improve your mood or to make yourself feel better?

PCL\_PROBS\_ALCOHOL\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	5173	18.24
1	Yes	5368	18.93
2	No	17815	62.83

Q79c. Thinking about the problems in Q78: During the last 12 months when you were having some of these problems, did you ever, even once, use an opioid drug to improve your mood or to make yourself feel better?

#### PCL PROBS OPIOID 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	5099	17.98
1	Yes	594	2.09
2	No	22663	79.92

## Q80a. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Little interest or pleasure in doing things PHQ8\_LITTLE\_INTEREST\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1130	3.99
1	Not at all	16720	58.96
2	Several days	7734	27.27
3	More than half the days	1769	6.24
4	Nearly every day	1003	3.54

## Q80b. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Feeling down, depressed, or hopeless PHQ8\_FEEL\_DOWN\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1175	4.14
1	Not at all	15693	55.34
2	Several days	8729	30.78
3	More than half the days	1806	6.37
4	Nearly every day	953	3.36

Q80c. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Trouble falling or staying asleep, or sleeping too much

PHQ8\_TROUBLE\_SLEEP\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1170	4.13
1	Not at all	11903	41.98

Q80c. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Trouble falling or staying asleep, or sleeping too much

PHQ8\_TROUBLE\_SLEEP\_W5

Value	Label	Frequency	Percent
2	Several days	9472	33.40
3	More than half the days	3234	11.40
4	Nearly every day	2577	9.09

Q80d. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Feeling tired or having little energy PHQ8 FEEL TIRED W5

Value	Label	Frequency	Percent
-94	Coded Missing	1153	4.07
1	Not at all	10902	38.45
2	Several days	11020	38.86
3	More than half the days	3243	11.44
4	Nearly every day	2038	7.19

Q80e. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Poor appetite or overeating PHQ8\_POOR\_APP\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1159	4.09
1	Not at all	16904	59.61
2	Several days	6639	23.41
3	More than half the days	2346	8.27
4	Nearly every day	1308	4.61

Q80f. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Feeling bad about yourself, or that you are a failure or have let yourself or your family down PHQ8\_FEEL\_BAD\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1146	4.04
1	Not at all	20027	70.63
2	Several days	4863	17.15
3	More than half the days	1413	4.98
4	Nearly every day	907	3.20

Q80g. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Trouble concentrating on things, such as reading the newspaper or watching television

PHQ8\_TROUBLE\_CONC\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1117	3.94
1	Not at all	17570	61.96
2	Several days	6654	23.47
3	More than half the days	1946	6.86
4	Nearly every day	1069	3.77

Q80h. Over the last 2 weeks, how often have you been bothered by any of the following problems?: Moving or speaking so slowly that other people could have noticed / being so fidgety or restless that you have been moving around a lot more than usual?

PHQ8\_MOVE\_SLOWLY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1144	4.03
1	Not at all	23307	82.19
2	Several days	2605	9.19
3	More than half the days	871	3.07
4	Nearly every day	429	1.51

Q81a. During the last 30 days, about how often did you feel: So sad that nothing could cheer you up? SAD\_W5

	Value	Label	Frequency	Percent	
	-94	Coded Missing	1090	3.84	
	1	None of the time	18791	66.27	
	2	A little of the time	5332	18.80	
	3	Some of the time	2169	7.65	
	4	Most of the time	772	2.72	
	5	All of the time	202	0.71	

Q81b. During the last 30 days, about how often did you feel: Nervous? NERVOUS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1124	3.96
1	None of the time	14266	50.31
2	A little of the time	8002	28.22
3	Some of the time	3177	11.20
4	Most of the time	1364	4.81
5	All of the time	423	1.49

Q81c. During the last 30 days, about how often did you feel: Restless or fidgety?

RESTLESS\_W5

		_		
-	Value	Label	Frequency	Percent
	-94	Coded Missing	1126	3.97
	1	None of the time	15260	53.82
	2	A little of the time	7539	26.59
	3	Some of the time	2913	10.27
	4	Most of the time	1161	4.09
	5	All of the time	357	1.26

Q81d. During the last 30 days, about how often did you feel: Hopeless? HOPELESS W5

Value	Label	Frequency	Percent
-94	Coded Missing	1156	4.08
1	None of the time	19640	69.26
2	A little of the time	4514	15.92
3	Some of the time	1896	6.69

Q81d. During the last 30 days, about how often did you feel: Hopeless? HOPELESS W5

Value	Label	Frequency	Percent
4	Most of the time	807	2.85
5	All of the time	343	1.21

## Q81e. During the last 30 days, about how often did you feel: That everything was an effort?

#### LETHARGIC W5

Value	Label	Frequency	Percent
-94	Coded Missing	1127	3.97
1	None of the time	16231	57.24
2	A little of the time	6439	22.71
3	Some of the time	2508	8.84
4	Most of the time	1405	4.95
5	All of the time	646	2.28

### Q81f. During the last 30 days, about how often did you feel: Worthless?

#### WORTHLESS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1113	3.93
1	None of the time	22034	77.70
2	A little of the time	2993	10.56
3	Some of the time	1310	4.62
4	Most of the time	579	2.04
5	All of the time	327	1.15

# Q82a. Have you ever been told by a doctor or other health professional that you had any of the following mental health conditions?: Depression DEPRESSION W5

#### Value Label Frequency Percent -9--4 Coded Missing 1189 4.19 1 6063 21.38 Yes 2 No 21104 74.43

# Q82a. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: Depression- Year first told DEPRESSION DX YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	23128	81.56
1900-2021	Valid range	5228	18.44

# Q82a. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: Depression-Year of last visit DEPRESSION\_LAST\_VISIT\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	23547	83.04
1900-2021	Valid range	4809	16.96

Q82b. Have you ever been told by a doctor or other health professional that you had any of the following mental health conditions?: Post-traumatic stress disorder (PTSD) PTSD\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1274	4.49
1	Yes	5138	18.12
2	No	21944	77.39

Q82b. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: Post-traumatic stress disorder (PTSD)- Year first told PTSD\_DX\_YR\_W5

_	Value	Label	Frequency	Percent
	-94	Coded Missing	23791	83.90
	1900-2021	Valid range	4565	16.10

Q82b. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: Post-traumatic stress disorder (PTSD)- Year of last visit

#### $PTSD\_LAST\_VISIT\_YR\_W5$

Value	Label	Frequency	Percent
-94	Coded Missing	24337	85.83
1900-2021	Valid range	4019	14.17

# Q82c. Have you ever been told by a doctor or other health professional that you had any of the following mental health conditions?: An anxiety disorder, other than PTSD ANXIETY W5

Value	Label	Frequency	Percent
-94	Coded Missing	1325	4.67
1	Yes	4347	15.33
2	No	22684	80.00

Q82c. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: An anxiety disorder, other than PTSD- Year first told

#### ANXIETY\_DX\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	25018	88.23
1900-2021	Valid range	3338	11.77

Q82c. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: An anxiety disorder, other than PTSD-Year of last visit

#### ANXIETY\_LAST\_VISIT\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	25341	89.37
1900-2021	Valid range	3015	10.63

Q82d. Have you ever been told by a doctor or other health professional that you had any of the following mental health conditions?: Problems with your use of alcohol or drugs ALCOHOL\_DRUGS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1284	4.53
1	Yes	1364	4.81
2	No	25708	90.66

Q82d. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: Problems with your use of alcohol or drugs- Year first told

ALCOHOL\_DRUGS\_DX\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27293	96.25
1900-2021	Valid range	1063	3.75

Q82d. If YES, please provide the year you were first told you had that condition and the year you last visited a doctor or other health professional for that condition.: Problems with your use of alcohol or drugs- Year of last visit

ALCOHOL\_DRUGS\_LAST\_VIS\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27402	96.64
1900-2021	Valid range	954	3.36

Q82e. Have you ever been told by a doctor or other health professional that you had any of the following mental health conditions?: Other mental health problems, including problems with your nerves or emotions

NERVES\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1327	4.68
1	Yes	2825	9.96
2	No	24204	85.36

Q82e. If YES, please provide the year you were first told you had that condition: Other mental health problems, including problems with your nerves or emotions

NERVES\_DX\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	26595	93.79
1900-2021	Valid range	1761	6.21

Q82e. If YES, please provide the year you last visited a doctor or other health professional for that condition: Other mental health problems, including problems with your nerves or emotions NERVES LAST VISIT YR W5

Value	Label	Frequency	Percent
-94	Coded Missing	26727	94.26
1900-2021	Valid range	1629	5.74

Q83. During the last 12 months, have you had a counseling or therapy session lasting 30 minutes or longer for any of the conditions listed in the previous question? Please do not include visits that were for medication only.

COUNSEL\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	15218	53.67

Q83. During the last 12 months, have you had a counseling or therapy session lasting 30 minutes or longer for any of the conditions listed in the previous question? Please do not include visits that were for medication only.

COUNSEL 12M W5

Value		Label	Frequency	Percent
1	Yes		3888	13.71
2	No		9250	32.62

Q84a. During the last 12 months, for which of the following conditions have you had counseling or therapy?: Depression COUNSEL 12M DEPRESSION W5

Value	Label	Frequency	Percent
 0	Not Selected	25930	91.44
1	Selected	2426	8.56

Q84a. During the last 12 months, for which of the following conditions have you had counseling or therapy?: PTSD  $\,$ 

COUNSEL\_12M\_PTSD\_W5

 Value	Label	Frequency	Percent
 0	Not Selected	26498	93.45
1	Selected	1858	6.55

Q84a. During the last 12 months, for which of the following conditions have you had counseling or therapy?: An anxiety disorder, other than PTSD

**COUNSEL 12M ANXIETY W5** 

Value	Label	Frequency	Percent
0	Not Selected	26632	93.92
1	Selected	1724	6.08

Q84a. During the last 12 months, for which of the following conditions have you had counseling or therapy?: Problems with your use of alcohol or drugs

COUNSEL 12M ALC DRUGS W5

Value	Label	Frequency	Percent
0	Not Selected	28040	98.89
1	Selected	316	1.11

Q84a. During the last 12 months, for which of the following conditions have you had counseling or therapy?: Other mental health problems, including problems with your nerves or emotions

COUNSEL\_12M\_NERVES\_W5

 Value	Label	Frequency	Percent
0	Not Selected	27074	95.48
1	Selected	1282	4.52

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: Psychiatrist COUNSEL 12M PSYCHIATRIST W5

 Value
 Label
 Frequency
 Percent

 0
 Not Selected
 26598
 93.80

 1
 Selected
 1758
 6.20

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: Psychologist COUNSEL\_12M\_PSYCHOLOGIST W5

Value	Label	Frequency	Percent
0	Not Selected	26693	94.14
1	Selected	1663	5.86

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: Other mental health professional, such as a social worker, counselor, psychotherapist, or mental health nurse

**COUNSEL 12M OTHER MHPROF W5** 

Value	Label	Frequency	Percent
0	Not Selected	26792	94.48
1	Selected	1564	5.52

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: General practitioner, family doctor, or other medical doctor

**COUNSEL 12M MD W5** 

Value	Label	Frequency	Percent
0	Not Selected	27585	97.28
1	Selected	771	2.72

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: Nurse, occupational therapist, or other health professional

COUNSEL\_12M\_OTH\_HLTH\_PROF\_W5

Value	Label	Frequency	Percent
0	Not Selected	28132	99.21
1	Selected	224	0.79

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: Religious or spiritual advisor, such as a minister, priest, or rabbi

COUNSEL\_12M\_RELIGIOUS\_W5

Value	Label	Frequency	Percent
0	Not Selected	28040	98.89
1	Selected	316	1.11

Q84b. During the last 12 months, which of the following professionals have you seen for counseling or therapy?: Any other practitioner COUNSEL\_12M\_OTHER\_PRAC\_W5

Value	Label	Frequency	Percent
0	Not Selected	28193	99.43
1	Selected	163	0.57

Q84c. During the last 12 months, on average, how often did you have counseling or therapy sessions?

COUNSEL\_12M\_FREQ W5

Value	Label	Frequency	Percent
-94	Coded Missing	24672	87.01
1	More than once a week	221	0.78
2	Once a week	1185	4.18
3	Two to three times a month	821	2.90

Q84c. During the last 12 months, on average, how often did you have counseling or therapy sessions?

COUNSEL\_12M\_FREQ\_W5

Value	Label	Frequency	Percent
4	Once a month	663	2.34
5	Less than once a month	794	2.80

Q84d. During the last 12 months, overall, how helpful was the counseling or therapy that you had?

COUNSEL\_12M\_HELPFUL\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	24664	86.98
1	Very helpful	1629	5.74
2	Somewhat helpful	1376	4.85
3	Slightly helpful	524	1.85
4	Not at all helpful	163	0.57

Q85. During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: Depression

**DEPRESSION 12M RX W5** 

Value	Label	Frequency	Percent
0	Not Selected	25321	89.30
1	Selected	3035	10.70

Q85. During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: PTSD PTSD 12M RX W5

Value	Label	Frequency	Percent
0	Not Selected	26916	94.92
1	Selected	1440	5.08

Q85. During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: An anxiety disorder, other than PTSD

ANXIETY 12M RX W5

 Value	Label	Frequency	Percent
 0	Not Selected	25907	91.36
1	Selected	2449	8.64

Q85. During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: Problems with your use of alcohol or drugs

ALC DRUGS\_12M\_RX\_W5

Value	Label	Frequency	Percent
0	Not Selected	28169	99.34
1	Selected	187	0.66

Q85. During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: Other mental health problems, including problems with your nerves or emotions

NERVES\_12M\_RX\_W5

Value	Label	Frequency	Percent
0	Not Selected	27298	96.27

Q85. During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: Other mental health problems, including problems with your nerves or

**NERVES 12M RX W5** 

Value	Label	Frequency	Percent
1	Selected	1058	3.73

**Q85.** During the last 12 months, for which of the following mental health conditions have you taken any prescription medication?: None of the above

MH RX NONE W5

Value	Label	Frequency	Percent
0	Not Selected	19833	69.94
1	Selected	8523	30.06

O86a. During the last 12 months, have you experienced any of the following situations?: Could not pay for food, housing, or other basic necessities for a period of 3 months or longer

NOPAY\_NECESS\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1192	4.20
1	Yes	831	2.93
2	No	26333	92.87

Q86b. During the last 12 months, have you experienced any of the following situations?: Serious problems at work or lost a job LOSE JOB 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	1259	4.44
1	Yes	2122	7.48
2	No	24975	88.08

Q86c. During the last 12 months, have you experienced any of the following situations?: Serious legal problems

LEGAL\_PROB\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1235	4.36
1	Yes	707	2.49
2	No	26414	93.15

Q86d. During the last 12 months, have you experienced any of the following situations?: Serious family problems involving your spouse or partner, child, or parents

FAMILY\_PROB\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1207	4.26
1	Yes	3738	13.18
2	No	23411	82.56

Q86e. During the last 12 months, have you experienced any of the following situations?: Took care of a close family member or friend with a serious or life-threatening illness

CARE FAMILY 12M W5

Value	Label	Frequency	Percent	

Q86e. During the last 12 months, have you experienced any of the following situations?: Took care of a close family member or friend with a serious or life-threatening illness

CARE\_FAMILY\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1193	4.21
1	Yes	3818	13.46
2	No	23345	82.33

Q86f. During the last 12 months, have you experienced any of the following situations?: The death of a spouse or partner, close family member, or friend

**DEATH CLOSE 12M W5** 

Value	Label	Frequency	Percent
-94	Coded Missing	1156	4.08
1	Yes	6357	22.42
2	No	20843	73.50

O87a. Since 9/11, has your life been threatened by any of the following situations?: A disaster, either natural or human-made

THREAT DISASTER POST911 W5

Value	Label	Frequency	Percent
-94	Coded Missing	1226	4.32
1	Yes	4912	17.32
2	No	22218	78.35

Q87b. Since 9/11, has your life been threatened by any of the following situations?: A serious accident, including a car accident, an accident at work, or another type of accident

THREAT\_ACCIDENT\_POST911\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1192	4.20
1	Yes	2667	9.41
2	No	24497	86.39

Q87c. Since 9/11, has your life been threatened by any of the following situations?: An attack with a gun, knife, or some other weapon

THREAT\_WEAPON\_POST911\_W5

Value	Label	Frequency	Percent
 -94	Coded Missing	1185	4.18
1	Yes	717	2.53
2	No	26454	93.29

Q87d. Since 9/11, has your life been threatened by any of the following situations?: An attack without a weapon, but with the intent to kill or seriously injure you

THREAT NOWEAPON POST911 W5

Value	Label	Frequency	Percent
-94	Coded Missing	1196	4.22
1	Yes	842	2.97
2	No	26318	92.81

Q87e. Since 9/11, has your life been threatened by any of the following situations?: A situation in which someone used physical force or threat of force to make you have some type of unwanted sexual contact THREAT\_SEXUAL\_POST911\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1187	4.19
1	Yes	385	1.36
2	No	26784	94.46

Q87f. Since 9/11, has your life been threatened by any of the following situations?: Any other situation in which you were seriously injured or feared you might be killed or seriously injured

THREAT OTHER POST911 W5

Value	Label	Frequency	Percent
-94	Coded Missing	1230	4.34
1	Yes	1604	5.66
2	No	25522	90.01

Q87g. Since 9/11, has your life been threatened by any of the following situations?: A situation in which you saw someone seriously injured or violently killed

THREAT\_WITNESS\_POST911\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1205	4.25
1	Yes	1943	6.85
2	No	25208	88.90

Q87h. Since 9/11, has your life been threatened by any of the following situations?: A life-threatening illness

THREAT\_ILLNESS\_POST911\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1234	4.35
1	Yes	3605	12.71
2	No	23517	82.93

Q88a. Prior to your 18th birthday: Did a parent or other adult in the household often or very often swear at you, insult you, put you down, humiliate you, or act in a way that made you afraid that you might be physically hurt?

ACE\_VERBAL\_ABUSE\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1342	4.73
1	Yes	4239	14.95
2	No	22775	80.32

Q88b. Prior to your 18th birthday: Did a parent or other adult in the household often or very often push, grab, slap, or throw something at you, or ever hit you so hard that you had marks or were injured?

ACE PHYSICAL ABUSE W5

Value	Label	Frequency	Percent
-94	Coded Missing	1353	4.77
1	Yes	3210	11.32
2	No	23793	83.91

Q88c. Prior to your 18th birthday: Did an adult or person at least 5 years older than you ever touch or fondle you, have you touch their body in a sexual way, or attempt or actually have oral, anal, or vaginal intercourse with you?

ACE SEXUAL ASSAULT W5

Value	Label	Frequency	Percent
-94	Coded Missing	1399	4.93
1	Yes	2447	8.63
2	No	24510	86.44

Q88d. Prior to your 18th birthday: Did you often or very often feel that no one in your family loved you or thought you were important or special, or that your family didn't look out for each other, feel close to each other, or support each other?

ACE\_EMOTIONAL\_NEGLECT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1384	4.88
1	Yes	3375	11.90
2	No	23597	83.22

Q88e. Prior to your 18th birthday: Did you often feel that you didn't have enough to eat, had to wear dirty clothes, and had no one to protect you, or that your parents were too drunk/high to take care of you or take you to the doctor if you needed it?

ACE PHYSICAL NEGLECT W5

Value	Label	Frequency	Percent
-94	Coded Missing	1338	4.72
1	Yes	884	3.12
2	No	26134	92.16

Q88f. Prior to your 18th birthday: Was a biological parent ever lost to you through divorce, abandonment, or other reason?

ACE\_PARENT\_SEPARATION\_W5

 Value	Label	Frequency	Percent
-94	Coded Missing	1349	4.76
1	Yes	4916	17.34
2	No	22091	77.91

Q88g. Prior to your 18th birthday: Was your mother/stepmother often/very often pushed, grabbed, slapped, or had something thrown at her; sometimes/often/very often kicked, bitten, hit with a fist, or hit with something hard; or ever repeatedly hit ...?

ACE\_MOTHER\_ABUSED\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1373	4.84
1	Yes	1422	5.01
2	No	25561	90.14

Q88h. Prior to your 18th birthday: Did you live with anyone who was a problem drinker or alcoholic, or who used street drugs?

ACE\_SUBSTANCE\_ABUSE\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1345	4.74
1	Yes	4697	16.56
2	No	22314	78.69

## Q88i. Prior to your 18th birthday: Was a household member depressed or mentally ill, or did a household member attempt suicide? ACE\_MENTAL\_ILLNESS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1356	4.78
1	Yes	3599	12.69
2	No	23401	82.53

### Q88j. Prior to your 18th birthday: Did a household member go to prison?

#### ACE\_PRISON\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1341	4.73
1	Yes	953	3.36
2	No	26062	91.91

#### Q89. Have you smoked at least 100 cigarettes in your entire life? SMOKE\_LIFETIME\_100\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1066	3.76
1	Yes	10341	36.47
2	No	16949	59.77

### Q90. Do you now smoke cigarettes every day, some days, or not at all? SMOKE\_NOW\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	17482	61.65
1	Every day	1068	3.77
2	Some days	739	2.61
3	Not at all	9067	31.98

## Q91. In what month and year did you last smoke a cigarette, even one or two puffs? (Month)

#### SMOKE\_LAST\_MM\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	20593	72.62
1	January	1471	5.19
2	February	444	1.57
3	March	465	1.64
4	April	510	1.80
5	May	597	2.11
6	June	971	3.42
7	July	517	1.82
8	August	468	1.65
9	September	634	2.24
10	October	594	2.09
11	November	426	1.50
12	December	666	2.35

### Q91. In what month and year did you last smoke a cigarette, even one or two puffs? (Year)

#### SMOKE\_LAST\_YR\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	19626	69.21
1900-2021	Valid range	8730	30.79

### Q92. On average, how many cigarettes do you smoke per day? SMOKE\_PERDAY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	25446	89.74
0-99	Valid range	2910	10.26

### Q93. How soon after waking do you smoke your first cigarette? SMOKE\_FIRSTCIG\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	26431	93.21
1	Within 5 minutes	208	0.73
2	5 to 30 minutes	553	1.95
3	31 to 60 minutes	396	1.40
4	More than 60 minutes	768	2.71

## Q94. In the last 12 months, have you tried an electronic cigarette, also known as an e-cigarette or a vape product?

#### ECIG\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1239	4.37
1	Yes	2232	7.87
2	No	24885	87.76

## Q95. In the last 30 days, how often did you use an electronic cigarette? $ECIG\_FREQ\_30D\_W5$

Value	Label	Frequency	Percent
-94	Coded Missing	26140	92.19
1	Every day	191	0.67
2	Some days	306	1.08
3	Not at all	1719	6.06

## Q96a. Have you ever – even once – had a drink of any type of alcoholic beverage? Do not include times when you only had a sip or two. ALCOHOL\_DRINK\_EVER\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1052	3.71
1	Yes	24941	87.96
2	No	2363	8.33

### Q96b. How long has it been since you last drank an alcoholic beverage?

#### ALCOHOL\_DRINK\_LAST\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	3577	12.61
1	Within the last 30 days	17300	61.01

### Q96b. How long has it been since you last drank an alcoholic beverage?

ALCOHOL DRINK LAST W5

Value	Label	Frequency	Percent
2	More than 30 days ago but within the last 12 months	3752	13.23
3	More than 12 months ago	3727	13.14

### Q96c. During the last 30 days, how many days did you have at least 1 drink of any alcoholic beverage?

ALC\_30D\_NDAYS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	11133	39.26
1-30	Valid range	17223	60.74

### Q96d. On the days when you drank, about how many drinks did you drink on average?

ALC NDRINKS W5

Value	Label	Frequency	Percent
-94	Coded Missing	10496	37.02
0-50	Valid range	17860	62.98

### Q96e. In the last 30 days, what is the maximum number of drinks you have consumed on one single occasion?

ALC\_NDRINKS\_MAX\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	10504	37.04
0-50	Valid range	17852	62.96

## Q96f. (If male) Considering all types of alcoholic beverages, how many times during the last 30 days did you have 5 or more drinks on one occasion?

ALC\_DRINK\_GE5\_NTIMES\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	16589	58.50
0-99	Valid range	11767	41.50

Q96g. (If female) Considering all types of alcoholic beverages, how many times during the last 30 days did you have 4 or more drinks on one occasion?

ALC\_DRINK\_GE4\_NTIMES\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	21477	75.74
0-99	Valid range	6879	24.26

### Q97a. During the last 12 months, has a doctor or other health professional given you a prescription for a pain reliever?

RX\_PAIN\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1172	4.13
1	Yes	5353	18.88
2	No	21831	76.99

Q97b. During the last 12 months, have you ever – even once – taken the pain reliever that you were prescribed?

RX\_PAIN\_TAKEN\_12M\_W5

Value	Label	Frequency	Percent
 -94	Coded Missing	21555	76.02
1	Yes	4667	16.46
2	No	2134	7.53

Q97c. During the last 12 months, have you ever – even once – taken more of the pain reliever than you were prescribed? This includes taking a higher dosage or taking it more often than directed.

RX\_PAIN\_MORE\_12M\_W5

 Value	Label	Frequency	Percent
-94	Coded Missing	22871	80.66
1	Yes	405	1.43
2	No	5080	17.92

## Q97d. During the last 12 months, have you ever – even once – taken a prescription pain reliever that was not prescribed to you?

RX\_PAIN\_FOR\_OTHER\_12M\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1417	5.00
1	Yes	958	3.38
2	No	25981	91.62

## Q97e. During the last 12 months, on average, how often have you taken a prescription pain reliever that was not prescribed to you? RX PAIN OTHER FREQ 12M W5

Value	Label	Frequency	Percent
-94	Coded Missing	27416	96.69
1	More than once a week	105	0.37
2	Once a week	59	0.21
3	Two or three times a month	124	0.44
4	Once a month	85	0.30
5	Less than once a month	567	2.00

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To relieve physical pain

 $RX\_PAIN\_MISUSE\_RELIEF\_W5$ 

_	Value	Label	Frequency	Percent
	0	Not Selected	26777	94.43
	1	Selected	1579	5.57

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To relax or relieve tension

RX\_PAIN\_MISUSE\_TENSION\_W5

Value	Label	Frequency	Percent
0	Not Selected	28051	98.92
1	Selected	305	1.08

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To experiment or to see what it's like

RX PAIN MISUSE EXPERIMENT W5

Value	Label	Frequency	Percent
0	Not Selected	28325	99.89
1	Selected	31	0.11

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To feel good or get high

RX\_PAIN\_MISUSE\_HIGH\_W5

Value	Label	Frequency	Percent
0	Not Selected	28257	99.65
1	Selected	99	0.35

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To help with my sleep

RX\_PAIN\_MISUSE\_SLEEP\_W5

Value	Label	Frequency	Percent
0	Not Selected	27962	98.61
1	Selected	394	1.39

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To help with my feelings or emotions

RX\_PAIN\_MISUSE\_FEELINGS\_W5

Value	Label	Frequency	Percent
0	Not Selected	28197	99.44
1	Selected	159	0.56

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: To increase or decrease the effect(s) of some other drug

RX\_PAIN\_MISUSE\_DRUG\_EFF\_W5

Value	Label	Frequency	Percent
0	Not Selected	28335	99.93
1	Selected	21	0.07

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: Because I am 'hooked' or I have to have it

RX PAIN MISUSE HOOKED W5

Value	Label	Frequency	Percent
0	Not Selected	28327	99.90
1	Selected	29	0.10

Q97f. Now think about the last time you used a prescription pain reliever in any way a doctor did not direct you to use. What were the reasons you used the prescription pain reliever the last time?: I used it for some other reason

RX\_PAIN\_MISUSE\_OTHER\_W5

Value	Label	Frequency	Percent
0	Not Selected	28256	99.65
1	Selected	100	0.35

Q98. Have you ever stayed overnight or longer at a hospital, rehabilitation facility, or mental health center so you could receive treatment or counseling for alcohol or drug use?

ALC\_DRUG\_HOSP\_OVERNIGHT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1069	3.77
1	Yes	902	3.18
2	No	26385	93.05

Q99. When did your stay(s) occur?
ALC\_DRUG\_HOSP\_OVERNITE\_WHEN\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	27474	96.89
1	Before 9/11	282	0.99
2	After 9/11	491	1.73
3	Both before and after 9/11	109	0.38

Q100a. For each statement, please indicate to what extent it is true or not true about you.: I can always manage to solve difficult problems if I try hard enough.

SELFEFF\_TRY\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1239	4.37
1	Not at all true	415	1.46
2	Hardly true	640	2.26
3	Moderately true	11487	40.51
4	Exactly true	14575	51.40

Q100b. For each statement, please indicate to what extent it is true or not true about you.: If someone opposes me, I can find the means and ways to get what I want.

SELFEFF\_WANT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1493	5.27
1	Not at all true	2380	8.39
2	Hardly true	5318	18.75
3	Moderately true	16195	57.11
4	Exactly true	2970	10.47

Q100c. For each statement, please indicate to what extent it is true or not true about you.: It is easy for me to stick to my aims and accomplish my goals.

SELFEFF\_ACCOMPLISH\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1305	4.60
1	Not at all true	629	2.22
2	Hardly true	2306	8.13
3	Moderately true	15583	54.95
4	Exactly true	8533	30.09

Q100d. For each statement, please indicate to what extent it is true or not true about you.: I am confident that I could deal efficiently with unexpected events.

SELFEFF\_EFFICIENT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1280	4.51
1	Not at all true	551	1.94
2	Hardly true	1656	5.84
3	Moderately true	13341	47.05
4	Exactly true	11528	40.65

Q100e. For each statement, please indicate to what extent it is true or not true about you.: Thanks to my resourcefulness, I know how to handle unforeseen situations.

SELFEFF RESOURCEFUL W5

Value	Label	Frequency	Percent
-94	Coded Missing	1305	4.60
1	Not at all true	518	1.83
2	Hardly true	1576	5.56
3	Moderately true	13756	48.51
4	Exactly true	11201	39.50

Q100f. For each statement, please indicate to what extent it is true or not true about you.: I can solve most problems if I invest the necessary effort.

SELFEFF\_EFFORT\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1266	4.46
1	Not at all true	318	1.12
2	Hardly true	1004	3.54
3	Moderately true	11746	41.42
4	Exactly true	14022	49.45

Q100g. For each statement, please indicate to what extent it is true or not true about you.: I can remain calm when facing difficulties because I can rely on my coping abilities.

SELFEFF\_COPING\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1291	4.55
1	Not at all true	651	2.30
2	Hardly true	2390	8.43
3	Moderately true	13525	47.70
4	Exactly true	10499	37.03

Q100h. For each statement, please indicate to what extent it is true or not true about you.: When I am confronted with a problem, I can usually find several solutions.

**SELFEFF SOLUTIONS W5** 

Value	Label	Frequency	Percent
-94	Coded Missing	1267	4.47
1	Not at all true	377	1.33
2	Hardly true	1680	5.92

Q100h. For each statement, please indicate to what extent it is true or not true about you.: When I am confronted with a problem, I can usually find several solutions.

SELFEFF\_SOLUTIONS\_W5

Value	Label	Frequency	Percent
3	Moderately true	13876	48.93
4	Exactly true	11156	39.34

Q100i. For each statement, please indicate to what extent it is true or not true about you.: If I am in trouble, I can usually think of a solution.

SELFEFF\_THINK\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1287	4.54
1	Not at all true	343	1.21
2	Hardly true	1218	4.30
3	Moderately true	13743	48.47
4	Exactly true	11765	41.49

Q100j. For each statement, please indicate to what extent it is true or not true about you.: No matter what comes my way, I'm usually able to handle it.

**SELFEFF HANDLE W5** 

Value	Label	Frequency	Percent
-94	Coded Missing	1270	4.48
1	Not at all true	448	1.58
2	Hardly true	1489	5.25
3	Moderately true	13491	47.58
4	Exactly true	11658	41.11

Q101a. How often is someone available: To take you to the doctor if you need to go?

SOCSUPP DOCTOR W5

Value	Label	Frequency	Percent
-94	Coded Missing	1163	4.10
1	None of the time	1788	6.31
2	A little of the time	1855	6.54
3	Some of the time	2665	9.40
4	Most of the time	7588	26.76
5	All of the time	13297	46.89

Q101b. How often is someone available: To have a good time with? SOCSUPP\_GOODTIME\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1200	4.23
1	None of the time	710	2.50
2	A little of the time	2372	8.37
3	Some of the time	4565	16.10
4	Most of the time	8833	31.15
5	All of the time	10676	37.65

Q101c. How often is someone available: To hug you? SOCSUPP\_HUG\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1231	4.34
1	None of the time	1620	5.71
2	A little of the time	2426	8.56
3	Some of the time	3432	12.10
4	Most of the time	6608	23.30
5	All of the time	13039	45.98

## $\bf Q101d.$ How often is someone available: To prepare your meals if you are unable to do it yourself?

SOCSUPP\_MEALS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1190	4.20
1	None of the time	2404	8.48
2	A little of the time	1899	6.70
3	Some of the time	2757	9.72
4	Most of the time	6436	22.70
5	All of the time	13670	48.21

## Q101e. How often is someone available: To understand your problems?

SOCSUPP\_PROBS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1209	4.26
1	None of the time	1238	4.37
2	A little of the time	2601	9.17
3	Some of the time	4506	15.89
4	Most of the time	8214	28.97
5	All of the time	10588	37.34

## Q102. In the last 30 days, have you visited, talked, texted, or emailed with friends at least twice? SOCSUPP\_COMM\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1090	3.84
1	Yes	26128	92.14
2	No	1138	4.01

## $\ensuremath{\mathrm{Q}103}.$ In the last 30 days, have you attended a religious service at least twice?

#### SOCSUPP\_RELIGIOUS\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1148	4.05
1	Yes	6907	24.36
2	No	20301	71.59

## Q104. In the last 30 days, have you been actively involved in a volunteer organization or club?

SOCSUPP\_CLUB\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1194	4.21

## Q104. In the last 30 days, have you been actively involved in a volunteer organization or club? SOCSUPP\_CLUB\_W5

Value		Label	Frequency	Percent
1	Yes		7101	25.04
2	No		20061	70.75

## Q105. About how many close friends or relatives do you have now? Include people you feel at ease with and can talk with about what is on your mind.

CLOSE\_NUM\_W5

Value	Label	Frequency	Percent
-94	Coded Missing	1453	5.12
0-99	Valid range	26903	94.88

## Language of interview LANGUAGE\_W5

Value	Label	Frequency	Percent
Е	English	27855	98.23
S	Spanish	267	0.94
SC	Simplified Chinese	119	0.42
TC	Traditional Chinese	115	0.41

#### Mode of survey USERMODE W5

	Value	Label	Frequency	Percent
P	APER	Paper	12953	45.68
,	WEB	Web	15403	54.32

### Age group at Wave 5 interview AGE INTGRP W5

Value	Label	Frequency	Percent
	Coded Missing	2	0.01
2	18–24	316	1.11
3	25–44	2218	7.82
4	45–64	15223	53.69
5	≥65	10597	37.37

#### Age group on 9/11 AGE\_911GRP

Value	Label	Frequency	Percent
	Coded Missing	2	0.01
1	<18	1001	3.53
2	18–24	1182	4.17
3	25–44	14459	50.99
4	45–64	11293	39.83
5	≥65	419	1.48