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World Trade Center Health Registry New 9/11 Child Cohort Feasibility Project

Tracing Protocol

Prepared for

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1. Introduction and Overview of Tracing Needs

The World Trade Center Health Registry 9/11 Child Cohort Feasibility Project is being conducted by the New York City Department of Health and Mental Hygiene (DOHMH) with federal funding from the National Institute for Occupational Safety and Health (NIOSH). This feasibility project will provide WTCHR and NIOSH with information needed to make a data-driven decision regarding the establishment of a new cohort of persons exposed to 9/11 in NYC as children. RTI International will serve as the contractor to DOHMH for tracing activities.

DOHMH will provide RTI the sample of former New York City Public school students who are currently 18 to ~36 years of age. Sample members have experienced many changes in their lives since their enrollment in New York City public schools, including milestones such as high school graduation, secondary education in and out of the New York City metropolitan area, relocation, starting a career, and for some, marriage. In response to potential operational challenges this project presents, including less stable living arrangements of young adults, lack of Social Security number, and outdated contact information, and to help ensure project goals are met, RTI has developed this Tracing Protocol.

Successfully locating and contacting sample members will be critical to the success of 9/11 Child Cohort Feasibility Project. This Tracing Protocol describes the strategies RTI will use to ensure the highest possible locate rate, describes safeguards to protect data, sources used for batch and intensive tracing, and includes call scripts and protocols tracing specialists (tracers) will use during tracing efforts. Our approach has been tailored based on our knowledge of the sample and our experience tracing young adults on other projects. This Tracing Protocol documents all phases of tracing, including batch tracing and intensive tracing part 1 and part 2 Telephone Outreach. RTI's Tracing Operations Unit uses standardized and customized systems, tools, and schedules to keep project staff and DOHMH informed and up to date on the status of cases, and on improvements to procedures and protocols.

The Tracing Protocol will remain flexible throughout the project. This flexibility will allow RTI to maximize tracing outcomes based on new services or ongoing findings. RTI will follow a tracing schedule that uses of the best available services and most up-to-date findings at any given point in the project lifecycle.

The tracing design begins with DOHMH providing a file of records containing contact information for 1,000 students who were born on or before 9/11/2001 and attended New York public schools at some point during or after the 2001/2002 school year. RTI will use this contact information to conduct batch tracing. Once batch tracing is completed, DOHMH will send a letter to the student at the current contact information for the student or parent/guardian if updated. If not updated, DOHMH will send a letter to the student using the contact information obtained from the New York City Department of Education (DOE). Students whose letters are returned as undeliverable with no forwarding address or have not responded to the initial mailing after 3 weeks, will move to intensive tracing (part 1). Similarly, for students whom intensive tracing (part 1) does not yield current contact information, and whose letters are returned as undeliverable to the address found during intensive tracing (part 1) or have not responding to the (part 1) mailing after 4 weeks will move to intensive tracing (part 2) telephone outreach. During this phase, tracers will attempt to obtain updated contact information via telephone

Table 1. 9/11 Child Cohort Feasibility Project Schedule

Task Descriptions	Date	
	Start	End
Planning Meeting for Deliverable 1	3/6/2019	-
Deliverable 1—Tracing Plan		
RTI Delivers Draft Tracing Plan	3/28/19	-
DOHMH Reviews Draft Tracing Plan	3/28/19	4/17/19
RTI Delivers Final Tracing Plan	4/25/19	-
Deliverable 2—Conduct Batch Tracing		
Planning Meeting for Deliverable 2	5/27/2019	-
DOHMH Delivers Records File	6/3/19	
RTI Conducts Batch Tracing	6/3/19	6/21/19
RTI Delivers Draft Batch Tracing Results	6/28/19	6/28/19
DOHMH Reviews Draft Batch Tracing Results	7/1/19	7/8/19
RTI Revises Draft Batch Tracing Results Based on DOHMH Feedback	7/8/19	7/12/19
RTI Delivers Final Batch Tracing Results	7/15/2019	-
Deliverable 3—Conduct Intensive Tracing (Part 1)		
Planning Meeting for Deliverable 3	6/24/2019	-
RTI Conducts Intensive Tracing	7/1/19	10/25/19
RTI Delivers Draft Intensive Tracing Results	11/1/19	11/1/19
DOHMH Reviews Draft Intensive Tracing Results	11/4/19	11/11/19
RTI Revises Draft Intensive Tracing Results Based on DOHMH Feedback	11/11/19	11/14/19
RTI Delivers Final Intensive Tracing Results (Part 1)	11/15/2019	-
Deliverable 4—Conduct Intensive Tracing (Part 2)		
Planning Meeting for Deliverable 4	10/26/2019	-
RTI Conduct Intensive Tracing (Part 2)	11/1/2019	1/24/2020
RTI Delivers Draft Intensive Tracing Results	1/31/20	1/31/20
DOHMH Reviews Draft Intensive Tracing Results	2/3/20	2/10/20
RTI Revises Draft Intensive Tracing Results Based on DOHMH Feedback	2/10/20	2/14/20
RTI Delivers Final Intensive Tracing Results (Part 2)	2/15/2020	-
Deliverable 5—Tracing Recommendations Report		
Planning Meeting for Deliverable 5	2/20/2020	-
RTI Develops Tracing Recommendations Report	3/2/2020	3/31/2020
RTI Delivers Preliminary Recommendations Report Outline	2/25/20	
DOHMH Reviews Preliminary Recommendations Report Outline	2/26/20	3/4/20
RTI Delivers Final Recommendations Report Outline	3/6/20	-
RTI Delivers Draft Tracing Recommendations Report	3/13/20	-
DOHMH Reviews Draft Tracing Recommendations Report	3/16/19	3/23/19
RTI Revises Draft Intensive Tracing Results Based on DOHMH Feedback	3/23/20	3/30/20
RTI Delivers Final Intensive Tracing Results (Part 2)	3/31/20	-

2. Conducting Batch Tracing

DOHMH will provide extracted record information for 1,000 students and their parents/guardians. RTI will begin the tracing process by conducting batch tracing on all 1,000 students and their parents/guardians using the address from the student's most recent available school year. The completeness and accuracy of this locating address will affect the efforts needed to locate sample members for the 9/11 Child Cohort Feasibility Project. We will focus on obtaining contact information that has been verified in the past 5 years. Sample members will be traced using this locating data obtained from DOHMH and includes sample members full name, gender, date of birth, place of birth, parent/guardian name, relationship to child, language spoken at home, address, home phone, cell phone, work phone, email and a unique ID.

Batch database searches will be the initial step of tracing cases and involves matching contact information from multiple databases. The batch tracing step may confirm existing information or provide information that is more up to date. Batch tracing is valuable because it identifies the most current contact information, thereby focusing our contacting efforts on the most promising leads.

Through LexisNexis, RTI will use the FastData suite of strategic data services to access multiple databases containing consumer records, business records, deceased records, and public records (see Chapter 3 Data Security for information on data security with tracing vendors). FastData can also provide information on other household members. We will also use FastData to access:

- A national directory assistance database which is updated daily.
- The National Change of Address (NCOA) database. NCOA is a database consisting of change-of-address data submitted by individuals to the U.S. Postal Service (USPS) when they move to a new address. We will send all name and address information for sample members to NCOA. Searches may result in new addresses or confirmation of existing address. Almost 160 million records are updated weekly and stored for 4 years.
- Premium Phone Append, a residential telephone number lookup service that uses combinations of address and name to match phone numbers to sample members RTI can access landline, cellular, and Voice over Internet Protocol numbers in the United States and Puerto Rico (for use during intensive tracing part 2 telephone outreach).

RTI's tracing unit continually evaluates the tools available for batch tracing. Our protocol will begin with FastData; RTI has identified this service as the most useful based on our previous tracing work for other projects, but we may also include additional vendors.

Throughout the tracing period, it is typical to identify sample members who are now deceased. If a sample member is identified deceased during batch tracing, the case will be coded as deceased. RTI will attempt to verify the information through other tracing sources beyond the source where the information was first obtained.

2.1 Batch Tracing Data Processing

See Chapter 3 Data Security for information on secure file transfer with tracing vendors. RTI receives from the batch tracing vendor the data file with returned results appended.

At the end of the batch tracing stage, we will provide DOHMH with a brief report summarizing tracing activities and results as well as electronic data files that will provide updated student and parent/guardian contact information. Each variable (name, address, various phone numbers, and e-mail) will indicate the source of that piece of information. Each case will include a locating status code. A case is assigned a located code based on updated contact information that has been cross referenced against multiple tracing vendors. If current contact information was not found for the student or parent/guardian, we will indicate that no current information was available during the batch tracing stage.

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3. Tracing Operations Unit and Systems

3.1. RTI Tracing Operations Unit

Intensive tracing operations for the 9/11 Child Cohort Feasibility Project will be conducted by tracing specialists (tracers) within RTI's Tracing Operations Unit located at our Research Operations Center (ROC) in Raleigh, NC. The Tracing Operations Unit is dedicated exclusively to tracing and locating sample members. RTI's tracers are trained professionals who specialize in tracing and locating hard-to-find sample members. Tracers are trained on all systems and processes used in locating sample members. Tracers will be provided an overview of the 9/11 Child Cohort Feasibility Project and strategies for locating and contacting sample members. RTI-ROC tracers have access to a broad portfolio of tracing resources that are continuously updated and available for use.

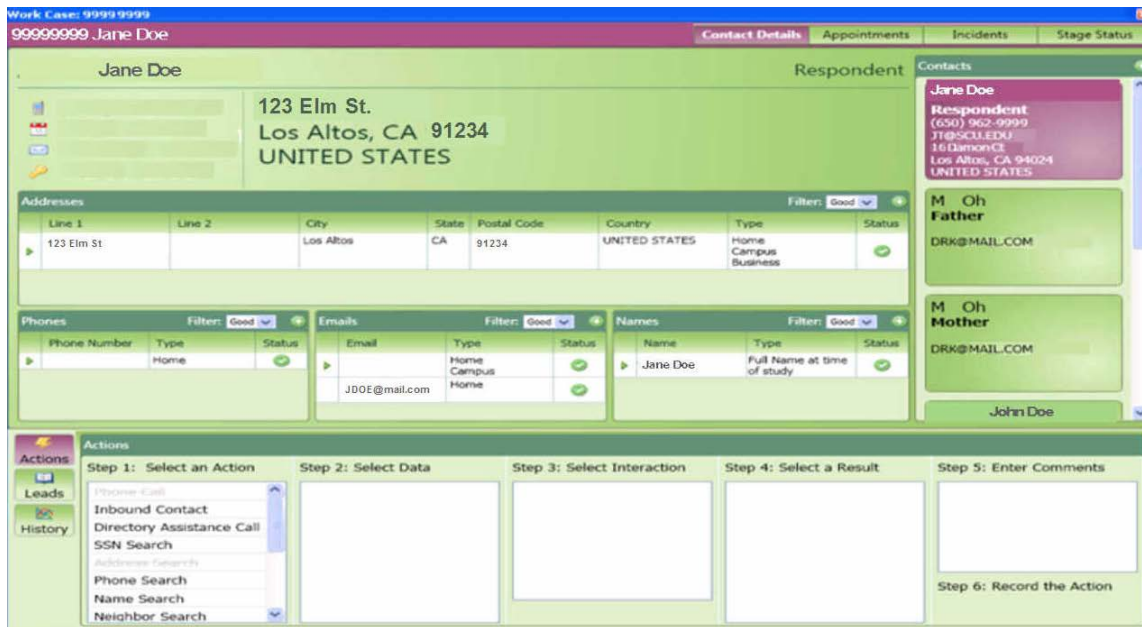
3.2 RTI Tracing Case Management System (CMS)

RTI's data collection system features an integrated database structure that houses all sample member data in one centralized location, as well as a suite of data collection applications that function in concert. This suite of applications is called "Symphony" at RTI. The integrated database and tracing system serve to maximize the efficiency of tracing operations. This flexible structure is designed to:

- store all locating information in a centralized location, allowing data collection systems to access the same contact information;
- create a streamlined system where information updated in one application is communicated seamlessly to another (e.g., tracing and telephone data collection operations); and
- allow for sufficient supervisor oversight for each case designated for intensive tracing.

Figure 2 shows an example of the Tracing CMS interface used by tracers. The Tracing CMS includes all sample member details like name, address, phone numbers, e-mail addresses, and other contact information associated with the sample member. The protocol for entering updated contact information in the CMS is provided in **Appendix A**.

Figure 2. Tracing CMS



3.3 Data Security

RTI systems are designed to protect sample member data from unauthorized access and all staff are trained to uphold the highest standards of confidentiality. During tracing activities, all applications that access sample members' personally identifiable information will be housed within an enhanced security network (ESN) that is designed to address Federal Information Processing Standards (FIPS) publication FIPS-199 security requirements for moderate-risk data. Domain account controls will be in place to limit access to project resources located within the ESN to appropriate project staff. In addition, tracers working on the 9/11 Child Cohort Feasibility Project are required to sign a confidentiality and nondisclosure certification, and a criminal background check.

All tracing vendors must meet RTI's data security requirements and sign data use and master service agreements. RTI-ROC maintains a data use agreement (DUA) with each of our tracing vendors. The DUA is a signed contractual document that ensures appropriate security controls are in place to protect sample files in motion and at rest between RTI and our various vendors. Each DUA outlines:

- who in the vendor organization has access to the data included in our tracing queries;
- how study data will be safeguarded at the vendor's processing site;
- the specific data security controls, security policies, and accreditation required to work with study data; and
- strict nondisclosure clauses that prevent the vendor from using any of the data received from RTI for unauthorized purposes.

For batch tracing, RTI will gather the information required for tracing by external vendors into a formatted .csv file in the ESN. We will encrypt the file with a password using FIPS 140-2-compliant encryption and upload the password-protected encrypted file to our approved tracing vendor's SFTP

server. The tracing vendor will decrypt the file in its secure environment, develop updated contact information, encrypt the file with a password using FIPS 140-2–compliant encryption, and upload the file to the vendor’s SFTP server. RTI will move the file inside our ESN, decrypt the file, and load it into our secure database.

For intensive tracing, the Tracing CMS works in the ESN with access to tracing databases through a fully encrypted connection.

We only use vendors that disclose their privacy and security plans and are known key providers to financial and law enforcement agencies.

RTI will also implement any security requirements that are outlined in the DUA between RTI and DOHMH.

3.4 Project Staffing

Staffing for the RTI tracing operations includes the following project team:

- Laura DiGrande, Senior Public Health Consultant, will provide senior technical leadership to ensure that project implementation is client focused and adheres to NYC DOHMH expectations.
- Ariana Napier, Project Director, is responsible for overall project direction and will lead all the technical work, reporting and fiscal management.
- Nick Kinsey, Programmer, is responsible for all programming and data security requirements needed for batch tracing, intensive tracing, telephone outreach, and data delivery activities.
- Timothy Nesius, Tracing Director, will supervise all tracing and telephone staff and provide tracing updates.
- Tracing Specialist will perform intensive tracing (part 1 and part 2).
- Quality Control staff will review work completed by tracers. QC staff confirms all possible resources and efforts were focused appropriately and effectively in updating contact information for sample members.

4 Tracing Specialist Training

The tracing team will be assembled for a training session prior to beginning each intensive tracing effort (part 1 and part 2). Tracing specialists are trained on tracing best practices, recording contact information, project-specific protocols, administering telephone scripts, and answering frequently asked questions (FAQs). The tracing specialist protocols are provided in **Appendix A**, telephone scripts are provided in **Appendix B**, and responses to anticipated FAQs are provided in **Appendix C**.

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5 Intensive Tracing (Part 1)

Cases that need to undergo intensive tracing (part 1) will come from one of two sources: cases where the DOHMH letters were returned as undeliverable with no forwarding address, or cases where a sample member was sent a letter and does not respond after 3 weeks. During this stage of intensive tracing, tracers will review contact information for each case individually and perform a series of real-time searches of the contact information that might help locate the student. Approximately 800 cases will require this stage of tracing.

The specific purpose of this intensive tracing step is to obtain updated contact information. A successful locating effort requires the use and blending of multiple sources of information. The most useful sources for this population identified from previous efforts are the following:

- **LexisNexis**—In addition to the batch search capabilities, LexisNexis offers a comprehensive set of databases allowing access to a substantial selection of locating information, including credit header information, real estate data, voters' registration, and professional licenses. LexisNexis has proven to be an effective search tool for cases with name and little else in the way of data elements available for searching.
- **Experian**—A consumer/credit database agency offering millions of previous addresses, dates of residence, spousal information, and some telephone numbers. Experian has been identified as a valuable search tool when tracers have multiple data elements (e.g., name and address) available.
- **FastData**—In addition to the batch search capabilities, FastData provides a range of searches including consumer records, business records, and household member information. FastData is a valuable search tool for cases with missing or limited information because of its ability to conduct searches using only the address.

5.1 Protocol for Intensive Tracing

The priority is to obtain current contact information for students, or if student contact information is not available, current contact information for the parents/guardians. Utilizing the Tracing Case Management System (CMS) (see **Section 3.2 Figure 2**) for efficient review and recording of all sample member data located, tracers will follow prescribed protocols for intensive tracing efforts provided in **Appendix A**. Tracers will spend a maximum of 1 hour per case.

5.2 Intensive Tracing Data Processing

RTI will provide DOHMH with daily data deliveries of outcomes for each case. As with all data deliveries, we will use DOHMH required secure file transfer system.

At the end of the intensive tracing stage, we will provide DOHMH with a brief report summarizing tracing activities and results as well as electronic data files that will provide updated student and parent/guardian contact information. Each variable (name, address, various phone numbers, and e-mail) will indicate the source of that piece of information. Each case will include a locating status code. A case is assigned a located code based on updated contact information that has been cross referenced against multiple tracing vendors. See **Appendix D** for DOHMH provided locating and outcome codes. If

current contact information was not found for the student or parent/guardian, we will indicate that no current information was available during the intensive tracing stage.

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6 Intensive Tracing (Part 2)—Focus on Telephone Outreach

We will use intensive tracing (part 2) for cases in which intensive tracing (part 1) did not yield current information. We will also trace cases where DOHMH letters that were sent to addresses found in intensive tracing (part 1) were returned as undeliverable with no forwarding address and cases who did not respond to the part 1 mailing after 4 weeks. At this stage, we will attempt to contact students and parents/guardians by telephone to update their contact information. We anticipate that there will be approximately 300 cases in this stage.

6.1 Protocol for Intensive Tracing (Part 2)

The focus of the telephone outreach is to call students to obtain their current contact information, or call their parents/guardians, if current contact information is not available for the student. Once we reach a contact, we will attempt to collect current name and address, updated phone numbers, and current e-mail address for the student. Tracers will follow protocols for telephone outreach provided in **Appendix A** and telephone scripts provided in **Appendix B**.

Tracers will conduct intensive tracing for the 9/11 Child Cohort Feasibility Project using the Tracing CMS (see **Section 3.2 Figure 2**). Intensive tracing requires tracers to assess each case individually to determine the best course of action; therefore, the first step is to thoroughly review the case history to identify available contacting information to locate the sample member. Tracers locate sample members through a series of steps. These steps are based on a comprehensive and proven set of procedures that have been used successfully on other recent studies of young adult populations.

Tracers will call telephone numbers collected during batch and previous intensive tracing (part 1) to attempt to reach the sample member. If none of the telephone numbers are current, RTI will utilize LexisNexis, Experian and the FastData to search for alternate telephone numbers to reach the sample member. When new information is returned, tracers will call the case and attempt to update the contact information.

Because some people we contact will have caller ID, RTI will use “NYC DEPT. HEALTH” for caller ID text. RTI will confirm all phone lines used for tracing will display this text when making outbound calls.

6.2 Other Locating Options

RTI continues to monitor new tracing sources and evaluate their suitability to complement or replace current sources. Potential tracing vendors are evaluated on numerous criteria, such as cost and quality of the results, data security practices of the vendor, and the data sources accessed by the search. Our goal is to access the widest breadth of sources possible while limiting search redundancy and upholding strict data security standards. RTI does not employ generic web searching, such as searching social media websites or unsecured search engines, as a locating method because these sites do not have approved DUAs with RTI. Only vendors that ensure the security of the searches they provide can safely be used as sources for locating data.

6.3 Use of LanguageLine Solutions

Parent's language will be included in the sample file DOHMH provides RTI. RTI will use LanguageLine Solutions to provide interpretation services by telephone. RTI has planned for English and Spanish speaking tracers and will use LanguageLine services as needed for non-English and non-Spanish speaking sample members. We expect up to 45 cases that may require LanguageLine Solutions translation. When a translator is required, tracers will initiate a three-way call between the tracer, sample member, and the translator. The tracer will phone the LanguageLine and need only provide the agent with basic account information and identify the language needed for a translator before quickly being connected to an interpreter. LanguageLine has been used in the past for the WTCHR, and RTI has experience working with translators on the phone. See **Appendix B** for the protocol tracers will use when engaging LanguageLine Solutions.

6.4 Case Assignment

Tracers will make up to three call attempts to each available number, making sure that calls are varied by days of the week and times of day to maximize the chance of speaking to someone. We will leave voicemail messages on the first and third attempts for home and cell phone numbers. We will not leave voicemail for work numbers. Tracers will spend a maximum of 1 hour per case.

6.5 Intensive Tracing (Part 2) Data Processing

RTI will provide DOHMH with daily data deliveries of outcomes for each case. As with all data deliveries, we will use DOHMH required secure file transfer system.

At the end of the intensive tracing telephone outreach stage, we will provide DOHMH with a brief report summarizing tracing activities and results as well as electronic data files that will provide updated student and parent/guardian contact information. Each variable (name, address, various phone numbers, and e-mail) will indicate the source or who tracers spoke with and provided the updated information. Each case will include a locating status code. A case is assigned a located code once the tracer confirms the contact information with the sample member or a contact at the sample member's telephone number. See **Appendix D** for DOHMH provided locating and outcome codes. If no contact was made and updated information was not found for the student or parent/guardian, that case will be identified as "unlocatable" and will be coded as such.

7 Reporting

7.1 Project Communication

Communication with DOHMH is essential to meet project goals. RTI will participate in conference calls with DOHMH to provide project updates and planning for each subsequent deliverable. RTI will schedule planning meetings in conjunction with DOHMH and distribute meeting minutes within 2 business days. Between scheduled meetings, RTI will keep the entire project team updated via email and telephone as needed.

7.2 Reporting Tracing Results to WTCHR

During intensive tracing (part 1 & 2), RTI will provide DOHMH with daily data deliveries of outcomes for each case. As with all data deliveries, we will use DOHMH required secure file transfer system.

At the end of each tracing stage, we will provide DOHMH with a brief report summarizing tracing activities and results as well as electronic data files with updated student and parent/guardian contact information as available. Each variable (name, address, various phone numbers, and e-mail) will indicate the source of that piece of information. Each case will include a locating status code. See **Appendix D** for DOHMH provided locating and outcome codes. If current contact information was not found for the student or parent/guardian, we will indicate that no current information was available during that tracing stage.



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Appendices

Appendix A – Tracing Specialist Protocols

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Intensive Tracing (Part 1) Protocol

- Conduct a LexisNexis search on student/parent/guardian using the most recent available school year contact information for the student and/or parent/guardian(s).
- Conduct a FastData search on student/parent/guardian using the most recent available school year contact information for the student and/or parent/guardian(s).
- Conduct an Experian search on student/parent/guardian using the most recent available school year contact information for the student and/or parent/guardian(s).
- Add all new contact information in the tracing Case Management System (CMS) within Symphony (see **Section 3.2 Figure 2**).
- If addresses match from 2 of the 3 searches code as located.
- When all 3 searches return different contact information, none matching, add all returned contact information in the tracing CMS and code as contact information unconfirmed.
[PENDING: Tracing Director will advise project team on procedures for selection of unconfirmed contact information.]

Intensive Tracing (Part 2) Telephone Outreach Tracing Protocol

Caller ID Text When Conducting Tracing

- Because some people we contact will have caller ID, RTI will use “NYC DEPT. HEALTH” for the caller ID text. RTI will confirm all phone lines used for tracing will display this text when making outbound calls.

Guidelines for Contacting Sample Members

- Make 1st attempt at contacting the student/parent/guardian through the cell phone number. If the sample member is not reached, leave a message on the voice mail (if the 1st or 3rd round of calls), then immediately...
- Make 2nd attempt at contacting the student/parent/guardian through the home phone number. If sample member is not reached, leave a message on the voice mail (if the 2nd round of calls), then immediately...
- Make 3rd attempt at contacting the sample member through the work phone number.
- If the sample member is not reached during these three call attempts, allow a minimum of 2 business days before trying these three numbers again (a “round” of calls). We will make up to 3 call attempts to each available telephone number, making sure that calls are varied by days of the week and times of day to maximize the chance of speaking to someone.
- If a sample member is not reached, a message should be left on the cell phone for the 1st and 3rd rounds and the home phone for the 2nd round. Please note that *no messages should be left on the work phone*. *If the work phone is answered by a receptionist, ask to speak with the sample member. If the receptionist asks what the call is pertaining to, tell them it is of a personal nature. No further information should be disclosed.*
 - Failed attempts include:
 - No answer
 - Answering machine pick up
 - Someone else besides the sample member answers the phone
 - A busy signal does not count as a failed attempt. If the phone is busy, try again about 30 minutes later the same day when time allows and/or until the phone rings. (A fast-busy signal means that the line has been disconnected and it should be logged as such.)

When all Attempts Have Failed

- If all of the above attempts at reaching the sample member have failed, code the case in the tracing CMS as “not located”.

Talking to the Sample Members Protocol

-
- Identify yourself as calling on behalf of the New York City Department of Health.
 - If sample member is parent/guardian remind the person that you're trying to update contact information to send their child information only. You are not collecting any personal information besides address, phone and email address.
 - Emphasize the importance of getting up-to-date contact information and making sure that their mailing address is correct.
 - Tell sample member that they are only being asked to update their contact information so that the New York City Department of Health can send them information about a potential research study to learn about the health effects of 9/11.
 - Sample members will be given the option of calling the World Trade Center Health Registry at 866-692-9827 or sending an email to the WTCHR at 9-11MillenniumCohort@health.nyc.gov to update their information if they are reluctant to provide it at the time of the call.

SEE SECTION APPENDIX B FOR SAMPLE MEMBER SCRIPTS

Talking to Non-Sample Members Protocol

- Identify yourself as calling on behalf of the New York City Department of Health.
- When speaking with non-sample members, do not make assumptions that just because a spouse (or any other family member) answers the phone that we can give them confidential information about the sample member.
- Talking with a non-sample member counts as one failed attempt at contacting the sample member.

SEE APPENDIX B FOR NON-SAMPLE MEMBER SCRIPT

Leaving Home and Cell Phone Messages for the Sample Member

- Leave a message on the cell voicemail during the 1st and 3rd round of calls. Leave a voice message on the home phone during the 2nd round of calls.
- If the sample member does not call back in two business days after leaving the first message, make another round of calls and another message should be left on the home or cell phone. Answering machine messages will alternate between cell phone and home phone depending on the round of the calls.
- Never leave a message on a work voice message. If the work phone is answered by a receptionist, ask to speak with the sample member. If the receptionist asks what the call is pertaining to, tell them it is of a personal nature. No further information should be disclosed.

SEE APPENDIX B FOR ANSWERING MACHINE SCRIPT

Updating the Tracing CMS Protocol

- Updated information should be entered in Symphony (i.e. name, address, phone numbers, and email).

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- If sample member refuses to update information over the phone, then offer the option to update their information by calling or emailing the World Trade Center Health Registry at 866-692-9827 or 9-11MillenniumCohort@health.nyc.gov and code call outcome as refusal.
 - If the sample member asks to be removed from the sample, try to find out their reasons and attempt to encourage them to remain in the sample by explaining that you are only updating contact information so the New York City Department of Health can send them information about a potential study they are planning to help learn more about the health effects of 9/11 and there is no commitment at this time, you're just asking to send them more information (see FAQs). If they insist, make note and change sample member to refusal.

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Appendix B – Telephone Outreach Scripts

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Telephone Outreach Script to Student Sample Member

Introductory Scripts

Hello, may I speak with (SAMPLE MEMBER NAME)?

[If Sample Member]:

Hello, my name is _____ and I'm calling on behalf of the New York City Department of Health about a potential research study on 9/11 health effects. I'm trying to reach (SAMPLE MEMBER NAME). Are you (SAMPLE MEMBER NAME)?

IF YES PROCEED WITH INTRODUCTION.

IF NOT: Do you know (SAMPLE MEMBER NAME)?

IF YES: Do you know how I can reach (SAMPLE MEMBER NAME)? [Proceed to Script for Unknown Person]

IF LANGUAGE BARRIER:

- Ask person on the phone what language they speak and tell them you will get a translator.
- Call LanguageLine at 1-xxx.xxx.xxxx
- Provide LanguageLine agent with RTI project account information and inform of the language an interpreter is needed.
- LanguageLine will connect to an interpreter immediately.

INTRODUCTION:

Hi, (SAMPLE MEMBER NAME). I'm calling because the New York City Department of Health's World Trade Center Health Registry is contacting former New York City public school students.

We are updating contact information in order to send you information about a potential research study on 9/11-related health effects. Can I update your contact information?

IF SAMPLE MEMBER SEEMS HESITANT TO PROVIDE INFORMATION: We are not asking you to make a decision now. We just want to send you more information about this potential study to gauge your interest. You can decide once you receive the information if you're interested in this kind of research. Can I update your contact information?

YES—CONTINUE

NO—THANK AND TERMINATE

UPDATING SAMPLE MEMBER CONTACT INFORMATION:

Thank you, I have your name as (SAMPLE MEMBER NAME). Is that the name you currently go by?

YES

NO—RECORD NEW NAME

What is your current mailing address?

What is the best phone number to use to contact you in the future?

Is this your home, cell or work phone number?

If we are unable to reach you at that number, is there another phone number where we may be able to reach you?

Is this your home, cell or work phone number?

What is the best email address to reach you?

[NOTE: REPEAT TO CONFIRM ALL UPDATED CONTACT INFORMATION; CONFIRM SPELLING]

Thank you for your time. You will receive a brochure in the mail in the coming weeks from the New York City Health Department. If you have any questions, please call the World Trade Center Health Registry at 1-866-692-9827.

[IF TALKING WITH AN UNKNOWN PERSON]:

Hello, my name is _____ and I'm calling on behalf of the New York City Department of Health. We are trying to reach (SAMPLE MEMBER NAME) about a potential research study on 9/11-related health effects.

IF CONTACT SEEMS TO KNOW SAMPLE MEMBER BUT IS HESITANT TO PROVIDE INFORMATION: At this time, we're only updating contact information so that the New York City Department of Health can send more information about the study.

DO YOU KNOW WHERE I CAN REACH HER/HIM?

What is his/her current mailing address?

What is the best phone number to use to contact him/her?

Is this their cell, home or work phone number?

Is there another phone number where we may be able to reach him/her?

Is this their cell, home or work phone number?

What is the best email address to reach him/her?

[NOTE: REPEAT TO CONFIRM ALL UPDATED CONTACT INFORMATION; CONFIRM SPELLING]

Thank you for your time. (SAMPLE MEMBER NAME) will receive a brochure in the mail in the coming weeks from the New York City Health Department. If you/she/he have any questions, please call the World Trade Center Health Registry at 1-866-692-9827.

IF CONTACT WILL NOT PROVIDE INFORMATION: May I leave a phone number with you for (SAMPLE MEMBER NAME) to call me back? The phone number is 1-xxx-xxx-xxxx. Thank you for your time.

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Telephone Outreach Script to Parent/Guardian

Hello, may I speak with (PARENT/GUARDIAN SAMPLE MEMBER NAME)?

IF PARENT/GUARDIAN

Hello, my name is _____ and I'm calling on behalf of the New York City Department of Health about a potential research study on 9/11 health effects. I'm trying to reach (PARENT/GUARDIAN SAMPLE MEMBER NAME). Are you (PARENT/GUARDIAN SAMPLE MEMBER NAME)?

IF YES PROCEED WITH INTRODUCTION.

IF NOT: Do you know (PARENT/GUARDIAN SAMPLE MEMBER NAME)?

IF YES: Do you know how I can reach (PARENT/GUARDIAN SAMPLE MEMBER NAME)?

IF NO: THANK AND TERMINATE

INTRODUCTION

Hi, (PARENT/GUARDIAN SAMPLE MEMBER NAME). I'm calling because the New York City Department of Health's World Trade Center Health Registry is contacting former New York City Public School students. We are trying to contact your son/daughter, (SAMPLE MEMBER NAME), to send him/her information about a potential research study on 9/11-related health effects.

At this time, we are only updating contact information. Can you provide me (SAMPLE MEMBER NAME)'s contact information so that we can send him/her this information?

IF PARENT/GUARDIAN SAMPLE MEMBER SEEMS HESITANT TO PROVIDE INFORMATION: We are not asking whether he/she wants to sign-up for the study now. We just want to send (SAMPLE MEMBER NAME) information about this potential study to gauge his/her interest. (SAMPLE MEMBER NAME) can decide once s/he receives the information if s/he is interested in this kind of research. Would you be willing to provide us with (SAMPLE MEMBER'S NAME) contact information?

YES—CONTINUE

NO—IF CONTACT WILL NOT PROVIDE INFORMATION: Would you please have (SAMPLE MEMBER'S NAME) call us at 1-xxx-xxx-xxxx to update his/her contact information so that we can send him/her the study information. Thank you.

ALT. SEND INFO TO PARENT/GUARDIAN TO PASS ALONG TO SAMPLE MEMBER?

Can we mail the study information to you to share with (SAMPLE MEMBER)?

YES—CONTINUE

NO—THANK AND TERMINATE

UPDATING PARENT/GUARDIAN SAMPLE MEMBER CONTACT INFORMATION:

Thank you, I have your name as (PARENT/GUARDIAN SAMPLE MEMBER NAME). Is that the name you currently go by?

YES

NO—RECORD NEW NAME

What is your current mailing address?

What is the best phone number to use to contact you in the future?

Is this your home, cell or work phone number?

If we are unable to reach you at that number, is there another phone number where we may be able to reach you?

Is this your home, cell or work phone number?

What is the best email address to reach you?

[NOTE: REPEAT TO CONFIRM ALL UPDATED CONTACT INFORMATION; CONFIRM SPELLING]

Thank you for your time. You will receive a brochure in the mail in the coming weeks from the New York City Health Department for your son/daughter. If you have any questions, please call the World Trade Center Health Registry at 1-866-692-9827.

Cell and Home Voicemail Scripts

First Message:

Hello. My name is _____, and I am calling on behalf of the New York City Department of Health. I am trying to reach (SAMPLE MEMBER NAME) about a potential research study on 9/11-related health effects. Someone from our office will be calling back in a few days. If this is (SAMPLE MEMBER NAME) or you know how we can reach him/her, please call us back at 1-xxx-xxx-xxxx Monday through Friday between the hours of 9am to 5pm; or you may leave a message at any time. Thank you.

Second Message:

Hello, this is a message for (SAMPLE MEMBER'S NAME). My name is ____ and I am calling on behalf of the New York City Department of Health. Someone from our office tried contacting you a few days ago about a potential research study on 9/11-related health effects. Please call our office at your next available convenience at xxx-xxx-xxxx Monday through Friday between the hours of 9am to 5pm; or you may leave a message at any time. Thank you.

Appendix C— Frequently Asked Questions (FAQ)

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FREQUENTLY ASKED QUESTIONS (FAQ)

Q: Why are you calling me?

A: I am calling on behalf of the New York City Department of Health to update your contact information so they can send you information about a potential 9/11 related research study of former New York City public school students. The study will help NYC Department of Health learn more about the health impacts of 9/11.

Q: Who are you?

My name is [ENTER NAME] and I work for RTI International, a nonprofit research institute with over 50 years of experience conducting research. RTI has worked with the New York City Department of Health on the World Trade Center Health Registry for several years now. To find out more about RTI, you can visit: rti.org

Q: What do you want me to do?

At this time, we're only seeking to update your contact information so that the New York City Department of Health can send you information about a potential 9/11-related research study.

Q: What is the purpose of this study?

The New York City Department of Health's World Trade Center Health Registry is looking to assess the feasibility of establishing a new cohort or group of people exposed to the 9/11 disaster in NYC as children, together with a demographically similar comparison group of people not exposed as children for research on the health impacts of the WTC disaster. The research obtained from this potential study will help us learn more about 9/11-health impact on those who were a child or teen at the time and help improve their health care.

Q: What is the World Trade Center Health Registry?

The World Trade Center Health Registry based in the NYC Department of Health was established to evaluate and monitor the long-term health consequences of those most affected by the World Trade Center Disaster on September 11th, 2001. The Registry has over 71,000 enrollees, making it the largest health registry in the United States. The data from the Registry is used to further understand the mental and physical health effects of September 11th, to facilitate future studies that examine specific populations or health conditions, to help identify persons who may be at increased risk for developing health problems, and to improve preparedness for future emergencies.

Q: How did you get my phone number?

To support this project, the New York City Department of Education provided the New York City Department of Health with a sample of former students who were born on or before 9/11/2001 and attended New York City public schools at some point during or after the 2001/2002 school year.

Q: Why should I give you my contact information?

The New York City Department of Health would like to send you information about a potential 9/11-related research study of former New York City public school students and gauge your interest. At this time, we are only sending information about the study so you can make an informed decision about whether or not you'd be interested in participating.

Q: Why do you need my phone number and email address if you are only planning to mail me information?

We are requesting your email address and phone number in case we need to contact you after we mail you the study brochure. If you are not comfortable providing your phone number and email now, will you please provide us with your mailing address?

Q: What does this have to do with me, I wasn't near the disaster site on 9/11?

The sample includes people who were students in schools near the World Trade Center disaster site as well as students at schools located several miles or more from the disaster site. The New York City Department of Health's World Trade Center Health Registry will compare a group of people who went to school near the disaster site with a group of people who did not go to school near the disaster site for research on the health impacts of the World Trade Center disaster.

Q: What would I be asked to do as part of this study?

This detailed information will be included in the materials you will receive from the New York City Health Department.

Q: Who is conducting this project?

The New York City Department of Health's World Trade center Health Registry with funding from the National Institute for Occupational Safety and Health (NIOSH).

Q: How do I know this is real and not a scam?

You can call the New York City Department of Health's World Trade Center Health Registry directly at 866-692-9827 and confirm the information about this study.

Q: Can I refer my friends or family to participate in addition to me or instead of me?

No, Only the selected sample of people can participate at this time.

Q: If I give you my information now, do I have to participate later?

No, participation in this study is completely voluntary.

Q: Do I get anything for participating/giving you my information?

No, there is no monetary incentive for providing your contact information.

Q: Talking about 9/11 causes emotional distress for me.

If you are experiencing emotional upset and feel a need to speak to someone, call NYC Well at 888-692-9355, a 24-hour, seven-day-a-week confidential hotline. You can also text "WELL" to 65173 or visit nycwell.cityofnewyork.us

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Appendix D— Locating and Outcome Codes

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Locating and Outcome Codes

Locating Codes (from RTI to DOHMH)

Outcome_Code

student_id/unique

first_name

middle_name

last_name

student_street_number

student_street_name

student_apartment/floor_number

student_city

student_state

student_zipcode

student_cell_num

student_home_phone_num

student_work_phone_num

parent_first_name

parent_last_name

relationship

parent_street_number

parent_street_name

parent_apartment/floor_number

parent_city

parent_state

parent_zipcode

parent_cell_num

parent_home_phone_num

parent_work_phone_num

parent_email

Outcome Code

S- Updated Student info

P- Updated Parent info

N- No update.

D- Decease Student

B- Both Student & Parent Updated

Relationship code

1-Mother

2-Father

3-Grandparent

10-Sister/brother

11-Other Relative

12-Step Parent

13-Surrogate Parent

14-Foster Parent

15-Agency

16-Ward of State

17-Other Legal Guardian

18-Non-relative

19-Emancipated Youth

Locating Codes (to RTI From DOHMH)

student_id/unique id

first_name

middle_name

last_name

sex

date of birth

student_street_number

student_street_name

student_apartment/floor_number

student_city

student_state

student_zipcode

student_cell_num

student_home_phone_num

student_work_phone_num

parent_1_first_name

parent_1_last_name

relationship

parent_1_spoken_language

parent_1_street_number

parent_1_street_name

parent_1_apartment/floor_number

parent_1_city

parent_1_state

parent_1_zipcode

parent_1_cell_num

parent_1_home_phone_num

parent_1_work_phone_num

parent_1_email

parent_2_first_name

parent_2_last_name

relationship

parent_2_spoken_language

parent_2_street_number

parent_2_street_name

parent_2_apartment/floor_number

parent_2_city

parent_2_state

parent_2_zipcode

parent_2_cell_num

parent_2_home_phone_num

parent_2_work_phone_num

parent_2_email

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