

Summary of Rights for Enrollees in the World Trade Center Health Registry New York City Department of Health and Mental Hygiene (Revisions to last approved version from 8/2019)

The Registry is a research study to learn about the long-term physical and mental health impacts of the 9/11 disaster and health care needs. More than 71,000 people voluntarily enrolled in the Registry from 2003 to 2004 and completed the initial health survey. They were also asked to complete follow-up surveys from 2006 to 2007, 2011 to 2012, 2015 to 2016 and 2020 to 2021.

The Registry is operated by the New York City Department of Health and Mental Hygiene (Health Department). The Registry is funded by the National Institute for Occupational Safety and Health's (NIOSH) World Trade Center (WTC) Health Program. The Health Department plans to maintain the Registry for many more years with NIOSH funding.

As an enrollee, during that time you may:

- Be asked to complete surveys about your physical and mental health about every three years. Your answers and those of other enrollees will help us understand the full impact of the 9/11 disaster, plan for future health care needs, and may also help save lives and reduce injuries in future disasters. Completing Registry surveys does not provide you with direct financial benefits.
- Be asked periodically to provide the Registry with your updated contact information so that we can stay in touch with you and send you information about Registry surveys and findings.
- Be contacted by Registry staff with information about 9/11-related no-cost health services based on your survey answers. The Registry also provides enrollees with assistance in applying for 9/11-related health care services.
- Be contacted by Registry staff occasionally with other health information.
- Receive an invitation from the Registry to join other 9/11-related research studies conducted by the Registry or by researchers outside of the Registry. Some of these outside researchers may ask you to have the Registry share your survey answers with them. This would only happen with your written permission.
- Be offered a personal visit from a member of the Registry's staff to help you complete a health survey, get information on health care services or inform you about a 9/11-related research study. We will **always** contact you ahead of time, tell you why we would like to visit and give you the opportunity to refuse. If you do not want our staff to **ever** visit you at home, please call us at 866-692-9827.

As you were told when you first enrolled in the Registry, your records will be linked periodically to other health data — such as cancer registries, hospital discharge data, and birth and death records — to better understand the full impact of the 9/11 disaster. For this reason, the Registry will periodically link your records to the NIOSH WTC Health Program, an additional source of health and clinical data. This will help us track 9/11-related health conditions, potential new conditions and evaluate 9/11-related care received. It also strengthens our ability to inform 9/11 health care policy and services for responders and survivors. Prior to matching to any additional sources of data, we would again send you a letter with an updated Summary of Rights at least 30 to 60 days in advance.

All Registry information is still held in strict confidence and protected by a federal certificate of confidentiality. This means that we cannot be forced to reveal identifying information about you, even if a court orders us to do so, unless you say it is OK. However, we must report suspected cases of child abuse, if you tell us you are planning to cause serious harm to yourself or others, or if we reasonably believe you are a threat to yourself or others to the proper authorities.

While there are no physical risks to taking Registry health surveys, some of the questions may be sensitive or may remind you of the events of 9/11. The Registry will provide you with resources to call if you feel emotional distress while answering survey questions or afterwards. One such resource is NYC Well, a free counseling and mental health service that can be reached at 888-692-9355.

Your participation in the Registry is voluntary. You have the right to withdraw from the Registry now or at any time in the future without penalty or loss of benefits to which you are otherwise entitled. You also have the right to decline to participate in any of the Registry activities at any time. If you fully withdraw from the Registry, any information you already provided would remain with the Registry but without a link to your personal identifying information.

If you have questions about your rights as a participant in the Registry, contact the chair of the NYC Health Department's Institutional Review Board, at 347-396-6118 or **irbadmin@health.nyc.gov**.

For other Registry questions, call 866-692-9827, email **wchr@health.nyc.gov** or visit **nyc.gov/9-11HealthInfo**. You can also visit the website anytime to find out about Registry findings.

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