



9.11 World Trade Center Health Program

Youth Research Cohort Update

**World Trade Center (WTC) Health Program
Meeting of the Scientific/Technical Advisory
Committee (STAC)**

September 23, 2024



<https://www.cdc.gov/wtc/youthcohort.html>

Youth Research Cohort (YRC)

- Background
- Recent Steps:
 - Requests for information
 - Decision on exposures while *in utero*
 - Youth Research Cohort Registration Portal for self-enrollment into the YRC
 - Consultation with the National Center for Education Statistics at the Department of Education.
 - Outreach and Communications



Established by the Consolidated Appropriations Act of 2023

Amended Sec. 3341(c) of the Public Health Service Act (42 U.S.C. § 300mm–51(c)):

(c) RESEARCH COHORT FOR EMERGING HEALTH IMPACTS ON YOUTH. —

- (1) IN GENERAL. — The WTC Program Administrator, in consultation with the Secretary of Education, shall establish a research cohort of sufficient size to conduct future research studies on the health and educational impacts of exposure to airborne toxins, or any other hazard or adverse condition, resulting from the September 11, 2001, terrorist attacks, including on the population of individuals who were 21 years of age or younger at the time of exposure, including such individuals who are screening-eligible WTC survivors or certified-eligible WTC survivors.

Youth Research Cohort Parameters

YRC must:

- **Be of sufficient size** to conduct future research studies on the health and educational impacts of 9/11 exposures;
- **Include sufficient representation** of individuals who were 21 years of age or younger at the time of exposure; and
- Include individuals who are **screening-eligible WTC survivors or certified-eligible WTC survivors.**

YRC may:

- Include **persons outside the New York City Disaster Area** in the area of Manhattan not further north than 14th Street; or the borough of Brooklyn; and
- Include age-appropriate **control populations** as needed for research purposes.

Approach for Youth Research Cohort Development

- **Phase I, Community Engagement:** Gather sufficient information from educators, scientists, and community members on options for establishing a youth cohort that will efficiently support future research.
- **Phase II, Options Development:** Use the information gathered in Phase I to develop a set of options for moving forward with establishing the youth cohort.
- **Phase III, Options Ranking:** Engage community in ranking the options developed in Phase II.
- **Phase IV, Option Selection and Implementation:** Use the information from Phase III to select the preferred option(s) for establishing the youth cohort.

Requests for Information from Public and Vendors

- RFI published in the *Federal Register* April-December 2023 [[Docket No. CDC-2023-0027, NIOSH-350](#)] for public comments on the approach to establishing the YRC and on best practices, design, and use. The FRN received **26 comments**.
- RFI [75D301-23-R-72680](#), published May 8, 2023, with two rounds of Q&A and a 120-day period to collect further public comments on best practices and preferred approaches to assemble the YRC, as well as methods to develop, coordinate, and manage outreach and education strategies. The Q&A received **12 comments**, including questions related to the composition of the YRC, potential future study details, and timelines for cohort development.
- Report published on the [Youth Research Cohort](#) webpage on August 6, 2024.

Themes from Public Comments

- Overwhelming support for YRC development.
- Ensure broad and diverse representation and meaningful involvement of community and public partner advisors throughout development.
- Expand enrollment criteria for broader participation (e.g., *in utero* exposure, persons outside ‘exposed’ area).
- Ensure a design that supports investigating a broad range of physical and mental health conditions.
- Utilize existing networks and resources available to NIOSH (e.g., NYC Community Boards, local community organizations) during all phases of development and recruitment.

Persons Exposed While *In Utero*

- On [June 23, 2023](#), the STAC recommended that the YRC include persons exposed while *in utero*.
- On [September 25, 2023](#), the Program agrees to explore the issue.
- On [May 1, 2024](#), following extensive scientific, legal, and policy review, the Program expands the YRC development to include persons exposed while *in utero*, given that:
 - The statutory language does not prohibit YRC enrollment, and
 - Inclusion may benefit the Program, including research conducted pursuant to the Zadroga Act.

YRC Registration Portal for Self-Enrollment

- On [June 23, 2023](#), the STAC suggests enrollment may be self-identified (with verification), based on a sampling frame, or both.
- On [March 5, 2024](#), the Program begins development of a secure web-portal for the collection of names, contact information, age at exposure, and other protected information needed for YRC self-enrollment.
 - Supports consent to be contacted for future research.
 - Allows bi-directional communication between the Program and participants
 - Includes provisions to opt out of YRC participation at any time.

Youth Research Cohort Registration Portal (Web-Portal) Status

- System Requirements Specification (SRS) documentation describing the necessary features of the web-portal was completed on June 17, 2024.
- Request for OMB approval for data collection anticipated for fall 2024. OMB approval can take more than a year for new packages.
- Software and infrastructure development by the Program is ongoing. Anticipated completion in March 2025.

Consultation with the Department of Education

- The Program consults with the Secretary of Education to establish the YRC.
- The Program partnered with the National Center for Education Statistics at the Department of Education (DoE).
- A kick-off meeting was held on June 6, 2024. Agenda included:
 - Review of previous related work and lessons learned from WTC Program and DoE research experiences.
 - A call to reestablish connections with the NYC DoE for potential data sharing supporting active recruitment.
- Follow-up meeting held August 13, 2024.

Outreach and Communications

- The Program launched a [Youth Research Cohort webpage](#) in 2023. Over **1,000** page views to date.
- This webpage includes :
 - Information on the Program's four-phase approach to involve and ensure the participation of 9/11 community and other external and scientific partners throughout the process.
 - Periodic updates on the latest cohort-related news.
 - A Youth Research Cohort eligibility map.
 - A prompt for subscribing to the Program's Youth Research eNews bulletins. **Currently, thousands of YRC topic subscribers.** Updates sent out quarterly.