

Youth Cohort Research Information

Summary of RFI and FRN Comments on the Youth Research Cohort

August 6, 2024

Background

As a part of community engagement (Phase I), the World Trade Center (WTC) Health Program (Program) solicited public comments on its proposed four-phase approach to establishing the Youth Research Cohort and on best practices, design, and uses of the Youth Research Cohort between April and December 2023. This report summarizes the approach, results, and findings from these requests for information.

Approach and Results

A **Federal Register Notice (FRN)** was published on April 26, 2023, seeking comments from interested parties (e.g., educators, researchers, clinicians, and community members) on the proposed four-phase approach to establishing the Youth Research Cohort and on best practices, design, and uses of the Youth Research Cohort.

The FRN received 26 submissions in total, 18 (69%) of which were deemed relevant to Youth Research Cohort development. Of those that were relevant, all expressed support for the intent to build a Youth Research Cohort, some emphasized the need for the Youth Research Cohort development to seek input from all relevant advisor partners, some requested to expand the Youth Research Cohort composition, and others to expand the impact area. Participants included many who identified themselves as survivors of the 9/11 attacks, several of whom were potentially eligible cohort members seeking to participate in the Youth Research Cohort, and a few community and educational groups. Some comments were a sentence or two in length, some submissions were a few pages, and another included a series of short personal stories. The comments determined to not be applicable communicated their concerns about vaccines and COVID-19, and another about opioids, each unrelated to the request for information on Youth Research Cohort development.

Concurrent with the FRN, the Program also published and promoted a **Request for Information (RFI)** with two rounds of open questions and answers (Q&A) and a 120-day period to collect public comments on best practices and preferred approaches to assemble a Youth Research Cohort, as well as methods to develop, coordinate and manage outreach and education strategies.

Summary of Public Comments and Recommendations

Design should ensure Youth Research Cohort development includes input from all relevant advisor partners.

Many submissions – including some from youth survivors – advocated that the design and methodology for the Youth Research Cohort development should include input from all relevant advisor partners. Some comments recommended Community-Based Participatory Research (CBPR) methods to encourage active partnerships between scientific researchers and community members. Some comments emphasized the need to tailor messaging to young survivors, including the use of financial incentives, connecting through texting and social media channels, as well as using peer-to-peer and traditional recruitment efforts.

Youth Cohort Research Information

Community and public advisors in the project should be representative of the population being served by the Youth Research Cohort.

Several comments addressed the need for a diverse body of participants to include approximately 50% women and appropriate racial and ethnic representation.

Expand Youth Research Cohort composition to include youth born shortly after 9/11 and children of rescue workers.

Multiple comments requested that the Youth Research Cohort include persons born shortly after 9/11, especially those born to parents who were exposed during pregnancy or before becoming pregnant. These submissions offered a reminder that fires continued smoldering months after 9/11 and may have prolonged risks of exposure beyond the initial impact period.

One commenter identified themselves as a 9/11 rescue worker and requested to include children of rescue workers in the Youth Research Cohort design as they may have increased risks of exposure, particularly in consideration of the proximal impacts of the disaster on their mental health.

Expand Youth Research Cohort composition to include those living just outside the exposure area.

A few comments expressed a desire to expand the exposure area to include those residing just outside of the qualifying (exposed) region. One commenter identified Staten Islanders as being exposed to high levels of airborne contaminants after the attacks and called attention to WTC debris stored at the Staten Island landfill.

Another recommended expanding the Youth Research Cohort composition to account for students who may have lived outside of the exposure area but attended school in closer proximity to the WTC buildings.

Youth Research Cohort design options should be selected to enable investigation into physical health, and mental health conditions.

Multiple commenters recommended that Youth Research Cohort design options that support investigation into a broad range of potential health effects

- Some commenters recommended that the Youth Research Cohort should be designed to address mental health considerations such as posttraumatic stress disorder (PTSD) for those who experienced the disaster first- or even second-hand (e.g., caregivers).
- Others recommended that design options should support investigation into neurocognitive development. Several expressed concern about a potential WTC-related risk of autism in youth survivors.
- One submission recommended that design options should address autoimmune issues.

The need for mental health resources for advisor partners.

Some commenters recommended establishing a mental health resource for participants engaging in the development of the Youth Research Cohort as their participation may trigger traumatic memories or experiences of the events from September 11, 2001.

Youth Cohort Research Information

Youth Research Cohort development should make use of NYC Community Boards' existing community networks.

Several NYC Community Boards recommended in identical comments that the Program should make use of the boards' extensive community networks to identify advisor partners throughout options development for the Youth Research Cohort. One comment from a local organization recommended that the Program reach out to NY Health Schools for unpublished information they collected about schools, children, and parents from 2001-2002.

Conclusion

The comment period from the FRN and RFI initiated by the Program received 38 submissions in total. Overall, the commenters overwhelmingly support the initiative and all recommended approaches to options development for the Youth Research Cohort.

Primary among these was a common recommendation to ensure broad and diverse representation and meaningful involvement of community and public partner advisors throughout options development.

Similarly, many submissions sought to clarify or expand enrollment criteria for broader participation in the Youth Research Cohort.

Another theme was the need for a cohort design that could investigate a broad range of physical and mental health conditions.

Local community organizations also offered to make their existing networks and resources available to the Program throughout all phases of Youth Research Cohort options development and into participant enrollment.