Translational Impacts of World Trade Center Health Program Research

A Mixed Methods Study

THOMAS W. CONCANNON, LAURA J. FAHERTY, JAIME MADRIGANO, SEAN MANN, RAMYA CHARI, SAMEER M. SIDDIQI, JUSTIN LEE, LIISA HIATT

Sponsored by the National Institute for Occupational Safety and Health
About This Report

In this report, we describe the findings and recommendations of a four-year study funded by the National Institute for Occupational Safety and Health of the World Trade Center Health Program’s research portfolio and its translational impact. We present results from a mixed methods assessment that integrates (1) a scoping review of nearly 1,000 peer-reviewed publications and thousands of pages of gray literature that reference research related to the health effects of 9/11, (2) stakeholder perspectives gathered through focus groups and interviews, and (3) a review of program documentation. This report is intended to guide program planning by the World Trade Center Health Program leadership as it aims to maximize the impacts of research investments and achieve its goal of translating research into care for those affected by the attacks on 9/11.

Community Health and Environmental Policy Program

RAND Social and Economic Well-Being is a division of the RAND Corporation that seeks to actively improve the health and social and economic well-being of populations and communities throughout the world. This research was conducted in the Community Health and Environmental Policy Program within RAND Social and Economic Well-Being. The program focuses on such topics as infrastructure, science and technology, community design, community health promotion, migration and population dynamics, transportation, energy, and climate and the environment, as well as other policy concerns that are influenced by the natural and built environment, technology, and community organizations and institutions that affect well-being. For more information, email chep@rand.org.

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Summary

Overview

The World Trade Center (WTC) Health Program (hereafter Program) provides medical monitoring and treatment for its Members: the responders and survivors who were at the WTC and related sites or located within the New York City disaster area during and after the terrorist attacks of September 11, 2001. Scientific research supported by the Program provides an evidence base for the health monitoring and clinical care of Members. In 2017, the National Institute for Occupational Safety and Health (NIOSH) contracted with RAND to conduct a four-year study to inform research program planning in the Program. The purpose of this assessment is to support Program planning, not to audit the Program or evaluate whether the Program is “succeeding” according to its legislative mandates.

Methods

In the first months of this study, the RAND team and Program leaders jointly developed four research questions to guide the analyses. The following research questions reflect our intent to support the planning work of the Program and its stakeholders:

1. What topics and questions have been addressed in WTC health-related research?
2. To what extent is WTC health-related research translational?
3. What are the facilitators of and barriers to translation of WTC health-related research?
4. To what extent has WTC health-related research had impact?

We integrated five quantitative and qualitative data sources to answer the research questions through a mixed methods analysis: (1) peer-reviewed publications through October 31, 2020, (2) Program documentation of research activities through February 2021, (3) transcripts of 12 structured focus group discussions with research stakeholders from December 2019 through February 2020, (4) transcripts of individual stakeholder interviews from October through November 2020, and (5) gray literature publications through November 30, 2020.

To examine the first research question (RQ1: What topics and questions have been addressed in WTC health-related research?), we collected data from nearly 1,000 peer-reviewed publications using an electronic abstraction form. We charted these data into categories using several descriptive taxonomies for research studies. These include the Population, Intervention/Exposure, Comparator, Outcome, Timing, Setting, and Study Design (PI/ECOTSS) approach to classifying research; a classification of studies into three categories (exposure characterization, exposure-outcome linkage, and outcome modification); and the National Institutes of Environmental Health Sciences (NIEHS) Translational Framework, among others. Finally, we assessed the range and extent of research using these classifications.
To answer the second research question (RQ2: To what extent is WTC health-related research translational?), we synthesized qualitative data from gray literature, Program documentation, focus groups, and interviews. From focus group and interview transcripts, we examined definitions of translational research in respondents’ own words. We also identified stakeholders’ views on the uses of existing research in future research, planning, policy, and care. Finally, we applied a machine-learning algorithm with these same words and uses of research to identify related text passages within thousands of pages of Program documentation and gray literature. Using these sources, we examined whether and how WTC health-related research is translated into use.

To answer the third research question (RQ3: What are the facilitators of and barriers to successful translation of WTC health-related research?), we again synthesized qualitative data from gray literature, Program documentation, focus groups, and interviews. We applied a priori codebooks to all sources and sorted data into tables by code to facilitate comparisons. Next, we deductively identified themes, or concepts that describe patterns in the data. Among these themes were the factors that might positively or negatively influence research translation.

To answer the fourth research question (RQ4: To what extent has WTC health-related research had impact?), we ran several analyses. Our a priori coding approach enabled the research team to view information from all five data sources across the same condition or population of interest (e.g., WTC responders, WTC survivors, all Program-covered conditions, and a preselected set of other conditions). We selected three of these topics to explore in case studies on research translation: research involving depression and anxiety, women’s health, and WTC-exposed youth. We applied the NIEHS Translational Research Framework to describe how research on these topics followed various translational pathways and achieved impact by directly informing Program planning and policy.

Findings

Our analyses resulted in the several key findings, organized by research question.

**RQ1: What Topics and Questions Have Been Addressed in WTC Health-Related Research?**

- **Finding 1.** WTC health-related research addresses a wide variety of health conditions and is balanced across Member populations.
- **Finding 2.** There is a high concentration of research that addresses fundamental questions about the health effects of 9/11 and a lower concentration of research on health care interventions for affected populations.

**RQ2: To What Extent Is WTC Health-Related Research Translational?**

- **Finding 3.** Program leaders, researchers, clinicians, and Members understand the fundamentals of translation and can describe, in their own words, how WTC health-
related research is used. However, almost all stakeholders struggled to give a comprehensive definition of translation.

- **Finding 4.** The Program has a strong record of documenting and disseminating Program-funded research, but the range of stakeholder preferences for receiving information about WTC health-related research is broad and presents challenges.

**RQ3: What Are the Facilitators of and Barriers to Translation of WTC Health-Related Research?**

- **Finding 5.** Facilitators of research translation include a focused mission to improve care through research; research infrastructure, such as the colocation of researchers and clinicians at Clinical Centers of Excellence and the collection, management, and analysis of data by the WTC Data Centers and WTC Health Registry; and the communication and dissemination of findings. Barriers to research translation include methodological limitations, fragmentation of the health care system, funding constraints, variable definitions of translation, and misaligned expectations about research.

**RQ4: To What Extent Has WTC Health-Related Research Had Impact?**

- **Finding 6.** Program research is used in decisions about care, planning, and policy.
- **Finding 7.** Stakeholders want to know how they can contribute to maximizing the impacts of research. Some stakeholders may need information and guidance to support their involvement in Program planning, policy, and research.

These findings serve as the basis for recommendations that NIOSH could implement to reinforce and strengthen the translational impact of Program research.

**Recommendations**

The mission of WTC Health Program–funded research is to inform improved care for Program Members. To support this work, we offer the following recommendations to reinforce and strengthen the translational impacts of Program research:

1. To ensure the Program is able to maintain a balanced portfolio in terms of topics and populations (Finding 1), the Program can build on and further develop existing research infrastructure and processes for conducting timely, objective, and continuous reviews of the Program research portfolio.
2. To come to a shared understanding of translation and align expectations about what such research can achieve for Members (Findings 3 and 4), the Program can gather input from stakeholders on a novel translational research framework.
3. To guide a more systematic approach to activities of the research program, the Program can pilot the translational framework in four key areas: research planning, monitoring, evaluation, and communication about research impacts (Findings 2, 3, 5, and 6).
4. To be responsive to stakeholders’ interest in contributing to maximizing the impacts of research (Finding 7), the Program can implement structured processes for stakeholder engagement in program planning, policy, and research activities.
Limitations

This study had a few limitations. First, in the scoping review, we included articles published up to and including October 31, 2020, and excluded conference abstracts. Consequently, this review did not capture research that was presented in conferences but not published, nor did it capture new research that was completed after October 2020. Also, because of this review’s large scope (consisting of nearly 1,000 publications), it covers a variety of populations and conditions. The scope and heterogeneity prevented a focused look within population and condition groups for summary effect estimates or strength of evidence assessments. Finally, as with all scoping reviews, some data items may be subject to misclassification.

Second, in qualitative data collection and analysis, we were unable to disentangle the degree to which certain stakeholders or views are overrepresented or underrepresented. We sought to examine the full range of stakeholder views on a given topic, but the qualitative findings may not be generalizable. As in all qualitative research, the views expressed by the stakeholders in this report (who, for the most part, are affiliated in some way with the Program) are opinions that may or may not be factually accurate.

Third, the search strategy we used to find gray literature involved a novel but unvalidated use of several search engines. As with the other qualitative data sources used in this report, the goal of examining gray literature was to ensure that no significant views of stakeholders were missed. Relatedly, the machine-learning algorithm we used to identify relevant text passages in the gray literature was developed and trained on manually coded data from focus group transcripts and therefore should be interpreted as an extension of those findings.

Finally, the NIEHS framework, although a promising way of examining a body of research, is novel and may need extensive testing and validation. It is unknown whether this framework on its own can capture all the distinctiveness and complexities of the Program’s research activities.

Conclusion

More than 20 years after the attacks on 9/11, the Program continues to carry out its focused research mission: to improve health care and outcomes of its Members. In support of this mission, the Program engages in ongoing planning activities that are grounded in rigorous assessments of existing research and future needs. This report is intended to support NIOSH in program-planning activities by critically examining the past decade of Program-supported research and looking ahead to the near- and longer-term research activities of the Program.
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<th>Description</th>
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<tbody>
<tr>
<td>CCE</td>
<td>Clinical Center of Excellence</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<td>CINAHL</td>
<td>Cumulative Index to Nursing and Allied Health Literature</td>
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<tr>
<td>CPAP</td>
<td>continuous positive airway pressure</td>
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<tr>
<td>CTSI</td>
<td>Clinical and Translational Science Institute</td>
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<tr>
<td>FDNY</td>
<td>Fire Department of New York</td>
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<td>FOA</td>
<td>funding opportunity announcement</td>
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<td>MWG</td>
<td>Medical Working Group</td>
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<td>NIEHS</td>
<td>National Institute of Environmental Health Sciences</td>
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<td>NIH</td>
<td>National Institutes of Health</td>
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<td>NIOSH</td>
<td>National Institute for Occupational Safety and Health</td>
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<tr>
<td>NOS</td>
<td>not otherwise specified</td>
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<tr>
<td>NYC</td>
<td>New York City</td>
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<tr>
<td>OMB</td>
<td>Office of Management and Budget</td>
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<tr>
<td>PECOTSS</td>
<td>Population, Exposure, Comparator, Outcome, Timing, Setting, and Study Design</td>
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<tr>
<td>PICOTSS</td>
<td>Population, Intervention, Comparator, Outcome, Timing, Setting, and Study Design</td>
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<tr>
<td>PTSD</td>
<td>posttraumatic stress disorder</td>
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<tr>
<td>RQ</td>
<td>research question</td>
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<tr>
<td>RSC</td>
<td>Responder Steering Committee</td>
</tr>
<tr>
<td>RTC</td>
<td>Research-to-Care</td>
</tr>
<tr>
<td>SSC</td>
<td>Survivor Steering Committee</td>
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<tr>
<td>STAC</td>
<td>Scientific/Technical Advisory Committee</td>
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<td>WTC</td>
<td>World Trade Center</td>
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## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Administrative data</td>
<td>Data originally collected for administrative purposes, such as payor claims from an inpatient hospital setting.</td>
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<tr>
<td>Ambulatory/outpatient setting</td>
<td>Clinics or doctors’ offices that may or may not be affiliated with an inpatient hospital.</td>
</tr>
<tr>
<td>Clinical data</td>
<td>Data originally collected for clinical management or treatment of individual patients.</td>
</tr>
<tr>
<td>Clinical intervention</td>
<td>A screening or testing procedure aimed at detecting health conditions, or a treatment delivered in the clinical setting aimed at managing a health condition or improving well-being and quality of life.</td>
</tr>
<tr>
<td>Community setting</td>
<td>Study population sampled from residents in the community.</td>
</tr>
<tr>
<td>Covered conditions</td>
<td>Specific physical and mental health conditions that have been determined to be caused by exposure to the 9/11 terrorist attacks. Under the James Zadroga 9/11 Health and Compensation Act of 2010, the Program provides treatment for these conditions (WTC Health Program, 2021c).</td>
</tr>
<tr>
<td>Emergency department setting</td>
<td>Urgent and emergency care locations offering referral to on-site inpatient units.</td>
</tr>
<tr>
<td>Environmental monitoring data</td>
<td>Data originally collected for the purpose of characterizing exposures or pollutants in a defined place.</td>
</tr>
<tr>
<td>Exposure characterization study</td>
<td>This type of study describes the spatial, temporal, intensity, and/or magnitude distributions of a physical or chemical stressor in the environment. Exposure characterization can be accomplished through measurement or modeling or, in some cases, a combination of both methods.</td>
</tr>
<tr>
<td>Exposure-outcome linkage study</td>
<td>Examines associations between one or more exposures and health outcomes.</td>
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<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
<td>Gray literature</td>
<td>Reports, monographs, working papers, and other documents that are distributed in print or electronic form but are not formally peer-reviewed before publication.</td>
</tr>
<tr>
<td>Group or population study</td>
<td>Research conducted in humans.</td>
</tr>
<tr>
<td>Health policy intervention</td>
<td>An effort or initiative undertaken at the population level to improve health and well-being through policy or programmatic change. Research studies can describe and/or examine the effect of such efforts.</td>
</tr>
<tr>
<td>Health services intervention</td>
<td>An effort or initiative undertaken at the population level with the goal of improving the way that health care is organized, delivered, or financed. Research studies can describe and/or determine the effect of such efforts.</td>
</tr>
<tr>
<td>In silico study</td>
<td>Research conducted primarily through computer simulations or modeling.</td>
</tr>
<tr>
<td>In vitro study</td>
<td>Research conducted primarily in a test tube, a culture dish, or otherwise outside of a living organism.</td>
</tr>
<tr>
<td>Inpatient setting</td>
<td>Study population sampled from patients admitted to a hospital.</td>
</tr>
<tr>
<td>James Zadroga 9/11 Health and Compensation Act of 2010 (Pub. L. 111-347, 2011)</td>
<td>The U.S. law that created the WTC Health Program, reopened the September 11th Victim Compensation Fund, and extended the WTC Health Registry. This law was reauthorized in 2015, extending the program until 2090.</td>
</tr>
<tr>
<td>Laboratory setting</td>
<td>Data collected from specimens in diagnostic, clinical, or research laboratories.</td>
</tr>
<tr>
<td>Longitudinal data</td>
<td>Data collected from the same study participants at multiple time points.</td>
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<tr>
<td>Mixed methods analysis</td>
<td>An assessment that integrates both quantitative and qualitative data to address research questions.</td>
</tr>
<tr>
<td>Nonhuman animal study</td>
<td>Research conducted in nonhuman animals.</td>
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</table>
Ongoing research  
Research that is in progress and has not been completed.  
Ongoing research projects may have resulted in abstracts and peer-reviewed publications, but the data collection and/or analysis continues.

Outcome modification study  
Examines characteristics or impacts of one or more health-related interventions that are intended to modify outcomes at the individual or population level. Outcome modification studies may include bench research, clinical research, health services research, implementation science, or policy analyses.

Peer-reviewed literature  
Research published in academic journals that has been subjected to a rigorous process by which peers review the quality of the work and adheres to the editorial standards of the journal.

Petitioned condition  
A health condition for which the Administrator of the Program has received a petition requesting addition to the list of WTC-Related Health Conditions. The James Zadroga 9/11 Health and Compensation Act of 2010 allows any interested party to submit a petition in accordance with the “Policy and Procedures for Handling Submissions and Petitions to Add a Health Condition to the List of WTC-Related Health Conditions” (WTC Health Program, 2021a).

Population registry data  
Data compiled on a defined population, such as those with a defined exposure or those with a defined condition or group of conditions.

Post-acute care or skilled nursing facility  
A rehabilitation or palliative services residential or hospital-based facility to which patients are admitted, usually after discharge from (or instead of an inpatient stay in) an acute care hospital.

Research  
A study published in article length after peer review; this definition was used as one of the criteria for inclusion in the scoping review.

Research data  
Data collected primarily for the purposes of a research study, in contrast with clinical or administrative data, which are not collected primarily for research purposes.
<table>
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<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Research impact</td>
<td>The use of research evidence in subsequent decisionmaking, including in future research, care, program planning, and policy.</td>
</tr>
<tr>
<td>Research stakeholder</td>
<td>An individual or organization who is responsible for or affected by decisions that may be informed by research evidence. The Program also calls its stakeholders research end users.</td>
</tr>
<tr>
<td>Scoping review</td>
<td>A review of literature that summarizes the content and extent of research on a topic or field. Scoping reviews employ systematic search, screen, and review methods. They often include all types of publications, including peer-reviewed and gray literature.</td>
</tr>
<tr>
<td>Systematic review</td>
<td>A review of literature that summarizes findings from research on a particular topic using explicit inclusion, search, screening, and abstraction strategies. Systematic reviews usually include homogeneous publication types and seek to identify summary effects of an intervention or exposure.</td>
</tr>
<tr>
<td>Translational research</td>
<td>The process of turning scientific observations into interventions that improve and enhance the health and well-being of individuals and populations (National Center for Advancing Translational Sciences, 2019; Vukotich, 2016; Woolf, 2008; Zerhouni, 2007).</td>
</tr>
<tr>
<td>World Trade Center Health Program</td>
<td>A program, established by the James Zadroga 9/11 Health and Compensation Act of 2010, that provides medical monitoring and treatment for responders at the World Trade Center and related sites and survivors who were in the New York City disaster area.</td>
</tr>
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World Trade Center Health Program Member

An individual with at least one of the following qualifying characteristics: (1) WTC responders, including Fire Department of New York responders and family members; New York City general responders (i.e., those who worked or volunteered in rescue, recovery, demolition, debris cleanup, and/or other support services in New York City); responders at the Pentagon; and responders in Shanksville, Pennsylvania, or (2) WTC survivors, referring to those present in the New York City disaster area in the dust or dust cloud on September 11, 2011; those who worked, resided, or attended school, childcare, or adult daycare in the New York City disaster area during or after September 11, 2001; those who were eligible for certain residential grants; or those whose place of employment was eligible for certain grants following 9/11 (WTC Health Program, 2020).

Zadroga Act

Background

The World Trade Center (WTC) Health Program (hereafter Program; described further in Appendix A) was established in 2010 by the James Zadroga 9/11 Health and Compensation Act (Pub. L. 111-347, 2011; hereafter Zadroga Act) and reauthorized in 2015 (Pub. L. 114-113, 2015). It is housed within the U.S. Department of Health and Human Services and administered by the Director of the National Institute for Occupational Safety and Health (NIOSH). The Program provides medical monitoring and treatment for its Members: responders and survivors who were at the WTC and related sites or located within the New York City (NYC) disaster area during and after the terrorist attacks of September 11, 2001.

The Program also supports scientific research to provide an evidence base for health monitoring and clinical care of Members. The Zadroga Act, Subtitle C, states,

the WTC Program Administrator shall conduct or support (1) research on physical and mental health conditions that may be related to the September 11, 2001, terrorist attacks; (2) research on diagnosing WTC-related health conditions; and (3) research on treating WTC-related health conditions (Pub. L. 111-347, 2011).

The Program’s research mission is “to investigate health impacts (and disability) arising from the 9/11 attacks and to optimize World Trade Center responder and survivor care” (WTC Health Program, undated a). Research translation, or the process of turning scientific observations into interventions that improve and enhance the health and well-being of individuals and populations (National Center for Advancing Translational Sciences, 2019; Vukotich, 2016; Woolf, 2008; Zerhouni, 2007), is at the core of this mission. The Program therefore seeks to support research that creates new knowledge, advances the field, and applies this knowledge directly to improving the health care of individuals affected by the 9/11 attacks.

Program leaders, clinicians, researchers, Members, and other end users of research share a mission-driven sense of urgency to prevent, screen, diagnose, and treat individuals affected by the 9/11 attacks using the best available evidence. However, translating research into improved health care is challenging. The path from generating new knowledge to changing clinical practice can be long and complex (Lenox, 2018): One frequently cited estimate suggests that research evidence takes approximately 17 years to move from conceptualization to changes in clinical care (Morris, Wooding, and Grant, 2011).

Program leaders want to understand the impacts of research investments to date and how to maximize those impacts going forward. In 2017, NIOSH engaged the RAND Corporation to conduct a four-year, independent assessment of the translational impacts of Program-supported research. The purpose of our assessment is to support Program planning, not to audit the
Program or evaluate whether the Program is “succeeding” according to its legislative mandates. Our recommendations are intended to align with five-year funding cycles of Program research throughout the lifetime of the Program, which is authorized to 2090 (Pub. L. 114-113, 2015).

We worked with NIOSH to co-develop research questions and sub-questions to guide this assessment (see Appendix B). As the assessment progressed, and with NIOSH’s input, we moderately restated the guiding research questions to ensure they are relevant to supporting the planning work of the Program and its stakeholders:

1. What topics and questions have been or will be addressed in WTC health-related research?
2. To what extent is WTC health-related research translational?
3. What are the facilitators of and barriers to translation of WTC health-related research?
4. To what extent has WTC health-related research had impact?

When possible, we examined research funded by NIOSH and related programs separately.

Overview of Methods

We integrated five quantitative and qualitative data sources to answer the research questions through a mixed methods analysis: (1) peer-reviewed publications through October 31, 2020, (2) Program documentation of research activities through February 2021, (3) transcripts of 12 structured focus group discussions with research stakeholders from December 2019 through February 2020, (4) transcripts of individual stakeholder interviews from October through November 2020, and (5) gray literature publications through November 30, 2020.

To examine the first research question (RQ1: What topics and questions have been addressed in WTC health-related research?), we collected data from nearly 1,000 peer-reviewed publications using an electronic abstraction form. We charted these data into categories using several descriptive taxonomies for research studies. These include the Population, Intervention/Exposure, Comparator, Outcome, Timing, Setting, and Study Design (PI/ECOTSS) approach to classifying research, our own classification of studies into three categories (exposure characterization, exposure-outcome linkage, and outcome modification), and the National Institutes of Environmental Health Sciences (NIEHS) Translational Framework, among others. Finally, we assessed the range and extent of research using these classifications.

To answer the second research question (RQ2: To what extent is WTC health-related research translational?), we synthesized qualitative data from gray literature, Program documentation, focus groups, and interviews. From focus group and interview transcripts, we examined definitions of translational research in respondents’ own words. We also identified stakeholders’ views on the uses of existing research in future research, planning, policy, and care. Finally, we applied a machine-learning algorithm with these same words and uses of research to identify related text passages within thousands of pages of Program documentation.
and gray literature. Using these sources, we examined whether and how WTC health-related research is translated into use.

To answer the third research question (RQ3: What are the facilitators of and barriers to successful translation of WTC health-related research?), we again synthesized qualitative data from gray literature, Program documentation, focus groups, and interviews. To do this, we applied a priori codebooks to all sources and sorted data into tables by code and subcode to facilitate comparisons. Next, we deductively identified *themes*, or concepts that describe patterns in the data. Among these themes were the factors that might positively or negatively influence research translation.

To answer the fourth research question (RQ4: To what extent has WTC health-related research had impact?), we ran several analyses. Our a priori coding approach enabled the research team to view information from all five data sources across the same condition or population of interest (e.g., WTC responders, WTC survivors, all Program-covered conditions, and a preselected set of other conditions). We selected three of these topics to explore in case studies on research translation: research involving depression and anxiety, women’s health, and WTC-exposed youth. We applied the NIEHS Translational Research Framework to describe how research on these topics followed various translational pathways and achieved impact by directly informing Program planning and policy.

For more detail on our methods, please refer to Appendix C.

**Organization of This Report**

The remainder of the report is organized into three chapters.

Chapter 2 presents several analyses. We start with a scoping review to describe the topics, conditions, and populations that WTC health-related research addresses (RQ1). We then examine the extent to which WTC health-related research can be considered translational (RQ2). Finally, we present a mixed methods assessment of impact, consisting of three topical case studies of research translation (RQ4).

In Chapter 3, we examine the facilitators of and barriers to research translation (RQ3).

In Chapter 4, we present four recommendations that NIOSH leaders can adopt in program planning to strengthen the translational impacts of Program research.

Although this report is of interest to a broad range of stakeholders, the primary audience is Program leaders who are charged with implementing the Program’s research mission. Therefore, we offer a concise report that directly connects research questions to findings and findings to recommendations. Detail on the Program, methods, and other supporting information are presented in the appendices.
2. Impacts of World Trade Center Health-Related Research

Introduction

WTC Health Program research is conducted with the purpose of developing evidence that can be translated into improvements in health care and health of Program members. Significant progress has been made to clarify how the process of research translation unfolds over time and how it might be accelerated. In the broadest sense, the use of research in any setting can be seen as evidence of translational impact.

This chapter presents three complementary assessments of the impacts of health-related research following the attacks of 9/11, organized by analytic method: (1) a quantitative impact assessment describing what has been published (RQ1), (2) a qualitative assessment exploring how stakeholders view putting WTC health-related research to use (RQ2 and RQ4), and (3) a mixed methods assessment using three case studies that illustrate how WTC health-related research is translated into care, planning, and policy (RQ4). This chapter therefore addresses three of our research questions: what has been studied with respect to the health effects of 9/11, to what extent the research is translational (i.e., used for real-world decisionmaking), and to what extent the research has had impact.

Key Findings in This Chapter

Research published from 2001 through October 2020 addresses a wide variety of WTC health-related topics, exposures, and conditions.

WTC health-related research is balanced across Member populations.

There is a high concentration of research on fundamental questions about the health effects of 9/11 and a lower concentration of research on health care interventions for affected populations.

Program research is used in decisions about care, planning, and policy.

Quantitative Impact Assessment

We completed a scoping review (Arksey and O’Malley, 2005; Cooper et al., 2021; Levac, Colquhoun, and O’Brien, 2010) to examine what has been published in the peer-reviewed literature on the health and health care of WTC populations (RQ1). Our approach followed systematic review methods and consisted of (1) a systematic search through October 31, 2020, of six databases and reference mining of selected previous reviews of Program research, (2) a title and abstract screening process with formal inclusion and exclusion criteria, (3) a full-text screening process with formal inclusion and exclusion criteria and adjudication, and (4) a double
review and data extraction of included full-text articles with adjudication and quality review. Data were extracted using a customized electronic form implemented in DistillerSR (DistillerSR, undated). Data analyses were performed using DistillerSR, Python (Python, undated), and Microsoft Excel (see Appendix C).

**Peer-Reviewed World Trade Center Health-Related Research (RQ1)**

Figure 2.1 presents the results of our systematic search, screen, and review of WTC health-related research. After applying a wide array of terms to search six peer-reviewed publication databases for research published from September 2001 through October 2020 (see Appendix D), we identified 10,865 records for screening. Removing duplicates left 7,310 records for inclusion. After screening titles and abstracts for relevance, we retrieved the full-text articles of 2,172 remaining records. These records were again checked for duplicates, and instances of multiple publications reporting one study were removed. The full-text records were then screened against predetermined exclusion criteria; we excluded full-text articles that were not in English, did not qualify as research (see Glossary), were not about the terrorist attacks on 9/11, were not about 9/11 populations, and were not about health.

**Figure 2.1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses**

- Records identified \( (N = 10,865) \)
- Records after duplicates removed \( (N = 7,310) \)
- Records screened \( (N = 7,310) \)
- Records excluded during title and abstract screening \( (N = 5,138) \)
- Records excluded during full-text review \( (N = 1,210) \)
  - Duplicate = 29
  - Multiple publications = 10
  - Not in English = 8
  - Not research = 537
  - Not about 9/11 attacks = 181
  - Not 9/11 population = 326
  - Not health-related = 119
- Publications included in review \( (N = 962) \)
After exclusions were applied, 962 full-text articles were included in the review. All included publications were abstracted using a detailed online query form (see Appendix E). Of the 962 included publications (Appendix F), 380 (39.5 percent) were funded by NIOSH and related programs, including all precursors to the Program, and 582 (60.5 percent) were supported by other funders (Table 2.1).

Study Types

We categorized the 962 studies into one of three study types: exposure characterization, exposure-outcome linkage, and outcome modification. A total of 48 publications sought to characterize the nature or extent of environmental health exposures resulting from the attacks, rescue or recovery activities, or cleanup in the months after the attacks (“exposure characterization,” \(N = 48\), 5.0 percent). A total of 739 publications examined links between those environmental health exposures and health outcomes in affected populations (“exposure-outcome linkage,” \(N = 739\), 76.8 percent). A total of 175 publications examined clinical, health services, programmatic, and policy responses that were designed to improve the health of affected populations (“outcome modification,” \(N = 175\), 18.2 percent).

Table 2.1. Three Study Types, by Funder

<table>
<thead>
<tr>
<th></th>
<th>NIOSH and Related ((N = 380))</th>
<th>Other Funders ((N = 582))</th>
<th>All Funders ((N = 962))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N)</td>
<td>%</td>
<td>(N)</td>
</tr>
<tr>
<td>Exposure characterization</td>
<td>9</td>
<td>2.4</td>
<td>39</td>
</tr>
<tr>
<td>Exposure-outcome linkage</td>
<td>335</td>
<td>88.2</td>
<td>404</td>
</tr>
<tr>
<td>Outcome modification</td>
<td>36</td>
<td>9.5</td>
<td>139</td>
</tr>
</tbody>
</table>

SOURCE: Author analysis of peer-reviewed publications.
NOTE: The percentages may sum to greater than 100 percent because of rounding.

We also analyzed trends in the study types from 2001 to 2020. The distributions of these three study types and funding sources have evolved over time. Figure 2.2 shows the distribution of study types by funding source (NIOSH and non-NIOSH) in three-year increments. Regardless of funding source, exposure-outcome linkage studies have predominated (blue bars), although there were a fair number of outcome modification studies from about 2001 to 2007 (pink bars), primarily consisting of descriptions of programs that were implemented in response to the 9/11 attacks rather than clinical interventions. Exposure characterization studies were also more common in the early years after the attacks (2001–2007), with fewer publications of this type since 2008 (green bars). There was a significant spike in the total number of publications on the tenth anniversary of the attacks. Program-supported research (darker bars) has increased over time as a share of all publications, regardless of funding. In the years just after the Program was established (2010–2012), the overall number of published studies supported by NIOSH and non-
NIOSH funders was roughly equal in number. Since 2012, most publications on 9/11 and health have been supported by NIOSH and related programs. The count of publications supported by NIOSH grew substantially after 2015.

Figure 2.2. Study Type, by Year and Funding Source

SOURCE: Author analysis of peer-reviewed publications.
NOTES: Publications supported by NIOSH and related programs are included in the darker bars. Publications supported by other funding are included in the lighter bars. From 2004 through 2018, bars represent a three-year count of publications. The first bar (September 2001 through 2003) represents a 2.3-year count. The last bar (January 2019 through October 2020) represents a 1.8-year count. Exposure characterization studies are depicted in green. Exposure-outcome linkage studies are depicted in blue. Outcome modification studies are depicted in pink.

World Trade Center Populations

We counted the number of publications reporting on studies in humans, including responders, survivors, and other population groups (Tables 2.2 and 2.3, \( N = 873 \) publications). Just over half of these studied responders (\( N = 485, 55.6 \) percent) in NYC, the Pentagon, and Shanksville, Pennsylvania, and 98.6 percent of these were focused on NYC responders (Table 2.2). Similarly, a little more than half of the articles studied 9/11 survivors (\( N = 463, 55.0 \) percent), including some with a special focus on youth at the time of the 9/11 attacks (\( N = 147, 16.8 \) percent; Table 2.3). NIOSH-funded publications were more likely to report on studies of responders than of survivors (responders: \( N = 304 \) of 358, 84.9 percent; survivors: \( N = 147 \) of 358, 41.1 percent), whereas publications supported by other funding were less likely to report on studies of responders than of survivors (responders: \( N = 181 \) of 515, 35.1 percent; survivors: \( N = 316 \) of 515, 61.1 percent).

Many studies included both populations, and because the two primary WTC population groups were studied in 53 percent and 56 percent of publications overall, we conclude that study of the two Member population groups has been balanced overall.
## Table 2.2. 9/11 Populations Studied, by Funder

<table>
<thead>
<tr>
<th>Population</th>
<th>NIOSH and Related (N = 358)</th>
<th>Other Funders (N = 515)</th>
<th>All Funders (N = 873)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>9/11 responder</td>
<td>304</td>
<td>84.9</td>
<td>181</td>
</tr>
<tr>
<td>NYC responder</td>
<td>304</td>
<td>100.0</td>
<td>174</td>
</tr>
<tr>
<td>FDNY</td>
<td>162</td>
<td>53.3</td>
<td>80</td>
</tr>
<tr>
<td>General responder</td>
<td>227</td>
<td>74.7</td>
<td>154</td>
</tr>
<tr>
<td>Pentagon responder</td>
<td>1</td>
<td>0.3</td>
<td>10</td>
</tr>
<tr>
<td>Shanksville responder</td>
<td>1</td>
<td>0.3</td>
<td>4</td>
</tr>
<tr>
<td>9/11 survivor</td>
<td>147</td>
<td>41.1</td>
<td>316</td>
</tr>
<tr>
<td>Other</td>
<td>25</td>
<td>7.0</td>
<td>128</td>
</tr>
</tbody>
</table>

**SOURCE:** Author analysis of peer-reviewed publications.
**NOTES:** FDNY = Fire Department of New York. Responder and survivor frequencies are denominated by studies conducted in humans only. NYC, Pentagon, and Shanksville responder percentages are relative to 9/11 responders. FDNY and general responder percentages are relative to NYC responders only. A small number of papers compared 9/11 responders and survivors to those affected by other large scale disasters; if the 9/11 population was greater than 50 percent of the total study population, then the study met our inclusion criteria, and it was assigned to both the 9/11 and “other” population categories. Because studies may involve more than one 9/11 population category or subcategory, percentages may sum to greater than 100 percent.

## Table 2.3. Youth and Adults Studied, by Funder

<table>
<thead>
<tr>
<th>Population</th>
<th>NIOSH and Related (N = 358)</th>
<th>Other Funders (N = 515)</th>
<th>All Funders (N = 873)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Youth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Born before 9/11 and exposed on 9/11</td>
<td>25</td>
<td>80.6</td>
<td>82</td>
</tr>
<tr>
<td>Born before 9/11 and parent exposed</td>
<td>13</td>
<td>41.9</td>
<td>47</td>
</tr>
<tr>
<td>In utero on 9/11</td>
<td>7</td>
<td>22.6</td>
<td>25</td>
</tr>
<tr>
<td>Adults</td>
<td>339</td>
<td>94.7</td>
<td>448</td>
</tr>
<tr>
<td>Elderly</td>
<td>2</td>
<td>0.6</td>
<td>4</td>
</tr>
<tr>
<td>Women</td>
<td>3</td>
<td>0.9</td>
<td>18</td>
</tr>
<tr>
<td>Pregnant women</td>
<td>6</td>
<td>1.8</td>
<td>22</td>
</tr>
<tr>
<td>Men</td>
<td>37</td>
<td>10.9</td>
<td>12</td>
</tr>
</tbody>
</table>

**SOURCE:** Author analysis of peer-reviewed publications.
**NOTES:** Youth and adult frequencies are denominated by studies conducted in humans only. Subcategory percentages are relative to youth or adult category. For the adult category, only publications that limited their study populations to a particular subcategory, such as elderly individuals or women, are called out in this table. Because studies may involve more than one adult or youth population category or subcategory, percentages may sum to greater than 100 percent.
Exposures

We also examined the 9/11-related exposures that were measured in exposure characterization and exposure-outcome linkage studies (Table 2.4, N = 788). About one in ten of these publications examined chemical exposures (N = 82, 10.4 percent), and just over three-quarters examined other 9/11 hazards (N = 605, 76.8 percent).

Table 2.4. 9/11 Exposures Studied, by Funder

<table>
<thead>
<tr>
<th>9/11-related chemical hazard</th>
<th>NIOSH and Related (N = 345)</th>
<th>Other Funders (N = 443)</th>
<th>All Funders (N = 788)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>9/11-related chemical hazard</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group 1</td>
<td>23</td>
<td>6.7</td>
<td>59</td>
</tr>
<tr>
<td>Group 2</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Group 3</td>
<td>2</td>
<td>8.7</td>
<td>19</td>
</tr>
<tr>
<td>Group 4</td>
<td>3</td>
<td>13.0</td>
<td>22</td>
</tr>
<tr>
<td>Group 5</td>
<td>15</td>
<td>65.2</td>
<td>41</td>
</tr>
<tr>
<td>Group 6</td>
<td>5</td>
<td>21.7</td>
<td>7</td>
</tr>
<tr>
<td>Other 9/11 hazard</td>
<td>283</td>
<td>82.0</td>
<td>322</td>
</tr>
<tr>
<td>Cold stress</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Heat stress</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Musculoskeletal injury</td>
<td>26</td>
<td>9.2</td>
<td>10</td>
</tr>
<tr>
<td>Bloodborne pathogens</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Present in WTC building on 9/11</td>
<td>36</td>
<td>12.7</td>
<td>30</td>
</tr>
<tr>
<td>Caught in dust cloud on 9/11</td>
<td>126</td>
<td>44.5</td>
<td>45</td>
</tr>
<tr>
<td>Present in NYC WTC area</td>
<td>200</td>
<td>70.7</td>
<td>235</td>
</tr>
<tr>
<td>Present in Shanksville</td>
<td>1</td>
<td>0.4</td>
<td>1</td>
</tr>
<tr>
<td>Present at the Pentagon</td>
<td>0</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>PTSD</td>
<td>54</td>
<td>19.1</td>
<td>27</td>
</tr>
<tr>
<td>Other</td>
<td>43</td>
<td>12.5</td>
<td>81</td>
</tr>
</tbody>
</table>

**SOURCE:** Author analysis of peer-reviewed publications.

**NOTES:** PTSD = posttraumatic stress disorder. Subcategory percentages are relative to category count. Because studies may involve more than one exposure category or subcategory, category or subcategory percentages may sum to greater than 100 percent. In some studies, musculoskeletal injuries and PTSD were treated as exposures and are therefore counted as such in this table. For definitions of Groups 1–6, see Box C.2.
Conditions

We also counted how many exposure-outcome linkage and outcome modification study publications addressed the Program’s covered and noncovered conditions through October 2020 (Table 2.5, \(N = 913\) publications). A little more than half of these publications focused on covered conditions, and just over two-thirds focused on noncovered conditions. Of all Program-funded publications focusing on a covered condition, the shares devoted to physical conditions and neuropsychiatric conditions were reasonably balanced (physical: \(N = 118, 58.1\) percent of Program-funded research on covered conditions; neuropsychiatric: \(N = 93, 45.8\) percent of Program-funded research on covered conditions). This distribution shifted somewhat toward research on covered neuropsychiatric conditions when considering all funders (physical: \(N = 182, 39.7\) percent; neuropsychiatric: \(N = 294, 64.1\) percent). Among all publications that addressed a covered neuropsychiatric condition, we found high concentrations of research on PTSD and aerodigestive disorders (PTSD: \(N = 248 \text{ of } 294, 84.4\) percent; aerodigestive disorders: \(N = 142 \text{ of } 294, 78.0\) percent).

Table 2.5. Conditions Studied, by Funder

<table>
<thead>
<tr>
<th></th>
<th>NIOSH and Related ((N = 370))</th>
<th>Other Funders ((N = 543))</th>
<th>All Funders ((N = 913))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N)</td>
<td>(%)</td>
<td>(N)</td>
</tr>
<tr>
<td>Covered conditions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Covered physical conditions</td>
<td>203</td>
<td>54.9</td>
<td>256</td>
</tr>
<tr>
<td>Acute traumatic injury</td>
<td>118</td>
<td>58.1</td>
<td>64</td>
</tr>
<tr>
<td>Aerodigestive disorders</td>
<td>93</td>
<td>78.8</td>
<td>49</td>
</tr>
<tr>
<td>Cancer</td>
<td>27</td>
<td>22.9</td>
<td>13</td>
</tr>
<tr>
<td>Musculoskeletal disorders</td>
<td>26</td>
<td>22.0</td>
<td>10</td>
</tr>
<tr>
<td>Covered neuropsychiatric conditions</td>
<td>93</td>
<td>45.8</td>
<td>201</td>
</tr>
<tr>
<td>Acute stress disorder</td>
<td>1</td>
<td>1.1</td>
<td>11</td>
</tr>
<tr>
<td>Adjustment disorder</td>
<td>2</td>
<td>2.2</td>
<td>6</td>
</tr>
<tr>
<td>Anxiety disorder (generalized and NOS)</td>
<td>9</td>
<td>9.7</td>
<td>40</td>
</tr>
<tr>
<td>Depression (NOS) and major depressive disorder</td>
<td>29</td>
<td>31.2</td>
<td>84</td>
</tr>
<tr>
<td>Dysthymic disorder</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>3</td>
<td>3.2</td>
<td>18</td>
</tr>
<tr>
<td>PTSD</td>
<td>83</td>
<td>89.2</td>
<td>165</td>
</tr>
<tr>
<td>Alcohol or substance use disorder</td>
<td>19</td>
<td>20.4</td>
<td>42</td>
</tr>
<tr>
<td>Noncovered conditions</td>
<td>249</td>
<td>67.3</td>
<td>389</td>
</tr>
</tbody>
</table>

SOURCE: RAND analysis of peer-reviewed publications.
NOTES: NOS = not otherwise specified. Subcategory percentages are relative to category count. Because studies may involve more than one outcome category or subcategory, category or subcategory percentages may sum to greater than 100 percent. Noncovered conditions refer to a range of health conditions, including stroke, irritable bowel syndrome, cardiovascular disease, neuropathy, and autoimmune conditions (see Box C.2 for more detail).
Translational Stages

Finally, we classified all publications into the five stages of translational science, as described by the NIEHS Translational Research Framework (Pettibone et al., 2018). The NIEHS framework builds on previous biomedical translational frameworks (Zerhouni, 2007) to describe how ideas and knowledge in the unique context of environmental health research move from one type of evidence to another. It is visualized in a diagram with concentric rings that describe major categories of translation and nodes within the rings that describe research activities (Figure 2.3). Starting from the center and working outward, the translational research stages include Fundamental Questions (purple ring), Application and Synthesis (light blue ring), Implementation and Adjustment (green ring), Practice (dark blue ring), and Public Health Impacts (black ring).

**Figure 2.3. NIEHS Translational Research Framework**

SOURCE: Pettibone et al., 2018.
NOTE: This model of translational research illustrates how ideas and knowledge move from one type of biomedical research to another.
The framework does not imply that research should cover every ring and node of the diagram, nor that it should start at fundamental questions before proceeding to questions on the outer rings. Rather, study of a topic may start on any ring, may skip rings, and may follow a nonlinear path between and within rings and nodes, consistent with the iterative and incremental nature of building an evidence base. Furthermore, although the NIEHS framework labels studies in the outermost ring with the term impact, we define the impact of research more broadly than that: the successful translation of research into any subsequent decisionmaking, including in future research, program planning, policy, and care. In our analyses, we used the following formal definitions of translational research and research impact:

- **Translational research.** The process of turning scientific observations into interventions that improve and enhance the health and well-being of individuals and populations (National Center for Advancing Translational Sciences, 2021).
- **Research impact.** The use of research evidence in subsequent decisionmaking, including in future research, care, planning, and policy.

Figure 2.4 shows that 70 percent of all WTC health-related publications were focused on fundamental questions. Nearly 28 percent were focused on application and synthesis of prior research, implementation and adjustment of a screening or intervention modality, or changes to clinical practice. Finally, approximately 2 percent were designed to examine changes in public health, economic outcomes, clinical outcomes, or environmental exposures.

**Figure 2.4. Types of Translational Research**

Summary

Our scoping review found that research published from 2000 through 2020 addressed a wide variety of WTC-related topics, exposures, and conditions. We also found that WTC health-
related studies were balanced across responder and survivor populations. Although we found concentrations of published research in some of these categories (adults, responders, PTSD, and aerodigestive disorders), we did not find evidence that these concentrations crowded out or excluded commitments to other populations and conditions of interest.

We found a concentration of research in earlier stages of translational science: publications that address fundamental questions about the health effects of 9/11 were far greater in number than those on developing, implementing, measuring, and broadly disseminating health care interventions and programs for Members. This concentration in the innermost ring of the NIEHS framework reflects early Program commitments to document health effects of 9/11 exposures. It should be expected to shift over time toward implementation and adjustment of health interventions and toward advancements in clinical care for Member populations.

Qualitative Impact Assessment

As noted earlier, the use of evidence to support decisionmaking can be seen as an impact of the research, including its use for decisions about care, program planning, and policy. Using findings from stakeholder focus groups and interviews, Program documentation, and gray literature, we found that WTC health-related studies are being used to (1) inform clinical care, (2) guide program planning, priority-setting, and policymaking, and (3) inform future disaster responses. Our analysis—based on manual coding of interview and focus group transcripts (see Appendix G), a systematic search of gray literature (see Appendix H), and machine-learning-enabled coding of gray literature and Program documentation (see Appendix C)—showed that WTC health-related research is being used by several types of end users.

Uses of World Trade Center Health-Related Research (RQ2 and RQ4)

Informing Clinical Care

First, stakeholders pointed to some examples of research that informed Members’ clinical care. One FDNY focus group participant shared that his physician’s expertise on conditions that affect firefighters who responded to the 9/11 attacks is important in his care. Not only does his physician stay up to date on sarcoidosis research, but he also advances the field through his own research, driven by what he sees in his patients. The participant observed,

We were all . . . picked up through the chest x-rays . . . . We do an annual on chest x-ray . . . . And if he didn’t have knowledge of [sarcoidosis], we might still be undiagnosed. So, thank God he was studying. And I don’t remember the numbers of guys that were [affected] prior to 9/11, but it was very little.

Similarly, a clinician-researcher described a study examining obstructive sleep apnea and nasal pathology. The research team hypothesized that high nasal resistance would prevent WTC responders from using continuous positive airway pressure (CPAP) but instead found that the CPAP was helpful in those with nasal congestion and mucosal edema because it seemed to open
their nasal passages. This finding “really informed my clinical practice in terms of actually educating the responders on how nasal congestion symptoms can actually be improved by their CPAP use,” according to an interview participant.

Another clinician-researcher studies the use of online psychotherapy to treat responders and survivors who live too far from one of the Clinical Centers of Excellence (CCEs; U.S. National Library of Medicine, 2021; see Appendix A). If online psychotherapy is found to be effective, it will be made available as a treatment option for PTSD.

Finally, several clinicians observed that research has influenced the clinical care guidelines that each CCE has developed, although they had difficulty identifying concrete examples of links between recent research and those guidelines.

Informing Planning, Prioritization, and Policymaking Within the Program

Program Planning

Research is incorporated into iterative cycles of program planning. Program leaders describe using research findings to “make better decisions in terms of programmatic efforts or clinical procedures or clinical protocols within our unique population.” One Program leader commented that research impacts all of our decisions from staffing to communications or bulletins to the membership . . . . I think about developing our EMR [electronic medical record] . . . to better detect some of the conditions that we’re seeing more often. And looking at the bigger picture with our program, we’ve started to see an uptick in interstitial lung disease. And based on that . . . we recruited an additional pulmonologist.

CCE staff cited examples of using research to “develop programs that will help us better care for our Members,” such as tailoring nutrition programs to reduce inflammation “because we know from our research that inflammation is leading to a lot of these illnesses that they experience.”

Research Prioritization

Program leaders have a foundation for involving stakeholders in research prioritization. Formal and ad hoc advisory bodies, such as the Scientific and Technical Advisory Council (STAC), Survivor Steering Committee (SSC), Responder Steering Committee (RSC), and special sessions and workshops on selected topics (e.g., cognitive dysfunction [Daniels et al., 2021]), have played a critical role in using WTC health-related research to inform future research priorities. To support prioritization, NIOSH tracks the volume of published research that comes out of each CCE and the WTC Health Registry (hereafter Registry) and closely monitors the number of submitted and funded research proposals by topical area (Spencer, 2014).

Tangible examples of stakeholder involvement in research prioritization can be seen in periods prior to the release of Program funding opportunity announcements (FOAs). Figure 2.5 shows the primary stakeholder inputs that have informed Program funding announcements since
the Program’s inception in 2011. With each successive FOA, the Program has solicited and incorporated input on research priorities from an increasing number of stakeholder groups, a practice that is becoming more commonly used across federal agencies and programs. Each stakeholder group has taken a slightly different approach to assessing the research portfolio to inform their input to NIOSH about future research priorities.

The first funding announcement (April 2011) was a Broad Agency Announcement that awarded contracts to establish the initial CCEs and Data Centers.

The second announcement, issued in March 2012 (National Institutes of Health [NIH], 2012), addressed some of the Medical Working Group’s (MWG’s) recommendations but was released only one month after the STAC issued its recommendations. The funding opportunity was broad: It sought research proposals to identify physical and mental health conditions related to the September 2001 terrorist attacks, as well as diagnosis and treatment options for those enrolled in the Program (WTC Health Program, undated a). Specific emphasis was given to studies of biomarkers of exposures or health outcomes, exposure-response relationships, patterns of illness (e.g., by age and gender), risk factors for disease, improvements in diagnosis and treatment, and emerging conditions (NIH, 2012).

In the four years prior to the release of the third FOA in 2016, the STAC and SSC offered ongoing input on research priorities (NIH, 2016; Spencer, 2014). For instance, newly emerging health conditions, the use of biomarkers for early cancer detection, health effects of WTC exposure on children and adolescents, PTSD treatments, and patterns of health care utilization and delivery were all identified as priorities (NIH, 2016). In addition, both organizations issued procedural recommendations to enhance public input into peer review. The third FOA focused on (1) linking WTC exposure to health conditions (particularly, cancer, multisystem and autoimmune disease, cardiovascular disease, neurologic disease, and illnesses among those exposed as children), (2) characterizing and developing care models that address WTC-related diseases and comorbidities, (3) health services research related to disaster-related injury and chronic disease, (4) functional ability and occupational outcomes for WTC-exposed populations, and (5) lessons learned in recovery processes (NIH, 2016; Spencer, 2014).

In the four years prior to the release of the fourth FOA in 2020, several stakeholder communities provided input. The STAC, SSC, and researchers at Program biannual research meetings reviewed research and contributed priorities. The FDNY shared formal recommendations in June 2019, focusing on research involving disease surveillance; early diagnosis, treatment, and efficacy; and mechanisms underlying WTC conditions. For the first time, the Program also published a notice in the Federal Register to solicit public comments on the scope of the funding announcements, a process that the Program has continued (Centers for Disease Control and Prevention [CDC], 2020a; NIH, 2020a; NIH, 2020b; NIH, 2020c).
Figure 2.5. Stakeholder Inputs to Program Funding Announcements (2011 to 2020)

SOURCE: Author analysis of Program documentation.
NOTE: WTCHP = World Trade Center Health Program. This figure shows that the rationale and priorities for the Program’s research mission were established and evolved with a variety of inputs from advisory committees, meetings, and stakeholders over the first ten years of the Program.
To better understand how stakeholders use research to inform future research priorities, we asked focus group participants to list topics they would most like to see emphasized in future research. We found that stakeholders can nominate long lists of potential priorities, yet they can also identify shared criteria for determining which items are at the top of the list. Appendix I shows the results of these discussions, which aligned on some populations and conditions and diverged on others.

Policymaking

Research also played an important role in the policy decision to renew the Program’s funding in 2015. For instance, a 2015 memorandum from the Congressional Committee on Energy and Commerce to the Subcommittee on Health cited data collected and maintained by the Program: “More than 30,000 enrollees have at least one WTC-related health condition, and over 3,600 have a certified cancer . . . . More than 100 firefighters have reportedly lost their lives to WTC-related health conditions” (House Committee on Energy and Commerce Democratic Staff, 2015, p. 6). Similarly, the director of the Rutgers University CCE offered evidence-based testimony in support of reauthorization, citing “research establishing markers for sleep apnea associated with environmental exposures” and describing a patient who, like many others, had benefited from improved diagnosis and treatment of this condition (Udasin, 2016). The Program Administrator also described in his testimony how the Program produces generalizable knowledge by advancing “our national understanding of the long-term health effects of 9/11 . . . [and] helps us better prepare for the medical needs arising from large-scale disasters that might occur in the future” (House Committee on Energy and Commerce, 2015).

Finally, research informs the Program Administrator’s policy decisions regarding which health conditions, screening tests, diagnostic tests, and therapies the Program will cover (Daniels et al., 2021). The STAC contributes to these decisions by “reviewing the scientific and medical evidence and making recommendations to the WTC Program Administrator about eligibility criteria and WTC-related conditions” (CDC, 2020b).

Response to Future Disasters

Program research has helped the United States and several other countries prepare for and respond to other disasters. In the words of a Registry researcher, “Although 9/11 was a unique event, disasters you have all throughout the world, and certain things that we’ve learned here can be generalized as a disaster population.” An FDNY focus group participant had a similar perspective: “It’s really important for similar disasters down the line that we’ve become the advocates for this . . . because of what we went through, it’s going to be important to future generations.” A researcher commented that studying the health effects of 9/11 is “turning tragedy into an opportunity” if it improves preparation for the next major disaster.

To illustrate these points, several examples were offered by focus group and interview participants. Registry participants described a visit from leaders of the Flint, Michigan, water
contamination registry, known as the Flint Registry (Flint Registry, undated), to discuss “operational aspects, policy, lessons learned.” Registry participants also explored with members of the United Kingdom’s National Health Service how to follow up on the health of people who experienced the Grenfell Tower fire in West London. A group from South Korea visited the Registry to learn more about following up on the mental health of those affected by the capsizing in June 2019 of a ferry carrying school children. In 2010, researchers assisted with registry planning after the Deepwater Horizon oil spill. Researchers affiliated with CCEs provided information on respiratory exposures and effects to Australian colleagues grappling with unprecedented wildfires in 2019. Finally, the Registry presented at a 2019 National Academies of Science, Medicine, and Engineering workshop on planning for a registry following a radiological incident (National Academies of Science, Engineering, and Medicine, 2019).

Mixed Methods Impact Assessment: Topical Case Studies of Research Translation

In this section, we address RQ2 and RQ4 in three case studies that trace the translation and impacts of WTC health-related research on depression and anxiety, women’s health, and youth. We apply the NIEHS Translational Research Framework (Figure 2.3) to trace the research and describe its impacts. Integrating several data sources—peer-reviewed publications, gray literature, Program documentation, and insights from focus group and stakeholder interviews held in 2019 and 2020—these case studies demonstrate how research has accrued over time to inform care, Program planning, and policy.

About the NIEHS Translational Research Framework

In the NIEHS framework, translational milestones are research activities and program outcomes that build on past research and program activities; these can be mapped to rings and nodes on the diagram. Translational bridges are links between translational milestones, which can be indicated with arrows connecting rings or nodes to each other. This visualization, which we illustrate in Figures 2.6, 2.7, and 2.8, helps us map how research, policy, and planning connect to one another along different translational pathways. For example, if a study establishes a link between 9/11 exposure and a certain outcome, that is considered a translational milestone in the Fundamental Questions ring of the framework and is denoted in Figures 2.6, 2.7, and 2.8 with a “1” next to the node that most closely describes the study or body of work. In an adaptation of the NIEHS model for this assessment, we take a broader view of impact that does not require a body of research to “reach” the outer Public Health Impacts ring of the framework. Instead, we define any translational bridge as evidence of impact.
**Topic Selection**

In 2021, we published an assessment of the translational research impacts of research on PTSD and cancer (Madrigano et al., 2021). Most PTSD-focused research was concentrated in the Fundamental Questions ring of the NIEHS framework and showed that PTSD is a common outcome of exposure to 9/11. A smaller number of PTSD-focused publications were grouped in the Application and Synthesis ring of the NIEHS framework; these tended to test interventions to treat the condition in different contexts. WTC research on cancer was also concentrated on the Fundamental Questions ring and was associated with downstream changes in individual behavior, policy, and clinical practice.

Building on these earlier case studies, we selected depression and anxiety, women’s health, and youth for the next set of case studies because our scoping review identified a sufficient volume of publications on these topics and because they were identified in focus groups and interviews as high priority. In the case of research involving youth, additional Program documentation was available for review to provide important context for the case study.

We did not select other topics that were of interest to some stakeholders—autoimmune conditions, cognitive outcomes, and cardiovascular disease—because there were not enough publications to support an NIEHS framework analysis. For instance, our scoping review identified a small number of publications focused on autoimmune conditions ($N = 5$) and cognitive outcomes ($N = 6$), as well as a small but recently growing number on cardiovascular disease outcomes ($N = 16$).

**Depression and Anxiety**

Our review of published literature identified 118 publications that focused on WTC-related depression and anxiety, with 31 (26 percent) funded by NIOSH and related programs. Most of this research was focused on linking 9/11 exposures to depression and anxiety symptoms (exposure-outcome linkage studies, $N = 95$, 81 percent). In this case study, we grouped depression and anxiety together because of the frequency with which they co-occur and the overlap in effective treatments (e.g., selective serotonin reuptake inhibitors).

**Translational Milestones in Depression and Anxiety Research**

A substantial proportion of this work answers the question, “Is depression and anxiety associated with exposure to the WTC disaster?” We identify research on this question as translational milestone 1 in the Fundamental Questions ring (see Figure 2.6). A smaller proportion assessed clinical, health services, or policy interventions for mental and behavioral health, with a focus on anxiety and depression (outcome modification studies, $N = 23$, 19 percent). These studies included clinical testing of therapeutic interventions as well as implementation of established practices in the WTC-affected population, represented by translational milestones 2 and 3 in the Implementation and Adjustment and Practice rings of Figure 2.6. Finally, our review identified evidence for population health improvement, both from
an early program (Project Liberty) and from services provided after the establishment of the Program (Bellehsen et al., 2019; Donahue et al., 2006). These publications provide preliminary evidence (indicated with gradient shading) of translational milestone 4 within the Public Health Impacts ring of Figure 2.6. Additional research using more-rigorous designs could strengthen the case for impact.

**Figure 2.6. Translational Milestones and Bridges: Depression and Anxiety**

![Figure 2.6. Translational Milestones and Bridges: Depression and Anxiety](image)

**Source:** Author analysis of peer-reviewed research and stakeholder views on Program research. NOTE: This diagram is adapted from the NIEHS model of translational research, which illustrates how ideas and knowledge move from one type of biomedical research to another (Pettibone et al., 2018). Numbers on the diagram illustrate where major translational milestones were reached for research on depression and anxiety. For instance, “1” denotes research on depression and anxiety achieving translational milestone 1. The black arrow denotes a translational bridge between translational milestone 1 to translational milestone 2. Gradient-shaded nodes indicate where there may be opportunities for new research or practice.

**Translational Bridges in Depression and Anxiety Research**

Much of the literature that examines depression and anxiety symptoms is not focused solely on the appearance of these conditions but rather on the relationships among a broad constellation of related mental health symptoms and conditions. Establishing the co-occurrence of conditions and the links between one health condition and another is an important contribution of this research, as we have noted elsewhere in relation to PTSD (Madrigano et al., 2021). This was described in stakeholder discussions when one stakeholder pointed to FDNY research demonstrating a link between PTSD and depression, saying, “I think that we then developed the ability to show that PTSD was transitioning to depression. . . . and was embraced by NIOSH as well.” Similarly, another stakeholder noted the importance of continuing this line of WTC-related research:
Well, I’ll tell you from a research point of view, there are very few long-term studies that have tracked people across their life course looking at sort of the trajectories of PTSD and depression. And I would love to see that continue because I think—just from pure research, nothing to do with the World Trade Center per se—there’s very little out there.

In sum, there is evidence of research translation from the Program that has contributed knowledge on the etiology and trajectory of WTC-related depression and anxiety over time, as well as clinical and programmatic interventions to treat these conditions. There may be opportunities to continue to build the depth of this evidence base, and the NIEHS framework can be used as a guide to explore additional pathways for research translation.

**Women’s Health**

Our assessment of peer-reviewed literature identified 21 publications that focused on women’s health (e.g., studies involving women participants, which focused on women survivors because of the small number of women responders), with three (14 percent) funded by NIOSH and related programs. About half examined links between exposures and health outcomes (exposure-outcome linkage studies, $N = 10$). Six of these studies focused on mental health conditions, including PTSD and depression, and the remaining publications covered a variety of other physical health conditions, including reproductive health outcomes, fibromyalgia, and DNA damage or change. One publication fell into another class (exposure characterization studies) because it measured exposure levels of benzo[a]pyrene-DNA adducts in maternal blood without independently examining its association with health outcomes.

**Translational Milestones in Women’s Health Research**

We refer to the research on women’s health that answers Fundamental Questions, such as *What are the outcomes of WTC-related exposures in women survivors?*, as translational milestone 1 in Figure 2.7. We use gradient shading to indicate that progress has been made but opportunities remain to both deepen and broaden (to other health outcomes) this body of research. One additional publication, classified within the Application and Synthesis category, reviewed reproductive health outcomes.
The other group of publications on women’s health addressed a program or intervention aimed at modifying health outcomes (outcome modification studies, $N = 9$). These publications described treatment programs and are indicated as translational milestone 2 in Figure 2.7.

Our scoping review identified few publications that focused on physical health conditions affecting women. In a focus group discussion, a researcher said,

One more gap I’d really love to see closed. . . . is that . . . there is no recognition on the part of the World Trade Center Health Program that uterine and endometrial cancers may be linked to 9/11-related exposures. And a number of us can report having phone calls with affected women who just are extremely upset, obviously, that their cancers are not covered and who don’t understand why.

Translational Bridges in Women’s Health Research

A translational bridge connects the body of research in translational milestone 1 to outcome-modification studies in translational milestone 2 (seven of the 11 Fundamental Questions studies were published in 2010 or earlier, and the majority of the Practice studies [$N = 7$] were published in 2011). As with the body of research categorized as Fundamental Questions, the Program can
consider broadening Practice research to other physical health outcomes; thus, we also display this node with gradient shading.

In summary, WTC-related research on women’s health has largely considered Fundamental Questions and issues of Practice, and most of it is focused on behavioral health. Going forward, Program stakeholders could consider examining other physical health conditions that are specific to women, including reproductive health outcomes and certain cancers. The Program can also consider how additional types of studies could provide new avenues for research translation by reviewing the variety of nodes within the NIEHS framework for which research on women’s health has not yet been conducted.

Research Involving Youth

The scoping review identified a substantial number of publications that focused on WTC youth populations, including children exposed to 9/11 in utero, infants, children, and adolescents who were affected by 9/11 directly or indirectly through a parent’s exposure. Overall, 147 such publications have been published, with 31 (21 percent) funded by NIOSH and related programs. Of those, the vast majority focused on linking 9/11 exposures to health conditions (exposure-outcome linkage studies, \( N = 107 \), 73 percent). Two publications assessed chemical exposure (exposure characterization) in this population. Many studies involving minors have focused on birth outcomes, asthma, and neuropsychiatric and behavioral conditions (particularly, PTSD). Research has also investigated a diverse set of outcomes that may be mediated through PTSD, including behavior, attachment, and school functioning. This large body of literature has also led to the publication of several synthesis studies focused on the same topics.

Translational Milestones in Research on Youth

This body of work addresses the question, *What are the health outcomes of WTC-exposed youth survivors?*, which we identify as translational milestone 1 in the Fundamental Questions ring and translational milestone 2 in the Application and Synthesis ring (Figure 2.8).

The remaining articles assessed clinical, health services, or policy interventions for pediatric mental and behavioral health (outcome modification studies, \( N = 38 \), 26 percent). Some (\( N = 5 \), 13 percent) of these studies represented the testing of interventions, included as translational milestone 3 in the Application and Synthesis ring, but half (\( N = 19 \), 50 percent) discussed the implementation of established practices in this population, represented by translational milestone 4 in the Practice ring. A small number of outcome modification studies (\( N = 4 \)) described the implementation of mental health services programs and assessed the utilization and change in trauma symptoms. These publications provide very early evidence (indicated with gradient shading) of translational milestone 5 within the Public Health Impacts ring (Figure 2.8).
Translational Bridges in Research on Youth

We can show how some of this translational pathway unfolded by looking at Program documentation and examining transcripts from our focus groups and interviews. For instance, in 2012 and 2014, the STAC and SSC prioritized research on physical effects and health trajectories among children and adolescents exposed directly or indirectly to 9/11 (Spencer, 2014; WTC Health Program Survivors Steering Committee, 2019). The Program responded by affirming this priority in a February 2016 funding announcement (NIH, 2016). In a June 2016 communication, Program leaders pointed to the successful track record of funding for youth-related proposals among Registry studies (36 percent of proposals in this category were funded by that time) and to $8.4 million of youth-focused research funding, third in volume after adult mental health and respiratory disease (WTC Health Program Scientific/Technical Advisory Committee, 2016).

The SSC has continued to urge the Program to prioritize research on children, young adults, and women. During the SSC’s September 2019 meeting, a stakeholder reiterated the desire to see more research conducted on physical health impacts in youth:

Although children are especially susceptible to harm from environmental exposures, eighteen years after 9/11, we still know very little about the physical health effects of the WTC disaster on the more than 35,000 children living or...
Although there is limited evidence to date, some stakeholders believe the health impacts on youth go beyond those that have been covered in research thus far, such as cardiometabolic and endocrine conditions, cancer, and other developmental trajectories. Our scoping review found a small number of publications that have explored some of these health conditions (e.g., WTC-related chemical exposures and cardiometabolic profiles in children; Koshy et al., 2017; Trasande et al., 2017; Trasande et al., 2018). However, as with most of the potential research priorities for the Program, our focus groups and interviews revealed differences of opinion about how to prioritize this topic.

The same stakeholders who are concerned that the health impacts to children go beyond what has already been studied have also asserted that a WTC young adult study cohort is needed to bring focus to youth-related health conditions and outcomes. In July 2020, in response to advocacy by the SSC, the Registry completed a resource-intensive study of the feasibility of assembling this cohort (Brackbill, 2020). This study concluded, in its publicly available report, that NYC Department of Education directory information was a viable source for locating former 9/11 students but found a low level of interest among those reached by mailed brochures in joining the proposed cohort. Therefore, more-extensive tracing and outreach efforts than those used in the feasibility study would be needed to form an epidemiologically useful cohort. The study also found that the extensive recruitment efforts “did not yield a representative sample, indicating a high likelihood of selection bias in any future recruitment for a children’s cohort” and that the “cost for similarly tracing the entire [New York City Department of Education] directory of 160,000 eligible students was estimated to be $48 million,” (Brackbill, 2020, p. vi).

Taken together, these findings suggest that research involving WTC youth has had substantial impact, particularly for those with respiratory and behavioral health conditions. Some, but not all, stakeholders call for an expansion of research into youth-related health, and a 2020 evaluation report shed light on the feasibility of creating a youth-focused cohort. Ongoing discussions will be needed to chart the best path forward for WTC youth-related health research.

Conclusion

In this chapter, we explain our conceptualization of impact as the use of research to inform decisions about other research, program planning, policy, and care. We show how impact can be visualized as the achievement of translational milestones in the NIEHS framework. Our quantitative, qualitative, and mixed methods assessments found that WTC health-related research is having impact. However, we recognize that aligning stakeholders around the complex concepts of translational research and research impacts will require time and resources, systematic approaches, and extensive planning by the Program. In the next chapter, we describe
the facilitators of and barriers to research translation, which lead to our recommendations in the final chapter on how to strengthen the translation of research into care.
3. Facilitators of and Barriers to Translation of World Trade Center Health-Related Research

In this chapter, we address RQ3, “What are the facilitators of and barriers to translation of WTC health-related research?” Through our analysis of qualitative data (specifically, focus groups, interviews, and Program documentation), we identified factors that support translation of WTC health-related research. We also identified several barriers to its uptake and use. Many of these facilitators and barriers are not unique to the Program; they are common to research funders that support a complex translational research portfolio. We describe them in more detail in the following sections.

Key Findings in This Chapter

Facilitators of translation of WTC health-related research include a focused research mission, research infrastructure, and communication and dissemination of findings.

Barriers to translation include methodological limitations of some research, fragmentation of the health care system, funding constraints, variable definitions of translation, and misaligned expectations about research.

Stakeholders understand the fundamentals of translation and can describe, in their own words, how research is used. However, almost all stakeholders struggled to give a comprehensive definition of translation.

The Program has a strong record of documenting and disseminating Program-funded research, but the range of stakeholder preferences for receiving information about WTC health-related research is broad and presents challenges.

Stakeholders want to know how they can contribute to maximizing the impacts of research, but they need information and guidance to support their involvement in Program planning, policy, and research.

Facilitators of Research Translation

We identified the following facilitators of research translation and use: a focused research mission, infrastructure to support research, and investments in research communication and dissemination.

A Focused Research Mission

The Program’s research mission is to support translational bridges from research to improved clinical care. A commitment to informing care through research is widespread across the research community and is manifested in several ways. First, the mission is emphasized regularly in Program publications, including the Program’s annual “Year in Review” newsletter (WTC Health Program, 2015; WTC Health Program, 2019a). Second, the Program’s support of the CCEs makes the feedback loop between research and care possible: Questions that arise in the
clinic inform research that, ideally, informs care delivered in the clinic. One clinician stakeholder described how he finds it “particularly useful when the patient is sitting in front of me to express how what they are presenting to me integrates with the research program.” He said it is “both reassuring to the individual and then strongly encouraging the individual to continue to participate” in the Program. A researcher with the FDNY articulated a similar view:

I feel that we are not a research group that is just working in some random corner of some institutional building and we throw our papers out into the ether and don’t care what the impact is. We know very clearly that our work is important.

Third, the Program’s clinician-researchers serve as champions of translational research by demonstrating and publishing on how to successfully build translational bridges between research and care. For instance, clinician-researchers routinely generate relevant research questions directly from their experience in the clinical program. When evidence is available, those same clinicians can apply it directly to patient care. They present on their research and care programs at national research meetings. Finally, they advocate to the public and policymakers with data-driven research findings. As a leader of one of the CCEs commented,

you need a champion, you need someone who actually is able to push out and tell the world not just from the point of view of a manuscript or a paper which we do . . . it’s also to tell everybody who we are, what our population is, what our strengths are . . . . And once they see it, they will want to come.

The same CCE leader said that, when speaking to Congress, it is powerful to bring a patient advocate or a patient who’s telling their story and say, look, Mr. Jones or Captain Smith is describing something and look, when we studied X, Y, or Z we found the exact same thing in hundreds, if not thousands, or so.

Firsthand patient stories, supported by data-driven research, are effective motivators for policy change.

Research Infrastructure

The Program’s extensive research infrastructure—including the colocation of clinicians and researchers within CCEs and the collection, management, and analysis of data by the Data Centers and Registry—serves as a facilitator of translation.

CCE-based research and care inform each other directly. Several researchers and CCE representatives who participated in focus groups described institutional mechanisms for researcher and clinician communication. These opportunities range from seminars to ad hoc conversations in hallways. Key to the success of this infrastructure is the colocation of researchers and clinicians so that individuals can share ideas, experience, and knowledge.

The Program supports three Data Centers (at FDNY, NYC Health + Hospitals, and Mount Sinai), another critical research investment. Comprised of data analysts, programmers, biostatisticians, physicians, and epidemiologists, staff at the Data Centers collaborate
with researchers to generate relevant research questions about WTC health consequences, prepare relevant data sets to assist in answering these questions, and consult and advise on data analysis and interpretation (Icahn School of Medicine at Mount Sinai, undated).

The Data Centers are also involved in patient outreach and member education. Since the Data Centers were first formed in 2002 (prior to the formation of the Program), data center–affiliated researchers have produced well over 200 scientific publications (Kubale et al., 2019).

The long-standing relationship between the Registry and CCEs was cited in focus groups as a key facilitator of translating research to care. For instance, one Registry participant said,

> We’ve had good communications . . . with our colleagues and the providers in the clinical programs. We’re just having kind of ongoing discussions. [The providers in the clinical programs] ask us, have you seen anything? And these discussions put topics and potential emerging conditions on our radar screen.

**Program Support for Research Communication and Dissemination**

In focus groups and interviews, researchers and Members identified the importance of tailoring communications about upcoming, current, and completed research to different stakeholders to facilitate its uptake and use. Program stakeholders reported strong, varied preferences about communication channels (e.g., social media) and frequency of contact with the Program. Some FDNY responders wanted frequent contact with the Program and to “know everything” about research within the Program. Youth survivors reported that completing Registry surveys, having their medical monitoring exam, and even receiving newsletters from the Program can trigger intense emotional responses. This distress may hinder participation in research studies and exemplifies one of the distinct challenges the Program faces in its communication efforts (WTC Medical Working Group of New York City, 2011). To address this challenge, NIOSH and the member outreach representatives at each CCE frequently contact Members to ascertain their preferred forms of engagement with the Program.

The Program has placed an increased emphasis in the past few years on using several communication channels and modalities for disseminating research findings to ensure that Members and other Program stakeholders are aware of relevant research, take it up, and use it. Table 3.1 lists some of these activities, which include both in-person dissemination and sharing findings through written products. We elaborate on several of them in this section.
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<td>• Biannual NIOSH-sponsored research grantee meetings in New York City</td>
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**Biannual Research Grantee Meetings**

The Program puts enormous effort into biannual NIOSH-sponsored research grantee meetings in New York City in June and November every year.\(^1\) At these daylong events, which are open to members of the SSC, researchers present their work and engage with others to stay abreast of recent studies. In 2016, NIOSH began asking researchers to focus attention on the ultimate purpose of the work by concluding presentations with impact statements. In particular, researchers are asked to describe the clinical implications of the research, but the statements may also be framed in terms of policy implications, planning implications, and research implications. Examples include the following:

- For a study on mental health symptoms in FDNY responders, a researcher recommended conducting focused outreach to responders who have persistent mental health symptoms, retirees who are at higher risk of depression, responders who arrived early on 9/11, and those with serious chronic conditions (Yip, 2017).
- For a study on pulmonary fibrosis in WTC responders in the Registry, a researcher recommended referring patients for lung transplant evaluation if they met certain criteria (e.g., worsening shortness of breath and/or worsening lung function tests, fibrosis on imaging, or increased oxygen needs; Cone, 2019).
- For a study on head and neck cancers in WTC responders, a researcher recommended that treatments to address risk factors for these types of cancers, such as medications for smoking cessation, be made available to Members (a clinical implication of the research) and that NIOSH explore certification for post 9/11 tobacco use (a policy implication of the research; Graber, 2019).
- For a study on longitudinal changes in PTSD symptoms in WTC survivors, a researcher identified a need for clinical trials to study different modalities of PTSD treatment and the effectiveness of those treatments (Rosen, 2019).

\(^1\) These meetings have been on hold since the start of the coronavirus disease 2019 (COVID-19) pandemic.
Workshops

NIOSH has also organized workshops for WTC researchers and clinicians on focused topics of research and clinical importance. For example, as discussed at an RSC meeting, NIOSH organized a “Cognitive Dysfunction Experts Meeting” in fall 2019 in conjunction with SUNY Stony Brook. Experts in the field, including representatives from CDC and NIH, reviewed the evidence on the impacts of 9/11 on cognitive decline, examined the available science on assessing cognition and neurodegeneration, discussed how the Program could incorporate that research into future medical monitoring of Members, and developed guidelines for “brain healthy” diets and exercises for the Program cohort as it ages (WTC Health Program, 2019c).

The Research to Care Community Engagement Event

In October 2017, the Program convened a well-attended Research to Care Community Engagement event to communicate with stakeholders. This conference, held in New York City on a Saturday to encourage community members to attend, was an opportunity for the Program to highlight the state of knowledge within key topic areas and respond to questions from attendees. Focus group members who attended the event reviewed it positively, appreciated hearing about the Program’s research efforts, and expressed hope that it would be repeated. The agenda and meeting summary show that this event was an opportunity for researchers to present their work, for the community to ask questions during a question-and-answer session, and for the Program to conduct a final session on community wellness (NIOSH, 2017).

Continuing Medical Education/Continuing Education Courses

Nurses, physicians, and allied health professionals must accrue a certain number of continuing medical education/continuing education (CME/CE) credits each year to maintain medical licensing and certification. The Program offers a series of online, self-guided CME/CE modules that share Program research findings with a broad audience of clinicians across the country and describe how they pertain to the screening of and treatment for patients who were affected by the 9/11 attacks (WTC Health Program, 2021b). In their course evaluations, more than 77 percent of the nearly 45,000 health professionals who accessed at least one of the Program courses as of May 2019 said they intended to change their clinical practice because of the information presented, with 50 percent “very committed” to making changes (Hurwitz, 2017). In addition, the 2017 Research to Care Community Engagement event offered attendees continuing medical education credit (Howard et al., 2018).

Peer-Reviewed Publications

Program leaders emphasize the importance of disseminating Program-funded research in the peer-reviewed literature, recognizing that rigorous peer review of the quality of Program research is critical to ensuring it is viewed as valid by end users. NIOSH requires a highly competitive independent scientific review process of all project proposals and closely tracks the research outputs of its Program, with a clear expectation conveyed at the grantee meetings that
researchers will produce peer-reviewed manuscripts in high-impact journals. In the words of a Registry focus group participant,

> When a paper gets published . . . it’s good science, and it stands there in the literature . . . . So I think that’s a key piece of what we do [that allows] people in the outside community that rely on what we do to take it and have some confidence that what we’re putting out has value.

**Member Education Products**

NIOSH’s communication efforts take a variety of forms, such as the Research Gateway website (WTC Health Program, undated a); Registry websites with study information, videos, and researcher profiles; social media; and electronic and print newsletters (Kelly et al., 2007; Webber et al., 2016). Focus group participants had varying levels of familiarity with the Research Gateway. Those who had visited the website appreciated that research was shared in lay language and easily digestible formats, such as short videos. Materials that are distributed to Members are translated into multiple languages and take various formats, such as brochures, fact sheets, and online videos. For example, a fact sheet the Program published in 2017 described recent Program-funded research on sleep disorders; noted the high prevalence of poor sleep in Members caused by obstructive sleep apnea, PTSD, and chronic rhinosinusitis; and provided actionable recommendations for how to improve one’s sleep hygiene (WTC Health Program, undated b). This fact sheet is one of many that draw a direct link between Program-funded studies and specific health-related guidance or related research advances. Recently, the Registry has begun to systematically track web traffic to its website using Webtrends Analytics and tracks Registry enrollee engagement with its electronic newsletter (Webtrends, undated).

**Barriers to Research Translation**

Translating research into tangible impact is not a straightforward task, particularly given the unique context of the Program. The unprecedented attacks on 9/11 generated significant attention early on from policymakers and the general public. For many responders and survivors of the attacks, this event has continued to affect their daily lives for nearly two decades. In this section, we describe stakeholder perspectives from focus groups and interviews on five barriers to research translation: methodological limitations, fragmentation of the U.S. health care system, funding constraints, variable definitions of research translation, and misaligned expectations of research.

**Methodological Limitations**

All health-related research—in any portfolio—is conducted on the data available for study, which may introduce methodological limitations. This common translational challenge affects WTC health-related research, for instance, when information on exposures and affected populations is unavailable, research participants are not representative of broader populations, or
there is no accepted “gold standard” for diagnosis of a potentially WTC-related condition (WTC Medical Working Group of New York City, 2011). To illustrate this point, researchers and Members discussed the limited availability of high-quality environmental sampling data to fully understand the 9/11 exposures. A related, persistent methodological challenge is the issue of controls, and since we have not had controls, it’s extremely difficult to generate the kind of evidence that would be slam dunk and say, “Oh, these are clearly [9/11] associated conditions.” As a result, Registry researchers described the effort that has been necessary to build trust over time in the quality of its research from external researchers. They felt that their efforts had generally succeeded; at first, however, “I think people were skeptical about whether or not the Registry was sufficiently well-designed to actually look at the effects of 9/11.”

**Fragmentation of the Health Care System**

NIOSH and several researchers observed that the fragmentation of the health care system can create barriers to translating research into care. Individuals across the United States who live with multiple chronic health conditions commonly receive care across a fragmented system and from multiple providers. The Program’s structure as a “good neighbor” that takes care of 9/11-associated conditions rather than as a “medical home” that serves as a “one-stop shop” is one type of fragmentation. Program Members may live with multiple conditions, some of which are covered by the Program (and therefore managed in the CCEs) and others that are not. One clinician-researcher shared how, through one of her studies, she was “uncovering very important clinical data” about potential liver dysfunction in her patient, but because it was not certified as a 9/11-associated condition, she had to refer her patient to another provider to confirm the diagnosis and treat the patient. She expressed disappointment that she was not able to translate the findings she uncovered through her research into her care of the patient.

**Funding Constraints**

When asked about prioritizing research topics, many stakeholders commented on the Program’s finite resources. A survivor said that she and others came to realize just how many unanswered research questions there are with respect to 9/11 and health impacts and how challenging it is for researchers to secure funding to conduct important studies. As with any research program, NIOSH leadership must make decisions about the research it will prioritize within existing funding constraints. Although limited resources may present a barrier of sorts to translating research—with more funding, presumably more translation might be possible—a widespread and growing understanding of this constraint could help NIOSH and stakeholders work through prioritization exercises and direct resources to research topics with the most potential to improve health care and outcomes.
Variable Definitions of Research Translation

A Program leader observed that to maximize translational impacts of research, stakeholders must align around a clear answer to the question “What is translation, and how do you actually do it?” However, when asked to explain what translational research means, few Program stakeholders were able to offer a formal or complete definition of this complex concept. Several noted that the traditional definition of translation was the movement of findings from “bench to bedside” but acknowledged that, for their program (with its emphasis on epidemiologic research rather than extensive bench science), that definition felt a bit like “trying to fit a round peg into a square hole.”

Stakeholders described translational research as research that

- “links” scientific findings to “how they affect a member’s life”
- “bridges the gap between descriptive epidemiological studies and empirically-informed interventions”\(^2\) (WTC Health Program, 2017)
- “stack[s] the evidence up . . . and then . . . you can actually apply it to people” or, in the words of another researcher, helps “to get over that sort of research hump in order to have enough supporting documentation” to change practice or policy
- creates a “feedback loop” between questions generated from clinical experience that are studied and used to improve care in the clinic.

Even though Program stakeholders could not offer a clear definition of what translational research is, they readily identified what it should, ideally, do: that it “make[s] some sort of improvement . . . something that will directly benefit the members of the program,” “helps to inform a path forward,” and “saves lives and improves people’s quality of life.” As a NIOSH leader said, “Translation is everything for us.” At the 2017 Research to Care community event, a clinician researcher addressed the 200 Members and their families in attendance with the following description of translational research: “Your care . . . inspires our research, which then helps our treatment” (NIOSH, 2017).

Misaligned Expectations About Program Research

A significant challenge for NIOSH is aligning the often disparate expectations from different stakeholders about what WTC-related research can and should achieve, as well as what the Program could do with better evidence. We identified four types of expectations for WTC health-related research.

Some Members who participated in our focus groups expressed a desire to understand whether their health conditions are linked to 9/11, not only to ascribe a cause and thus make meaning out of their experience but also to qualify for Program benefits. As one survivor said, “I didn’t associate [my health condition] with 9/11 without kind of this idea that there’s other people who have . . . this rare lymphoma out of the residents . . . . You need to know.” Clinician-

\(^2\) Program research principal investigator meeting, New York, November 15–16, 2017.
researchers share in the frustration of not being able to definitively conclude that certain health conditions are linked to 9/11 and then intervene on those conditions: In several focus groups, they took great care to cautiously explain all the caveats related to study design, available data, and the passage of time that prevent them from establishing causal links. Although it is true that some Program research can lead to the addition of covered conditions, the Program’s RTC model emphasizes another purpose: to improve the health of Members.

Some of the expectations fail to appreciate what research can accomplish quickly or at all. Several members pointed to the need for rapid expansions of available treatment options. A NIOSH focus group participant described the challenge of meeting this expectation, lamenting that “the main consumers of the research” are not seeing the fruits of the often long, slow, and frustrating process of building an evidence base to change care delivery. Parents of 9/11 survivors added another expectation: to know what their children “would have been” if the attacks had not occurred. One parent of a child who was exposed on 9/11 made an impassioned plea to study how “this person has changed completely and is somebody other than maybe who they were otherwise meant to be or would have been.” Other Members wanted research to forecast future health effects of 9/11 exposures. With statements such as “It’s only a matter of time” (from a survivor) and “I think we’ve got a tsunami coming” (from a responder), it is clear that many Members strongly desire to know what health conditions may develop for them down the line. A focus group participant from NIOSH described hearing from Members, “What should I be worried about in five years that’s gonna happen to me?” and a CCE leader described this fear as a “Damocles’s sword hanging over their heads.”

Where stakeholders differed was in their views about the feasibility of answering some questions, how they should be answered, and how they should be prioritized, given finite Program resources. If stakeholders have different notions about the purpose, possibilities, and limitations of research, this misalignment leads to understandable frustration when different stakeholders perceive that they are not heard, understood, and responded to. The Program can enhance its efforts to engage stakeholders to overcome these perceptions. It can also provide more-specific information about how (and by whom) Program planning, policy, and research is carried out and how Program stakeholders can contribute to maximizing research impacts.

Conclusion

As with any complex research program, the Program faces barriers to achieving its mission of translating research into improved care for Members. It has invested in several key facilitators of translation, and these serve as a strong foundation on which to build as it looks to continue to maximize the impacts of its research.
4. Synthesis of Findings and Recommendations

Our assessment was designed to support Program planning, not to audit the Program or evaluate whether the Program is “succeeding” according to its legislative mandates. The research questions, findings, and recommendations reflect our intent to support the planning work of the Program and its stakeholders.

In this chapter, we summarize the key findings of this mixed methods study and present four recommendations for NIOSH’s consideration.

Synthesis of Findings

Our analyses resulted in the following key findings, organized by research question.

RQ1: What Topics and Questions Have Been Addressed in WTC Health-Related Research?

- **Finding 1.** WTC health-related research addresses a wide variety of health conditions and is balanced across Member populations.
- **Finding 2.** There is a high concentration of research that addresses fundamental questions about the health effects of 9/11 and a lower concentration of research on health care interventions for affected populations.

RQ2: To What Extent Is WTC Health-Related Research Translational?

- **Finding 3.** Program leaders, researchers, clinicians, and Members understand the fundamentals of translation and can describe, in their own words, how WTC health-related research is used. However, almost all stakeholders struggled to give a comprehensive definition.
- **Finding 4.** The Program has a strong record of documenting and disseminating Program-funded research, but the range of stakeholder preferences for receiving information about WTC health-related research is broad and presents challenges.

RQ3: What Are the Facilitators of and Barriers to Translation of WTC Health-Related Research?

- **Finding 5.** Facilitators of research translation include (1) a focused mission to improve care through research, (2) research infrastructure, such as the colocation of researchers and clinicians at Clinical Centers of Excellence and the collection, management, and analysis of data by the WTC Data Centers and WTC Health Registry, and (3) the communication and dissemination of findings. Barriers to research translation include methodological limitations, fragmentation of the health care system, funding constraints, variable definitions of translation, and misaligned expectations about research.
RQ4: To What Extent Has WTC Health-Related Research Had Impact?

- **Finding 6.** Program research is used in decisions about care, planning, and policy.
- **Finding 7.** Stakeholders want to know how they can contribute to maximizing the impacts of research. Some stakeholders may need information and guidance to support their involvement in Program planning, policy, and research.

These findings serve as the basis for recommendations that NIOSH could implement to reinforce and strengthen the translational impact of Program research.

**Recommendations**

*Conduct Timely, Objective, Continuous Reviews of the Program Research Portfolio*

The Program has already begun to build on existing infrastructure and processes for conducting timely, objective, and continuous reviews of WTC health-related research. As many more publications accrue over time, it becomes both more critical and more complex to take continuous stock of what is being studied. Reviews of this nature provide a starting point for Program planning. Coupled with focused clinical reviews of the state and strength of evidence, systematic collection and review of publication data will help the Program point to new research priorities and allocate its finite resources.

The Program already has a strong foundation for conducting these reviews. For instance, NIOSH is building on the procedures we used to complete this review of nearly 1,000 publications. It has adapted our approach to collecting consistent and comparable data from a wide variety of publications on the software platform DistillerSR (DistillerSR, undated). The Program has also applied these methods to initiate new focused reviews on specific health conditions and populations, including Registry-specific research outputs involving youth (Brackbill, 2020).

Furthermore, the Program has already incorporated interim results from our analysis into its policy and planning work. Our interim analysis, for instance, confirmed Program leaders’ expectations of the need for research on health interventions and care programs. Our analysis provided documentation in support of the 2021 FOA calling for interventional research and a new opportunity solely focused on research involving survivors.

Going forward, the Program can consider other analytic approaches. For instance, the Program should consider adopting the machine-learning algorithms that we applied to the gray literature and Program documentation to routinely search for and abstract text-based data from Program documentation (e.g., annual reports, meeting minutes, policy documents, grant progress reports), gray literature, and peer-reviewed publication excerpts. As one example, impact statements from grant progress reports or presentations at the biannual research grantee meeting could be mined to identify translational accomplishments and nominate new research priorities. The Program can also consider analyses of the connections between related peer-reviewed
manuscripts, including citation trees or more-novel and more-user-friendly tools, such as Connected Papers, a website that creates visually appealing graphs that arrange manuscripts according to their similarity (Connected Papers, undated). The Program could conduct qualitative research to better understand how the Program’s translational bridges are formed and milestones are achieved and what it could do to further support those processes. Finally, the Program could explore the utility of integrating this qualitative research on translational bridges with quantitative data, such as Altmetric Attention Scores and other online engagement metrics (Altmetric, undated), to paint a more complete picture of how research moves along various translational pathways.

Gather Input from Stakeholders on a Novel Translational Research Framework

Research translation is a complex and challenging concept for the field as a whole and can be even more challenging when discussed in abstract terms. Through nearly two dozen interviews with stakeholders, it was clear that Program leaders, clinicians, and other end users of research understand the major elements of research translation but use variable terminology to describe it. Most referred to examples to describe their sense of research translation, and few could offer a comprehensive definition. A Program leader said,

Translational research is going from the clinic—you make an observation—you have to go to the lab and figure out where is that biological or mechanistic correlation to that observation, and then back to the clinic.

Another said, “Translation is everything for us,” but knowing clearly what it is and how to do it is not straightforward. We learned through focus groups and interviews that stakeholders have strongly held and differing opinions about future directions for the Program, which further complicates the challenge of embracing research translation. A shared language is critical to get all stakeholders—policymakers, program planners, researchers, and Members—to move in the same direction in pursuit of the Program’s research mission.

To formalize the process of translating research evidence, we believe that a systematic approach that is grounded in a tested framework is needed. The Program can continue to facilitate important discussions about translation by working to explore and establish shared terminology and aligned expectations regarding research impacts. Through a more systematic process, debates about how to achieve the research mission can become even more productive, decisions about how to get there may become clearer, and those decisions can be more effectively communicated to various internal and external Program stakeholders.

We identified the NIEHS framework as a promising model for describing and assessing research translation in the environmental health context. In Chapter 2, we demonstrated how this framework could be used to map nonlinear translational pathways that research and practice may follow. We showed in three case studies how research contributes to health impacts. The NIEHS framework introduces such concepts as “translational bridges,” which connect research studies, policy, planning, and clinical care. This terminology could help the Program describe critical
milestones in the evolution of Program care. Finally, this framework could help NIOSH highlight gaps where future research might be prioritized.

The Program endorsed our work on these case studies and has recognized the approach as promising, but the NIEHS framework is still novel. It is not yet fully tested in the Program context. For this reason, we recommend that NIOSH disseminate the NIEHS framework broadly through multiple communication channels and gather stakeholder input on it. The purpose of gathering stakeholder input is to understand how it should be adapted to the Program context and how it could be used most effectively in program activities.

**Pilot the Translational Framework in Four Key Activities of the Research Program:**

**Research Planning, Monitoring, Evaluation, and Communication About Research Impacts**

The NIEHS framework includes a taxonomy of translational research terms and definitions that can be leveraged to support research planning, monitoring, evaluation, and communication activities. We recommend that NIOSH use the framework in some or all of these activities to help inform how it can be effectively used to support Program-sponsored research.

The Program currently commits some of its resources to rigorous research portfolio management. Program leaders can use the framework to actively manage translational bridges and maximize the direct impacts of research. NIEHS offers tools and resources to help programs apply this framework to their research portfolios (NIEHS, 2019). For instance, the Program could pilot the NIEHS framework to develop illustrations and examples of the “translational pathways” that a portfolio of research can take. On key topics of interest to Program stakeholders, these illustrations could demonstrate the paths that research translation does follow, could follow, or should follow. Once those pathways are articulated, the Program can develop resources that help clinicians and researchers share information about evolving research needs and emerging findings, understand what to do with that information (e.g., update clinical guidelines, plan cross-CCE implementation research), and delineate who is responsible for what steps in the process of moving research along different translational pathways. These are all potential actions the Program could take to more actively, and more proactively, manage translational bridges.

NIOSH and Program stakeholders might work together to develop case studies of translation, such as those presented in Chapter 2, and use them to inform future research. Applications of the framework can inform future directions for a specific health condition or population by identifying translational bridges. Well-trodden translational bridges may develop within a program for many reasons, including the existence of champions, research infrastructure, and experience, which are some of the same facilitators of translation that the Program has been successful at using in the past (see Chapter 3 for more on the Program’s facilitators of translation).
The framework offers a common language by which the Program can communicate with diverse stakeholder communities, both within the Program and externally, about complex ideas. NIOSH can also use terminology and concepts in the framework to monitor, evaluate, and communicate about a body of research as it accumulates on a particular topic. It can assist as Program planners and policymakers assess the real and potential translational impacts of research. It can also assist as stakeholders communicate with each other about the contributions that individual studies make to the body of evidence on a topic (NIEHS, 2018).

**Reinforce and Strengthen the Program’s Structured Processes for Research Stakeholder Engagement**

Stakeholder engagement is the “meaningful involvement of patients, caregivers, clinicians and other healthcare stakeholders throughout the entire research process—from planning a study and establishing the research question, to conducting the study and disseminating results” (Forsythe et al., 2018). Over the past decade, the Program has also devoted an increasing amount of resources to the involvement of its research stakeholders in policy, planning, and clinical care decisions (see Figure 2.5). Efforts to engage stakeholders could be strengthened by broadening the Program’s routine contacts with a wider range of stakeholder representatives and by adopting formal processes for research-planning and priority-setting.

An important consideration, for instance, is whether individuals who engage with the Program are fully representative of the diversity of populations within researcher and Member communities. Attention to equity, diversity, and inclusion is expanding across the health sector and is an important focus for routine assessment and improvement in any program of engagement. Therefore, we observe that the Program may benefit from instituting routine checks to ensure the representation of the many voices that should be involved.

Key to the notion of meaningful engagement is the involvement of stakeholders across the entire research lifecycle, from planning research, to conducting research, to using it in communications and decisionmaking. An examination of the Program’s efforts to use established engagement frameworks and guidance will help illuminate new engagement activities and resources that can aid research program activities. Well-established guidance on stakeholder engagement shows research leaders how to develop a structured engagement plan across the research life cycle.

A stakeholder engagement planning matrix can be developed to structure an approach that is tailored to the Program (see Table 4.1). The cells of Table 4.1 present examples of activities to convene several stakeholder communities (in columns) as advisers or experts to inform research and program activities (in rows). The examples provided in this table are offered as illustrations only; the main benefit of an engagement planning matrix is to show how every community can be represented in engagement activities across the life cycle of research (Concannon et al., 2019). As the plan takes shape, the Program might share and revise it after consultation with stakeholders about how they would like to be involved. Once completed, the matrix will
facilitate a critical appraisal of the Program’s engagement activities by providing a quick overview of its critical elements: stakeholders, program and research activities, and engagement activities.
Table 4.1. Stakeholder Engagement Planning Matrix

<table>
<thead>
<tr>
<th>Life Cycle of Research</th>
<th>Example Research Program Activities</th>
<th>Stakeholder Community and Stakeholder Activity</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Survivors</td>
</tr>
<tr>
<td>Preparing for research (program level)</td>
<td>Building research capacity</td>
<td>Example: Peer-led training in research methods.</td>
</tr>
<tr>
<td></td>
<td>Refining research topics</td>
<td>Example: A moderated multistakeholder expert panel reviews and refines potential research proposals in response to an FOA.</td>
</tr>
<tr>
<td>Conducting research (research project level)</td>
<td>Defining research questions</td>
<td>Example: A research team convenes an advisory panel to assist in developing its Program research application.</td>
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<tr>
<td></td>
<td>Choosing relevant outcomes</td>
<td></td>
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<tr>
<td></td>
<td>Designing a research protocol</td>
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<tr>
<td></td>
<td>Drafting or revising study materials</td>
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<td></td>
<td>Recruiting participants</td>
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<tr>
<td></td>
<td>Collecting and analyzing data</td>
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<tr>
<td></td>
<td>Identifying results</td>
<td>Example: A research team convenes an advisory panel to review data and findings of research.</td>
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<tr>
<td></td>
<td>Interpreting findings</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disseminating evidence</td>
<td>Example: Research briefs are codeveloped by representatives of these audiences for these same audiences.</td>
</tr>
<tr>
<td>Life Cycle of Research</td>
<td>Example Research Program Activities</td>
<td>Stakeholder Community and Stakeholder Activity</td>
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<tr>
<td>------------------------</td>
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<td>---------------------------------------------</td>
</tr>
<tr>
<td>Using research (program or research project level)</td>
<td>Informing clinical care</td>
<td>Example: Research to Care community events are held to review care implications of recent intervention studies.</td>
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<tr>
<td></td>
<td>Conducting briefings and advocacy</td>
<td></td>
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<tr>
<td></td>
<td>Informing decisions about one’s health</td>
<td>Example: Research case studies using the NIEHS framework are codeveloped by researchers and the Program.</td>
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<tr>
<td></td>
<td>Guiding future research</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Responding to future disasters</td>
<td></td>
</tr>
</tbody>
</table>

**SOURCE:** Adapted from Concannon et al., 2019.

**NOTES:** Both program-level and research project–level activities (in rows) can be informed and supported by the engagement of stakeholders (in columns). Filling all cells in this matrix is not necessary; by starting the plan with a long list of program activities and a complete list of stakeholders, we do not mean to imply that all program activities require engagement, nor that every stakeholder community must be included in all activities.
Limitations

This study had a few limitations. First, in the scoping review, we included articles published up to and including October 31, 2020, and excluded conference abstracts. Consequently, this review did not capture research that was presented in conferences but not published, nor did it capture new research that was completed after October 2020. Also, because of this review’s large scope (consisting of nearly 1,000 publications), it covers a variety of populations and conditions. The scope and heterogeneity prevented a focused look within population and condition groups for summary effect estimates or strength of evidence assessments. Finally, as with all scoping reviews, some data items may be subject to misclassification.

Second, in qualitative data collection and analysis, we were unable to disentangle the degree to which certain stakeholders or views are overrepresented or underrepresented. We sought to examine the full range of stakeholder views on a given topic, but the qualitative findings may not be generalizable. As in all qualitative research, the views expressed by the stakeholders in this report (who, for the most part, are affiliated in some way with the Program) are opinions that may or may not be factually accurate.

Third, the search strategy we used to find gray literature involved a novel but unvalidated use of several search engines. As with the other qualitative data sources used in this report, the goal of examining gray literature was to ensure that no significant views of stakeholders were missed. Relatedly, the machine-learning algorithm we used to identify relevant text passages in the gray literature was developed and trained on manually coded data from focus group transcripts and therefore should be interpreted as an extension of those findings.

Finally, the NIEHS framework, although a promising way of examining a body of research, is novel and may need extensive testing and validation. It is unknown whether this framework on its own can capture all the distinctiveness and complexities of the Program’s research activities.

Conclusion

More than 20 years after the attacks on 9/11, the Program continues to carry out its focused research mission: to improve health care and outcomes of its Members. In support of this mission, the Program engages in ongoing planning activities that are grounded in rigorous assessments of existing research and future needs. This report is intended to support NIOSH in program-planning activities by critically examining the past decade of Program-supported research and looking ahead to the near- and longer-term research activities of the Program.
Appendix A. About the World Trade Center Health Program

Background

The James Zadroga 9/11 Health and Compensation Act was passed in 2010 and extended in 2015 to 2090. It amends the Public Health Service Act to provide services for individuals who were directly affected by the 9/11 terrorist attacks. Commonly called the Zadroga Act, it established the Program within the Department of Health and Human Services and designated NIOSH as the Program Administrator. This legislation defines six main activities for the Program: evaluation, medical monitoring, follow-up monitoring and treatment, education and outreach for eligible individuals, collection and analysis of physical and mental health data, and research on health conditions resulting from the attacks (Pub. L. 111-347, 2011). NIOSH is responsible for the general functioning of the Program, including reporting to Congress, reimbursing treatment costs, and providing scientific support for the Program’s decisions regarding coverage eligibility.

Structure of the Program

CCEs, funded by the Program, are authorized to provide medical monitoring evaluations and diagnostic and treatment services for qualifying conditions. Members who live outside of the metropolitan New York City area can access care for their 9/11-related conditions through the National Provider Network, which is a network of credentialed providers from different specialties. Data Centers collect, maintain, and analyze data from standardized assessments in a uniform and quality manner, receive and analyze health care claims data, provide annual health surveillance reports, conduct analyses for Program operational support and improvement, and supply approved data sets to NIOSH-funded researchers upon request. These Data Centers are the FDNY Data Center (for fire department responders), the Mount Sinai School of Medicine (for general responders), and the NYC Health + Hospitals (for survivors).

The Registry is an important source of information for Program-funded research (City of New York, undated). Under the auspices of the NYC Department of Health and Mental Hygiene, the Registry is an ongoing epidemiological cohort study that was established in 2002. The largest registry in the history of the United States to follow the health effects of a disaster, it includes waves of surveys conducted approximately every three years, with the fifth and most recent wave conducted in 2020–2021. There are 71,431 people in the cohort who had direct exposures on 9/11 or in the aftermath, including rescue and recovery workers, survivors, and around 2,000 children (City of New York, undated).
Research Advisory Groups

Several Program research advisory groups advise research activities. These include the STAC (which is made up of experts selected by the Program Administrator), the SSC, the RSC, and the MWG, including representatives from the FDNY and New York Police Department.

According to the Zadroga Act, NIOSH must investigate conditions with diagnostic or treatment uncertainty by gathering expert consensus and supporting ongoing research into conditions that may be related to the WTC attacks. The Zadroga Act directed NIOSH to establish the Program STAC to advise NIOSH on these decisions. The Program Administrator is responsible for screening and appointing experts to the STAC who have relevant expertise. STAC members, who serve three-year terms, review evidence related to health conditions that are potentially related to the 9/11 attacks, make recommendations for new health conditions deemed to be WTC-related, and identify research needs for the Program (WTC Health Program, 2019d).

The RSC and SSC collect input from stakeholders and coordinate the initial health evaluations, monitoring, and treatment for their respective stakeholders. The MWG disbanded in 2011 but previously reviewed clinical and research findings on the health effects of WTC exposure, reviewed the health services available, and acted as an adviser to the city government.

Program Stakeholders

The Program identifies three categories of stakeholders in Program-supported research: the funder (NIOSH), researchers, and research users. Figure A.1 depicts the relationship between the three stakeholder groups as a triangle connecting the funder, researchers, and research users.

Figure A.1. Triad of Program Stakeholders

![Triad of Program Stakeholders](image)

Each major category of stakeholders makes valuable contributions to the direction of the Program. Members of these groups were invited to participate in the qualitative part of our assessment (Table A.1).
Table A.1. Representatives of Each of the Major Stakeholder Types

<table>
<thead>
<tr>
<th>Stakeholder Types</th>
<th>Representatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funder</td>
<td>NIOSH program staff</td>
</tr>
<tr>
<td>Researchers</td>
<td>Principal investigators of studies funded by NIOSH</td>
</tr>
<tr>
<td></td>
<td>Registry researchers</td>
</tr>
<tr>
<td></td>
<td>Data scientists at WTC Health Program Data Centers</td>
</tr>
<tr>
<td>Research Users</td>
<td>Members and representatives of Member communities, such as advocacy organizations that are external to the Program</td>
</tr>
<tr>
<td></td>
<td>Clinicians caring for Members through the FDNY Responder Health Program, the CCEs, and the NYC Health and Hospitals System WTC Environmental Health Center</td>
</tr>
<tr>
<td></td>
<td>Health system leadership</td>
</tr>
<tr>
<td></td>
<td>Policymakers (state, local, and federal [WTC Health Program science team, CDC, other federal agencies])</td>
</tr>
</tbody>
</table>
Appendix B. Research Questions

Table B.1 shows the research questions and subquestions that we codeveloped with NIOSH to guide this study, mapped to the data sources used to address them. As the assessment progressed, and with NIOSH’s input, we refined the guiding research questions to ensure they were relevant to supporting the planning work of the Program and its stakeholders, as follows:

1. What topics and questions have been or will be addressed in WTC health-related research?
2. To what extent is WTC health-related research translational?
3. What are the facilitators of and barriers to translation of WTC health-related research?
4. To what extent has WTC health-related research had impact?
Table B.1. Research Questions and Data Sources

<table>
<thead>
<tr>
<th>Domain</th>
<th>Evaluation Question</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inventory assessment (Program-funded</td>
<td>What topics and questions have been or will be addressed in WTC health-related research?</td>
<td>NIOSH-generated data: In-progress research</td>
</tr>
<tr>
<td>and other WTC health-related research)</td>
<td></td>
<td>NIOSH generated data: documentation including</td>
</tr>
<tr>
<td></td>
<td></td>
<td>FOAs, principal investigator progress reports</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NIOSH-generated data: Program inventory of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>published research</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NIOSH-generated data: About the researchers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Members, other stakeholders (STAC minutes, R2C meeting, etc.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Independent data: peer-reviewed literature</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Independent data: gray literature</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Independent data: in-progress research (NIH reporter)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Primary data collection: stakeholder views (focus groups and interviews)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other (political context?) Zadroga act and any rule-making documentation</td>
</tr>
</tbody>
</table>

<p>|                                                                 | X | X | X | X | X | X | X | X | X |
| Of those, which have been funded by the Program?                  | X | X |   |   |   |   | X | X |
| Of those funded by the Program, which are in the pipeline?        | X | X |   |   |   |   | X |   |
| Of those funded by the Program, what entities or groups proposed them? | X | X |   |   |   |   | X | X |
| To what extent does Program-funded research address the priorities of the Program? | X | X |   |   |   |   | X | X |
| What are the gaps in WTC health-related research?                 | X | X |   |   |   |   | X | X | X |</p>
<table>
<thead>
<tr>
<th>Domain</th>
<th>Evaluation Question</th>
<th>Data Source</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Process evaluation</strong></td>
<td>To what extent is Program-related research translational?</td>
<td><em>NIOSH</em>-generated data: in-progress research documentation including FOAs, principal investigator progress reports</td>
</tr>
<tr>
<td></td>
<td>Does the research identify the stakeholders it seeks to inform?</td>
<td><em>NIOSH</em>-generated data: Program inventory of published research</td>
</tr>
<tr>
<td></td>
<td>Does the research describe stakeholder decisions it seeks to inform?</td>
<td><em>NIOSH</em>-generated data: About the researchers</td>
</tr>
<tr>
<td></td>
<td>Does the research establish evidence needed to support the decisions?</td>
<td><em>Independent data: peer-reviewed literature</em></td>
</tr>
<tr>
<td></td>
<td>Does the research present a plan for taking next steps?</td>
<td><em>Independent data: gray literature</em></td>
</tr>
<tr>
<td></td>
<td>To what extent does the research address each step of the Program’s RTC model?</td>
<td><em>Independent data: in-progress research (NIH reporter)</em></td>
</tr>
<tr>
<td></td>
<td>What are the facilitators of and barriers to successful translation of Program-funded research?</td>
<td><em>Primary data collection: stakeholder views (focus groups and interviews)</em></td>
</tr>
<tr>
<td></td>
<td>To what extent are the Program’s RTC model and stakeholders’ views on translational research aligned?</td>
<td><em>Other (political context?) Zadroga act and any rule-making documentation</em></td>
</tr>
<tr>
<td></td>
<td>What RTC inputs and other factors facilitate research translation?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do any RTC inputs fail to facilitate research translation?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>What factors are barriers to research translation?</td>
<td></td>
</tr>
<tr>
<td>Domain</td>
<td>Evaluation Question</td>
<td>Data Source</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Impact evaluation (Program-funded research only)</td>
<td>To what extent has Program-funded research had impact?</td>
<td>NIOSH-generated data: in-progress research documentation including FOAs, principal investigator progress reports</td>
</tr>
<tr>
<td></td>
<td>To what extent do stakeholders describe the research as relevant to the decisions they make? Which stakeholders and what decisions?</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>To what extent is the research transparent to stakeholders?</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>To what extent is the research useful to WTC stakeholders?</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Have research priorities changed as a result of the research? If so, how?</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Has WTC health care changed as a result of the research? If so, how?</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Has WTC population health been affected as a result of the research? If so, how?</td>
<td>X</td>
</tr>
</tbody>
</table>
Appendix C. Methods

Overview

This appendix presents our approach to quantitative and qualitative data collection and analysis for the scoping review, as well as our approach to qualitative data collection, coding, and synthesis of themes emerging from coded data. In this appendix, we also describe our approach to integrating quantitative and qualitative findings through the development of case studies of research impact.

Research Question Development and Refinement

The purpose of our assessment was to support Program planning, not to audit the Program or evaluate whether the Program is “succeeding” according to its legislative mandates.

In the first year of the project, the RAND project team and NIOSH codeveloped a priori research questions to guide this four-year effort. The research questions reflect our intent to support the planning work of the Program and its stakeholders.

The research questions, each with a set of associated subquestions, underwent multiple rounds of refinement. After NIOSH’s approval, the final step involved mapping these research questions to the various data sources that would be used to address them (Appendix B). As data collection and analysis progressed, the project team and NIOSH discussed on an ongoing basis which subquestions were most relevant to the Program and most feasible to answer, given available data.

Data Collection and Processing

We used five data sources for the quantitative and qualitative portions of our mixed methods analysis: (1) peer-reviewed publications through October 31, 2020, (2) Program documentation of research activities through February 2021, (3) transcripts of 12 structured focus group discussions with responders, survivors, Program leaders, clinicians and others that were conducted from December 2019 through February 2020, (4) transcripts of individual stakeholder interviews with Program leaders, researchers, clinicians, and others that were conducted in October and November 2020, and (5) gray literature publications through November 30, 2020, that cite or refer to WTC health-related research. These five data sources support our overall evaluation by incorporating perspectives of Program leaders, Members, and other stakeholders on the body of WTC health-related research included in our scoping review.
Data Source 1: Peer-Reviewed Publications

We used systematic methods to complete a scoping review of WTC health-related research (Arksey and O’Malley, 2005; Levac, Colquhoun, and O’Brien, 2010; Cooper et al., 2021). According to the methods prescribed by Arksey, 2005, and updated by Levac, 2010, and Cooper, 2021, scoping reviews can be seen as following several major steps: (1) identifying research questions (Appendix C, “Research Question Development and Refinement”), (2) identifying relevant publications using formal search methods (Appendix C, “Record Search”), (3) selecting publications using formal screening criteria (Appendix C, “Title, Abstract, and Full-Text Screening and Inclusion”), (4) charting data through quantitative and qualitative sorting and evaluating (Appendix C, “Full-Text Review”), and (5) collating, summarizing, and reporting the results (Chapter 2, “Impacts of World Trade Center Health-Related Research”).

Record Search

We used a systematic search strategy to find records in databases of peer-reviewed publications and gray literature. We grouped search terms into the following four hierarchical statements and adapted these statements to different databases:

- terms related to the terrorist attacks on September 11, 2001
- terms related to the numerical date (i.e., 9/11) and the type of disaster
- terms related to the NYC and New Jersey locations and the type of disaster
- terms related to the Shanksville, Pennsylvania, and Pentagon locations and the type of disaster.

A full list of search terms is presented in Appendixes C (peer-reviewed publications) and D (gray literature publications).

To find records of peer-reviewed publications, we searched six databases using terms relevant to the September 11, 2001, attacks. Using the four statements described in this section and in Appendix D, we searched titles, abstracts, and keywords in OVID MEDLINE, Psychinfo, Scopus, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Embase for records of peer-reviewed articles, books, book chapters, conference abstracts, and dissertations. We performed a validation step by comparing our peer-reviewed search results with two Program publication resources: Summary of World Trade Center Health Program Research: NIOSH Research Compendium (Kubale et al., 2018) and a Program publications EndNote Library (Clarivate Analytics, 2019). We reviewed and adjudicated any differences between our search results and these lists of pertinent publications.

Title, Abstract and Full-Text Screening and Inclusion

The next stage of the review was a screen of titles, abstracts, and full-text documents against predefined exclusion criteria. Records were excluded if they were (1) not in English, (2) not research, (3) not about the 9/11 attacks, (4) not about 9/11 populations, or (5) not relevant to health conditions, care, or outcomes. Titles and abstracts collected during the record search were
screened first. Records that passed sequentially through all five screens were included in the abstraction process described below. Those that did not pass the screening were excluded, and the first reason for exclusion was recorded. Records that were deemed uncertain proceeded to the full-text screening. Full-text articles were obtained, and the screening process was repeated until every record was determined to be eligible or ineligible for inclusion in the review. We reference-mined NIOSH’s Research Compendium (Kubale et al., 2019), EndNote Library (Clarivate Analytics, 2019), and a more recent publication entitled Research Related to Children (WTC Health Program, 2019b) to add publications to the final review. The results of the screening process are reported in the Preferred Items for Reporting on Systematic Reviews and Meta-Analyses (PRISMA) flowchart in Figure 2.1 (Liberati et al., 2009).

Full-Text Review

To guide the abstraction of data from peer-reviewed publications, we developed (in collaboration with NIOSH) a standardized data abstraction form covering the topics shown in Box C.1. Appendix E provides more detail on these topics by presenting an expanded version of this list of topics. Article identifying information was gathered from our search database when possible and from abstractions when not. Type of study is a classification we developed for this project. It is designed to assign every study into one and only one of three classes: exposure characterization, exposure-outcome linkage, or outcome modification. These terms are defined below and in the glossary. Items collected in the study content section were taken from PICOTSS and PECOTSS frameworks (Box C.2; Matchar, 2012). PECOTSS is the environmental equivalent of the Agency for Healthcare Research and Quality’s PICOTSS expansion of the PICO framework, which was developed for evaluations that focus on clinical interventions rather than exposures (Matchar, 2012). Type of evidence is a classification that uses three frameworks for translational science: the Tufts Clinical and Translational Science Institute (CTSI) Six Types of Evidence Framework (Selker et al., 2010), NIH Translational Science Framework (Zerhouni, 2007), and NIEHS Translational Research Framework for Environmental Health Sciences (Pettibone et al., 2018). Free-text capture includes open-ended response options that describe the studies’ objectives, findings, implications, limitations, and an “other” category used throughout the form.
Box C.1. Topics Covered in the Data Abstraction Form

<table>
<thead>
<tr>
<th>Article Identifying Information and Content</th>
<th>Types of Evidence and Translation</th>
<th>Free-Text Capture</th>
</tr>
</thead>
<tbody>
<tr>
<td>Authors and author affiliations</td>
<td>Tufts CTSI Six Types of Evidence Model</td>
<td>Study objectives</td>
</tr>
<tr>
<td>Title, abstract, journal, date of publication, and other citation data</td>
<td>NIEHS Translational Research Framework</td>
<td>Findings</td>
</tr>
<tr>
<td>Funder(s): NIOSH and related, non-NIOSH</td>
<td>NIH Translational Science Spectrum</td>
<td>Implications</td>
</tr>
<tr>
<td>Keywords</td>
<td></td>
<td>Limitations</td>
</tr>
<tr>
<td>Type of study: exposure characterization, exposure-outcome linkage, outcome modification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study content (PICOTSS/PECOTSS)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ultimately, 34 major abstraction items were derived from this list and included in a query form. The query form was coded into DistillerSR as a survey tool with drop-down, numeric-text, and free-text response options (which we did not report on in this analysis). A team of eight reviewers double-reviewed publications and abstracted data. The study leadership team adjudicated reviews.

**Study-Level Data**

To facilitate comparison across similar studies, we classified publications into three study types. *Exposure characterization studies* describe physical or chemical stressors in the environment. *Exposure-outcome linkage studies* examine associations between one or more exposures and health outcomes (including mental health). *Outcome modification studies* examine characteristics or impacts of one or more health-related interventions and may include clinical research, health services research, implementation science, or policy analysis.

Every publication was also tagged for two types of funding: (1) NIOSH and related programs or (2) other funders, including other federal agencies, foundations, or self-funded. Publications that did not report a source of funding were classified in the latter group.

We described characteristics of exposure characterization and exposure-outcome linkage studies using the PECOTSS framework and characteristics of outcome modification studies using the PICOTSS framework. To support program planning about where research has been concentrated to date and where it might be concentrated in the future, we applied several translational science frameworks for visualizing the entire body of evidence at a glance.
Box C.2. PI/ECOTSS Classifications

Populations
- **WTC survivors**: Minors (under age 18): Born before 9/11 and exposed on 9/11, born before 9/11 and parent was exposed on 9/11, in utero on 9/11. Adult survivors: non-elderly (18 to 65 years old), elderly (over age 65), men, women, pregnant women.
- **NYC responders**: First responders (e.g., FDNY and related personnel). General responders (e.g., law enforcement: WTC rescue, recovery, and cleanup workers).
- **Pentagon responders**: Shanksville, Pennsylvania, responders

Interventions
- Clinical: Screening or testing, treatment, or clinical management
- Health services
- Health policy

Exposures
- **9/11-related chemical hazard**: Persistent organic pollutants, such as polychlorinated dibenzodioxins (PCDDs), polybrominated dibenzodioxins (PBDDs), polychlorinated dibenzofurans (PCDFs), polychlorinated naphthalenes (PCNs), and polychlorinated biphenyls (PCBs)
- Group 2. Polycyclic aromatic hydrocarbons (PAHs) or other organic compounds not in Group 1 (other volatile organic compounds, benzene)
- Group 3. Metals (aluminum, cadmium, chromium, iron, lead, nickel, or titanium)
- Group 4. Other inorganics, such as radionuclides, silica, or asbestos
- Group 5. Gross particulate matter: dust, glass fragments, quarts grains, wood fibers, or other general debris
- Group 6. Any other agent not listed in Groups 1–5
- **Other 9/11-related hazard**: Cold stress, heat stress, musculoskeletal injury from fall or event, bloodborne pathogens, present in WTC building on 9/11, caught in dust cloud on 9/11, present in NYC WTC area, present in Shanksville, present at the Pentagon, other (free text)

Outcomes
- **Covered physical conditions**: Acute traumatic injury: Burn, complex sprain, eye injury, fracture, head trauma, tendon tear, other similar acute traumatic injuries. Cancer: Any cancer (cancer type not specified); blood and lymphoid tissue, digestive system, eye and orbit, female breast, female reproductive organs, head and neck, respiratory system, skin (melanoma and nonmelanoma), soft tissue, thyroid, urinary system, mesothelioma, other rare cancers
- **Musculoskeletal conditions**: Carpal tunnel syndrome, low back pain, other musculoskeletal disorders.
- **Aerodigestive disorders**: Asthma, chronic cough syndrome, chronic laryngitis, chronic nasopharyngitis, chronic respiratory disorder due to fumes/vapors, chronic rhinosinusitis, gastroesophageal reflux disorder (GERD), interstitial lung disease (e.g., sarcoidosis), reactive airways dysfunction syndrome (RADS), sleep apnea exacerbated by or related to another condition in the list of aerodigestive disorders, upper airway hyperreactivity, WTC-exacerbated chronic obstructive pulmonary disease (COPD)
- **Covered neuropsychiatric conditions**: Acute stress disorder, adjustment disorder, anxiety disorder (NOS), depression (NOS), major depressive disorder, dysthyemic disorder, generalized anxiety disorder, panic disorder, PTSD, alcohol or substance use disorder
- **Other conditions**: Stroke, irritable bowel syndrome, cardiovascular disease (e.g., hypertension, atherosclerosis), dementia, Parkinson's disease and Parkinsonism, neuropathy, autoimmune conditions (e.g., rheumatoid arthritis, multiple sclerosis, systemic lupus erythematosus), biliary cirrhosis

Intervention comparators: other treatment, another dose or duration of same treatment, usual care, placebo

Exposure comparators: unexposed, another level or duration of exposure

Time: Intervention, exposure, and follow-up time

Settings: Inpatient, ambulatory/outpatient, emergency department, post-acute care or skilled nursing facility, laboratory, community (free text), other (free text)

Study design
- Randomization: sampling, treatment assignment
- Data characteristics: prospective, longitudinal, use of validated measures
- Data type: administrative, clinical, research, population registry, or environmental monitoring data
An important dimension of research assessment is the type of evidence being produced. Type-of-evidence classifications help to understand how and by whom the study is meant to be deployed in practice. By grouping a body of evidence into a classification model, one can quickly see the concentration of types and intended uses of the studies that have been published.

We applied two frameworks for classifying evidence by type: the Tufts CTSI Six Types of Evidence Framework (Selker et al., 2010), and the NIEHS Translational Research Framework for Environmental Health Sciences (Pettibone et al., 2018). These are described in more detail below.

These models were selected and applied to 9/11 health-related research to show what types of evidence the Program and its stakeholders have, according to several different models for visualizing a body of research. Their selection does not imply an evaluation standard: for instance, that WTC evidence should equally cover every evidence type from prioritization to dissemination or every stage of translation from basic science through policy analysis. As described in one model, “[W]e stress that any specific translational research story may start in any translational category, may skip categories, and will likely follow a complex path from start to finish” (Pettibone et al., 2018). The Program and its stakeholders can use these visualizations to see the Program’s whole body of evidence at a glance and judge for themselves where research has been concentrated to date and where it might be concentrated in the future.

The Six Types of Evidence Framework presents a sequential flow of six types of evidence, described further in Box C.3. Evidence prioritization supports decisions on what to study next; evidence generation is the production of new evidence through new studies; evidence synthesis summarizes previously published studies in a single estimate; evidence integration includes simulations in which new studies and syntheses have left gaps; evidence dissemination and application shows how to deliver new information to patients, clinicians, and other stakeholders; and feedback and assessment is research on the processes and impacts of previous research (Selker et al., 2010). Each type of evidence may be developed through research.

The NIEHS Translational Research Framework, described further in Chapter 2, classifies environmental health research into five question types: fundamental questions, application and synthesis, implementation and adjustment, practice, and impact. Within each question type, four to six disciplines of research describe the approach or approaches used to answer the question. This framework thus depicts a nonlinear pathway in which the translation of research may be lateral across disciplines or directional through question types (Pettibone et al., 2018).

We assigned each peer-reviewed publication into one of the five question types. The result of our classification is visualized in Figure 2.4, an adaptation of the illustration developed by NIEHS to describe this framework (Figure 2.3).
Tufts CTSI Six Types of Evidence Model—Exposure Characterization, Exposure-Outcome Linkage, and Outcome Modification Studies (Selker et al., 2010)

- **Evidence prioritization**: A systematic process that uses prespecified criteria to prioritize or determine the most important evidence needed by patients, providers, and other decisionmakers to make informed choices about health interventions and strategies.

- **Evidence generation**: The creation of information that can help patients, providers, and other health decisionmakers compare the benefits and harms of various interventions and strategies for preventing, diagnosing, treating, and monitoring health conditions in real-world settings.

- **Evidence synthesis**: The process of systematically reviewing, evaluating, and integrating research evidence (related terms include systematic review, meta-analysis, research synthesis, and pooling).

- **Evidence interpretation/integration**: The processes of conducting cost-effective analysis and decision analysis of research evidence to specify the options, identify important outcomes, determine the chances of harm and benefit, evaluate the quality of studies, integrate the evidence, and report on clinically meaningful results.

- **Dissemination and application**: The active distribution of research findings to real-world settings that may include adopting into clinical practice, informing practice guidelines, influencing health policy, and teaching research subjects and the general public.

- **Feedback and assessment**: The process of assessing how well a research goal was met, often for the purpose of improving research.

NIEHS Translational Research Framework (Pettibone, 2018)

- **Fundamental questions**: The biological processes of how our bodies function and of the pathways and systems that are susceptible to the effects of environmental stressors. Examples include identification, observation, and understanding of these processes and systems.

- **Application and synthesis**: Experiments in a structured and predictable setting to gain deeper understanding of a process or particular effect. Examples include pilot tests of interventions, methods and approaches, new tools (e.g., exposure sensors), and other highly controlled settings. Also, the formal synthesis or integration of evidence from previous research to inform future research, risk assessment, and other decisionmaking.

- **Implementation and adjustment**: Implementing hypotheses in real-world settings and adjusting the product (intervention, tool, method, treatment, etc.) to account for differences in settings and populations. Examples include biomarker, screen, or assay validation; clinical testing; tool validation and use; and effectiveness testing. Much of the current work in dissemination and implementation science falls into this category.

- **Practice**: Moving established ideas into common practice to effect change among a broader population.

- **Impact**: Assessing the broader environmental, clinical, or public health impact of a practice, guideline, or policy.

**Free-Text Capture and Analysis of “Other” Response Options**

Several of the elements in the query form allowed reviewers to enter a brief free-text response to identify the intervention type in outcome modification studies and to elaborate on the “other” response option when selecting health conditions or outcomes reported in the publication. We performed a thematic analysis of these free-text options, creating a categorization scheme that we iteratively refined as we reviewed each free-text entry. The items include

- intervention types under the categories of screening or testing, treatment or management, or other interventions intended to modify outcomes
- health conditions and other outcomes used in exposure-outcome linkage studies that were not classified as covered or petitioned health conditions
• health conditions and other outcomes used in outcome modification studies that were not classified as covered or petitioned health conditions.

The query form also directed reviewers to copy and paste the entire relevant text for four data elements as shown in Box C.1. These include study objective(s), main finding(s), limitations, and implications of the research. These extensive free-text fields will be analyzed in the future using natural-language processing (if on a large number of articles) and/or manual qualitative coding (if for a focused deep dive) to draw conclusions about how researchers are communicating the objectives, findings, and implications of their research. RQ1 and RQ2 ("What topics and questions have been or will be addressed in WTC health-related research?" and "To what extent is Program-related research translational?") guided this analysis. The analysis of stated limitations in this report also shed light on the challenges of doing this type of study, which help to answer RQ3: “What are the facilitators of and barriers to successful translation of Program-funded research?”

Data Source 2: Program Documentation of Research Activities

We completed a thematic content analysis of Program research-related documentation. The analysis focused on documents published by the Program, including FOAs, a Request for Information published in the Federal Register, a searchable 370-page NIOSH-developed evidence report linking research abstracts to key milestones in the Program’s history (such as enabling legislation, recommendations, and budgets), Program records of clinicians who attended training courses for continuing medical education purposes and their course evaluations, logs of visits to the Registry’s website, and meeting transcripts and recommendations from the STAC, SSC, and RSC.

As with the focus groups, the analytic approach consisted of three steps: codebook development, coding, and analysis. First, we developed a preliminary codebook with definitions based on the scoping review of Program research and expert input from the study team, expert advisers, and study sponsors. The codebook included both substantive codes related to perceptions of Program research and descriptive codes related to research topics and activities conducted by the Program.

The second step involved an initial round of coding by one researcher of a randomly selected subset of each category of Program documents. The purpose of this initial round was to test and improve the appropriateness of the preliminary codebook and identify the need for additional documentation. The preliminary codebook was refined on the basis of these findings and again compared with the focus group codebook to ensure alignment.

The final phase entailed a complete round of coding using the revised codebook. Analytic tables were developed to present excerpted text relating to each code and organized into groups of codes related to each a priori research question guiding the assessment. Excerpts from the analytic tables were integrated with focus group data, developed into emerging themes, and supplemented with relevant excerpts from the gray literature, described below.
Data Source 3: Focus Groups with Program Stakeholders

From December 2019 through February 2020, we led 12 focus group discussions that explored several topics related to Program research. Focus groups discussions were held by web-enabled teleconference with nine categories of stakeholders:

- NIOSH staff
- general responders
- FDNY responders
- survivors (two groups)
- individuals who represented the views of their broader responder or survivor community
- CCE leadership
- two focus groups of CCE staff (e.g., clinicians, outreach coordinators)
- Registry researchers
- two focus groups of NIOSH-funded researchers.

Discussions were held in-person in the NYC area with Program Members, consisting of one session with FDNY responders, one with other first responders, one with survivors and community members, and one with survivors and community members who were parents or youth under age 18 on 9/11.

A total of 88 individuals attended the 12 focus groups. The median focus group size was 7.5 participants, with a range of three to ten. Of the 64 participants who responded to a brief post-focus group survey and provided demographic information, 34 (53 percent) were female and 58 (91 percent) were non-Hispanic; six of 63 (9.5 percent) participants who provided information on their race were Asian, two (3 percent) were African American, and 55 (87 percent) were white.

Focus groups were co-moderated and followed a semi-structured discussion guide that covered questions about the Program research mission, research priorities, use and translation of research, and dissemination and communication of research. The Office of Management and Budget (OMB) package for the focus group data collection activity can be found online (OMB, undated b). All questions were open-ended and included follow-up probes. Discussions lasted two hours and were audio recorded and transcribed by a professional transcription service.

Transcripts were de-identified by the research team and uploaded into the qualitative data management program Dedoose. The transcripts were then coded using a detailed codebook (Appendix G) by two researchers with expertise in qualitative data analysis. We used the focus group discussion guide, which was based on our research questions, to develop a priori codes. This codebook was developed in parallel with another codebook for Program documentation, described below. The two were frequently compared to ensure similar data would be collected for eventual integration. As coding progressed, we used an inductive approach to add subcodes (i.e., smaller categories of data) within the larger a priori codes.

Each researcher coded three transcripts independently and met with the other to compare their application of the codebook. The researchers divided up the remaining transcripts, coded...
independently, and met to discuss and refine the codebook. If changes were made, the previously coded transcripts were re-reviewed with the new codebook.

**Data Source 4: Interviews with Program Stakeholders**

From October 15 to November 30, 2020, we led 20 in-depth interviews held by web-enabled teleconference with the same nine categories of stakeholders as in the focus groups. Interviews were moderated by one researcher (with participation by another) and, as with the focus groups, followed a semistructured discussion guide that covered questions about the Program research mission, research priorities, use and translation of research, and dissemination and communication of research. The OMB package for the interview data collection activity can be found online (OMB, undated a). All questions were open-ended and included follow-up probes. Discussions lasted up to one hour and were audio recorded and transcribed by a professional transcription service.

As with the focus groups, transcripts were de-identified by the research team and uploaded into Dedoose. The transcripts were then coded using a detailed codebook by two researchers. Using the same procedure as the focus groups, we used the interview discussion guide, which was intended to delve deeper into topics of interest from the focus groups, to develop a priori codes. As coding progressed, we used an inductive approach to add subcodes (i.e., smaller categories of data) within the larger a priori codes.

Each researcher coded their assigned transcripts independently and met with the other to compare their application of the codebook. As coding progressed, the researchers met to discuss and refine the codebook. If changes were made, the previously coded transcripts were re-reviewed with the new codebook.

**Data Source 5: Gray Literature**

We used gray literature to further assess and develop themes that emerged from the focus group, interview, and Program documentation analyses.

**Search Strategy**

To find records of gray literature, we applied the same strategy, with minor modifications (Appendix H), to search Google, the Homeland Security Digital Library (Homeland Security Digital Library, undated), GovInfo (GovInfo, undated), and Think Tank Search, a custom search engine of more than 1,200 think tanks and research centers that is maintained by the Harvard Kennedy School (Harvard Kennedy School, 2021). In Google, we carried out three searches, two with limits to domain type (.org and .gov) and one without domain limits. Within each search, results were ranked according to order of appearance. Searches across all domains were combined, and lower-ranked duplicates were removed. Keyword searches using 9/11-related terms were performed on titles, descriptions, and web addresses of the unduplicated Google
results. The 9/11-related terms included WTC, World Trade, September 11, Sept. 11, 9/11, 9-11, ground zero, and tower.

Combined, these searches resulted in a total of 2,986 documents. They include documents from such entities as federal agencies (e.g., U.S. Government Accountability Office), city agencies (NYC Department of Health and Mental Hygiene), Congress (transcripts of committee hearings), and community organizations, as well as numerous news articles, magazine articles, and blog posts. The text content of web-based documents was extracted using an HTML parser. We used the content analysis toolkit Apache Tika to collect metadata from each PDF document and to collect machine-readable text from each PDF document page (Apache Software Foundation, 2019).

Analysis of Gray Literature

We used a machine-learning algorithm to apply a list of 190 codes to the 2,986 gray literature documents, as follows:

- 22 codes from the focus group codebook
- 14 codes from both the focus group and the Program documentation codebooks
- 32 codes from the interview codebook
- 89 from the Program documentation analysis
- 20 codes that were a composite of the other codes above
- 11 codes relating to text content and topics that only applied to the gray literature review.

We used these codes to identify relevant excerpts from the gray literature through automated text extraction. Because gray literature represents a large volume of data, the machine-learning algorithm allowed us to identify documents and pages that were relevant to prespecified topics regarding the health impacts of the 9/11 attacks and Program research translation. Two team members manually coded a sample of the more than 8,000 pages of gray literature text. These manual coding results, together with the manually coded text from the focus group transcripts and Program documents, were then used to train a machine-learning algorithm to code the remaining gray literature text (more than 613,000 pages total).

We applied a natural language processing and machine-learning algorithm, starting with manually coded pages, to code the full set of gray literature documents, using an approach developed for a similar text coding effort in a prior RAND project (Mendel et al., 2021). To do this, we extracted all text from each page and each manually coded text excerpt from the focus group transcripts, Program documentation, and gray literature documents. This text was then processed using a “bag of words” natural language processing approach, in which each page is transformed into a list of commonly used words and two-word phrases, with each word or phrase assigned a value based on the number of times that it shows up on that page (Sebastiani, 2002).

The manual coding results associated with each manually coded text excerpt, together with the list of words and phrases associated with each excerpt, were then used to train a machine-learning model. We followed a supervised classification approach similar to that in other text
classification efforts, in which manual coding results are used as “gold standard” data to train and validate machine-learning models (Mendel et al., 2021; Villani et al., 2018; Wilczyniski et al., 2004). The machine-learning model then assigned a classification score for each code and each page, representing the degree to which that page’s text resembled the text of other pages that a human reviewer had determined was relevant to that code. This model was trained and run five times on different samples of the manually trained data, following a stratified K-fold cross-validation approach (Kohavi, 1995).

We applied this algorithm to both the gray literature and the set of Program research-related documents, including documents that previously underwent the thematic content analysis described above. The algorithm was thus trained to reproduce, to the best of its ability, the same manual coding of text that was undertaken in the focus group transcripts and Program documentation reviews. We then manually reviewed the text passages coded by the algorithm as relevant to particular topics of interest to integrate their content with the other sources of data used in this analysis.

Data Integration and Mixed Methods Analysis

The goal of this mixed methods analysis was to integrate, throughout the project life cycle, the five data sources to answer the primary research questions and the associated subquestions shown in Appendix B: what has been studied about the links between 9/11 and health; to what extent is WTC health-related research translational; what facilitates and hinders translation of research into improved care; and what has been the impact of WTC-related research, with a focus on publications funded by the Program?

As described above, we abstracted data using a standardized abstraction form from the nearly 1,000 articles in our scoping review as the primary data source to determine what has been studied. We tagged articles in our review with the clinical conditions and populations that were the focus of the articles. By coding these same conditions and populations in the qualitative data (focus group and interview transcripts, Program documentation and gray literature), we were able to integrate findings from multiple data sources across the same condition or population of interest (e.g., WTC youth, PTSD), using the research questions as a guide. For instance, to address subquestions about the extent to which the research portfolio addresses the priorities of Program stakeholders and to what extent there are (perceived) gaps, we combined stakeholder views from focus groups and interviews with scoping review findings about topics that had been studied to date.

For the second main research question, about the facilitators (and, by extension, barriers) of research translation, we relied mostly on qualitative data. After codebooks were applied to each qualitative data source, the team integrated these data sources and conducted thematic analysis in several steps. We first sorted the excerpted data from focus groups, interviews, and Program documentation into tables by code and subcode to facilitate comparisons across data sources. The
compatibility of focus group, interview, and Program documentation codebooks facilitated their integration as we examined these data for discussions of the facilitators and barriers of translation (as well as for comments on the research portfolio and its impact). Next, we deductively identified themes, or concepts that describe patterns in the data. Then, excerpts from the gray literature were reviewed, compared with results from the other qualitative data sources, and sorted into those same themes. The research team also selected illustrative quotations that best conveyed their meaning.

For the final main research question on impact, we inductively processed excerpted data from the focus groups, interviews, Program documentation, and gray literature into emergent themes that identified examples of, and facilitators of, impact, which were grouped and split until a concise set of qualitative impacts (uses of research) and facilitators were identified that captured the most-salient challenges and opportunities facing the Program with respect to its translational research mission.

The themes that emerged through this mixed methods analysis illustrate critical opportunities for the Program to build on its past successes and overcome current and future challenges as it aims to maximize the impact of its research. These challenges are not unique to the Program; rather, they are common to all translational research. These themes served as the basis for our key findings and recommendations to NIOSH, in which we aimed to translate our thematic findings into actionable information.

Case Studies of Research Translation

We selected three topics to explore in a series of case studies on research translation: research involving depression and anxiety, women’s health, and WTC-exposed youth. We applied the NIEHS Translational Research Framework to describe how research on these topics proceeded through various translational steps and connected directly to Program planning and policy. As detailed in Chapter 2, translational steps are depicted in this framework on five “rings” corresponding to different kinds of research questions (fundamental questions, application and synthesis, implementation and adjustment, practice, or impact) and to several “nodes” on each ring that correspond to different types of research. Following steps laid out by NIEHS to guide the use of this framework (NIEHS, undated), we identified translational milestones by showing transitions across these rings and nodes over time.

First, we mapped each previously published peer-reviewed study and Program research-related document onto one translational ring and one node on that ring. Second, a timeline was created to describe how and when movement occurred within or between translational rings and nodes of the framework. Third, some Program research-related documentation and gray literature (e.g., legislation, covered condition determinations) were reviewed to find evidence of research translation into planning and policy. Finally, we reviewed all focus group transcripts related to the three case study topic areas (cancer, PTSD, youth) and extracted relevant excerpts. This final step allowed us to incorporate the perspectives of a variety of stakeholders and context.

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These three case studies build on a previously published article in which we applied the NIEHS Translational Research Framework to case studies of cancer and PTSD in the WTC context (Madrigano et al., 2021).
Appendix D. Scoping Review: Search Strategy for Peer-Reviewed Publications

**OVID MEDLINE**
Limit to 2001-October 31, 2020

**Statement #1: Common References to the Attack**
("world trade center" OR wtc OR (sep* adj1"11") OR (sep* adj1"11th") OR “ground zero”).ti,ab,kf.

**Statement #2: Numerical Date and Disaster Terms**
NUMERICAL DATE TERMS: “9/11”.ti,ab,kf.
HOMICIDE TERMS: (terror* OR attack* OR catastrophe* OR disaster* OR crash* OR (building* adj3 collaps*) OR (tower* adj3 collaps*) OR (building* adj3 burn*) OR (tower* adj3 burn*) OR (building* adj3 fire*) OR (tower* adj3 fire*) OR plane* OR airplane* OR jet* OR aircraft* OR burn* OR crash* OR hijack*).ti,ab,kf.

**Statement #3: NYC & NJ Location and Disaster Terms**
NYC & NJ LOCATION TERMS: ("new york" OR NY OR NYC OR “new jersey” OR NJ OR “lower Manhattan”).ti,ab,kf.
HOMICIDE TERMS: (terror* OR attack* OR catastrophe* OR disaster* OR crash* OR (building* adj3 collaps*) OR (tower* adj3 collaps*) OR (building* adj3 burn*) OR (tower* adj3 burn*) OR (building* adj3 fire*) OR (tower* adj3 fire*) OR plane* OR airplane* OR jet* OR aircraft* OR “twin tower*” OR hijack*).ti,ab,kf.

**Statement #4: Shanksville & Pentagon Locations and Disaster Terms**
SHANKSVILLE & PENTAGON LOCATION TERMS: (Shanksville OR “somerset county” OR stonycreek OR pentagon OR “Washington DC” OR “Washington D.C.” OR “district of Columbia” OR Arlington).ti,ab,kf.
HOMICIDE TERMS: (terror* OR attack* OR catastrophe* OR disaster* OR crash* OR (building* adj3 collaps*) OR (tower* adj3 collaps*) OR (building* adj3 burn*) OR (tower* adj3 burn*) OR (building* adj3 fire*) OR (tower* adj3 fire*) OR plane* OR airplane* OR jet* OR aircraft* OR “twin tower*” OR hijack*).ti,ab,kf.

**PSYCINFO**
Limit to 2001-October 31, 2020 phrase searching

**Statement #1: Common References to the Attack**
TI “world trade center” OR AB “world trade center” OR KW “world trade center” OR TI “wtc” OR AB “wtc” OR KW “wtc” OR TI(sep* N1 11) OR AB(sep* N1 11) OR KW(sep* N1 11) OR TI(sep* N1 11th) OR AB(sep* N1 11th) OR KW(sep* N1 11th) OR TI “ground zero” OR AB “ground zero” OR KW “ground zero”

**Statement #2: Numerical Date and Disaster Terms**
NUMERICAL DATE TERMS: TI 9/11 OR AB 9/11 OR KW 9/11
HOMICIDE TERMS: TI terror* OR AB terror* KW terror* OR TI attack* OR AB attack* OR KW attack* OR TI catastroph* OR AB catastroph* OR KW catastroph* OR TI disaster* OR AB disaster* OR KW disaster* OR TI collapse* OR AB collapse* OR KW collapse* OR TI tower* OR AB tower* OR KW tower* OR TI building* OR AB building* OR KW building* OR TI fire* OR AB fire* OR KW fire* OR TI plane* OR AB plane* OR KW plane* OR TI airplane* OR KW airplane* OR TI jet* OR AB jet* OR KW jet* OR TI aircraft* OR AB aircraft* OR aircraft* OR TI burn* OR AB burn* OR KW burn* OR TI crash* OR AB crash* OR KW crash* OR TI hijack* OR AB hijack* OR KW hijack*

**Statement #3: NYC & NJ Location and Disaster Terms**
HOMICIDE TERMS: TI terror* OR AB terror* KW terror* OR TI attack* OR AB attack* OR KW attack* OR TI catastroph* OR AB catastroph* OR KW catastroph* OR TI disaster* OR AB disaster* OR KW disaster* OR TI collapse* OR AB collapse* OR KW collapse* OR TI tower* OR AB tower* OR KW tower* OR TI building* OR AB building* OR KW building* OR TI fire* OR AB fire* OR KW fire* OR TI plane* OR AB plane* OR KW plane* OR TI airplane* OR
CINAHL
Limit to 2001-October 31, 2020; phrase searching; exclude medline records

Statement #1: Common References to the Attack
TI “world trade center” OR AB “world trade center” OR MW “world trade center” OR TI “wtc” OR AB “wtc” OR MW “world trade center” OR TI(sep* N1 11) OR AB(sep* N1 11) OR MW(sep* N1 11) OR TI(sep* N1 11th) OR AB(sep* N1 11th) OR MW(sep* N1 11th) OR TI “ground zero” OR AB “ground zero” OR MW “ground zero”

Statement #2: Numerical Date and Disaster Terms
NUMERICAL DATE TERMS: TI 9/11 OR AB 9/11 OR MW 9/11
DISASTER TERMS: TI terror* OR AB terror* OR MW terror* OR TI attack* OR AB attack* OR MW attack* OR TI catastrophe* OR AB catastrophe* OR MW catastrophe* OR TI disaster* OR AB disaster* OR MW disaster OR TI collaps* OR AB collaps* OR MW collaps* OR TI tower* OR AB tower* OR MW tower OR TI building* OR AB building* OR MW building* OR TI fire* OR AB fire* OR MW fire* OR TI plane* OR AB plane* OR MW plane* OR TI airplane* OR AB airplane* OR MW airplane* OR TI jet* OR AB jet* OR MW jet* OR TI aircraft* OR AB aircraft* OR MW aircraft* OR AB “twin tower” OR AB “twin tower” OR MW “twin tower” OR TI hijack* OR AB hijack* OR MW hijack*

Statement #3: NYC & NJ Location and Disaster Terms
NYC & NJ LOCATION TERMS: TI “New York” OR AB “New York” MW “new York” OR TI NY OR AB NY OR MW NY OR TI “New Jersey” OR AB “New Jersey” OR MW “new jersey” OR TI NJ OR AB NJ MW NJ OR TI “lower Manhattan” OR AB “Lower Manhattan” OR MW “lower Manhattan”
DISASTER TERMS: TI terror* OR AB terror* OR MW terror* OR TI attack* OR AB attack* OR MW attack* OR TI catastrophe* OR AB catastrophe* OR MW catastrophe* OR TI disaster* OR AB disaster* OR MW disaster OR TI collaps* OR AB collaps* OR MW collaps* OR TI tower* OR AB tower* OR MW tower OR TI building* OR AB building* OR MW building* OR TI fire* OR AB fire* OR MW fire* OR TI plane* OR AB plane* OR MW plane* OR TI airplane* OR AB airplane* OR MW airplane* OR TI jet* OR AB jet* OR MW jet* OR TI aircraft* OR AB aircraft* OR MW aircraft* OR AB “twin tower” OR AB “twin tower” OR MW “twin tower” OR TI hijack* OR AB hijack* OR MW hijack*

Statement #4: Shanksville & Pentagon Locations and Disaster Terms
SHANKSVILLE & PENTAGON LOCATION TERMS: TI Shanksville OR AB Shanksville OR MW Shanksville OR TI Stony creek OR AB stonycreek OR MW Stony creek OR TI pentagon OR AB pentagon OR MW pentagon OR TI “Washington DC” OR AB “Washington DC” OR MW “Washington DC” OR TI “Washington D.C.” OR AB
DISASTER TERMS: T1 terror* OR AB terror* OR MW terror* OR TI attack* OR AB attack* OR MW attack* OR TI catastrophe* OR AB catastrophe* OR MW catastrophe* OR TI disaster* OR AB disaster* OR MW disaster* OR TI crash* OR AB crash* OR MW crash* OR TI(building N3 collaps*) OR AB(building N3 collaps*) OR MW(building N3 collaps*) OR TI(tower N3 collaps*) OR AB(tower N3 collaps*) OR MW(tower N3 collaps*) OR TI(building N3 burn*) OR AB(building N3 burn*) OR MW(building N3 burn*) OR TI(tower N3 burn*) OR AB(tower N3 burn*) OR MW(tower N3 burn*) OR TI(building N3 fire*) OR AB(building N3 fire*) OR MW(building N3 fire*) OR TI(tower N3 fire*) OR AB(tower N3 fire*) OR MW(tower N3 fire*) OR TI plane* OR AB plane* OR MW plane* OR TI airplane* OR AB airplane* OR MW airplane* OR TI jet* OR AB jet* OR MW jet* OR TI aircraft* OR AB aircraft* OR MW aircraft* OR AB “twin tower” OR AB “twin tower” OR MW “twin tower” OR TI hijack* OR AB hijack* OR MW hijack*

SCOPUS
Limit 2001-October 31, 2020

Statement #1: Common References to the Attack


Statement #2: Numerical Date and Disaster Terms

NUMERICAL DATE TERM: TITLE-ABS-KEY(“9/11”)

DISASTER TERMS: TITLE-ABS-KEY (terror* OR attack* OR catastrophe* OR disaster* OR collaps* OR tower* OR building* OR fire* OR plane* OR airplane* OR jet* OR aircraft* OR burn* OR crash* OR hijack*) OR ABS(terror* OR attack* OR catastrophe* OR disaster* OR collaps* OR tower* OR building* OR fire* OR plane* OR airplane* OR jet* OR aircraft* OR burn* OR crash* OR hijack*) AND (EXCLUDE (SUBJAREA, “SOCI”) OR EXCLUDE (SUBJAREA, “ENGI”) OR EXCLUDE (SUBJAREA, “ARTS”) OR EXCLUDE (SUBJAREA, “COMP”) OR EXCLUDE (SUBJAREA, “EART”) OR EXCLUDE (SUBJAREA, “MATE”) OR EXCLUDE (SUBJAREA, “PHYS”) OR EXCLUDE (SUBJAREA, “AGRI”) OR EXCLUDE (SUBJAREA, “CENG”) OR EXCLUDE (SUBJAREA, “ENER”) OR EXCLUDE (SUBJAREA, “MATH”) OR EXCLUDE (SUBJAREA, “CHEM”) OR EXCLUDE (SUBJAREA, “VETE”) OR EXCLUDE (SUBJAREA, “Undefined”)) AND (EXCLUDE (SRCTYPE, “Undefined”))

Statement #3: NYC & NJ Location and Disaster Terms


DISASTER TERMS: TITLE-ABS-KEY (terror* OR attack* OR catastrophe* OR disaster* OR crash* OR plane* OR airplane* OR jet* OR aircraft* OR “twin tower”* OR hijack*) OR TERROR-ABS-KEY (building w/3 collaps*) OR TITLE-ABS-KEY (building w/3 collaps*) OR TERROR-ABS-KEY (building w/3 burn*) OR TITLE-ABS-KEY (tower* w/3 burn*) OR TITLE-ABS-KEY (building w/3 fire*) OR TITLE-ABS-KEY (tower* w/3 fire*)

Statement #4: Shanksville & Pentagon Locations and Disaster Terms

OR EXCLUDE (SUBJAREA, "VETE") OR EXCLUDE (SUBJAREA, "Undefined")) AND (LIMIT-TO (DOCTYPE, "cp"))

DISASTER TERMS: TITLE-ABS-KEY (terror* OR attack* OR catastrophe* OR disaster* OR crash* OR plane* OR airplane* OR jet* OR aircraft* OR “twin tower*” OR hijack*) OR TITLE-ABS-KEY (building w/3 collaps*) OR TITLE-ABS-KEY (tower* w/3 collaps*) OR TITLE-ABS-KEY (building* w/3 burn*) OR TITLE-ABS-KEY (tower* w/3 burn*) OR TITLE-ABS-KEY (building* w/3 fire*) OR TITLE-ABS-KEY (tower* w/3 fire*)

WEB OF SCIENCE
Limit to 2001-October 31, 2020
Indexes=SCI-EXPANDED, CPCI-SSH, BKCI-S, IC, Timespan=2001-2020

(notes: remove WTC from statement #1, changed Sep* to Sept*)

Statement #1: Common References to the Attack
TS=("world trade center") OR TS=(sept* NEAR/0 11) OR TS=(sept* NEAR/0 11th) OR TS="(ground zero")
Exclude: RESEARCH AREAS: (PLANT SCIENCES OR ENGINEERING OR REMOTE SENSING OR COMPUTER SCIENCE OR ZOOLOGY OR MARINE FRESHWATER BIOLOGY OR HISTORY PHILOSOPHY OF SCIENCE OR ASTRONOMY ASTROPHYSICS OR EDUCATION EDUCATIONAL RESEARCH OR AGRICULTURE OR MATERIALS SCIENCE OR PHYSICAL GEOGRAPHY OR ENERGY FUELS OR FOOD SCIENCE TECHNOLOGY OR CONSTRUCTION BUILDING TECHNOLOGY OR SCIENCE TECHNOLOGY OTHER TOPICS OR MATHEMATICAL METHODS IN SOCIAL SCIENCES OR NUCLEAR SCIENCE TECHNOLOGY OR INFORMATION SCIENCE LIBRARY SCIENCE OR CHEMISTRY OR GEOCHEMISTRY GEOPHYSICS OR THERMODYNAMICS OR PHYSICS OR OPTICS OR METEOROLOGY ATMOSPHERIC SCIENCES OR OCEANOGRAPHY OR ROBOTICS OR MATHEMATICS OR VETERINARY SCIENCES OR MECHANICS OR TELECOMMUNICATIONS OR AUTOMATION CONTROL SYSTEMS OR SPECTROSCOPY OR GEOLOGY OR FISHERIES OR WATER RESOURCES)

Statement #2: Numerical Date and Disaster Terms
NUMERICAL DATE TERMS: TS=("9/11")
DISASTER TERMS: TS=(terror* OR attack* OR catastrophe* OR disaster* OR collaps* OR tower* OR building* OR fire* OR plane* OR airplane* OR jet* OR aircraft* OR burn* OR crash* OR hijack*)

Statement #3: NYC & NJ Location and Disaster Terms
NYC & NJ LOCATION TERMS: TS=("new york" OR NY OR NYC OR “new jersey” OR NJ OR “lower Manhattan”) [excluding] RESEARCH AREAS: (ACOUSTICS OR ENGINEERING OR MATERIALS SCIENCE OR ENVIRONMENTAL SCIENCES ECOLOGY OR OPTICS OR METEOROLOGY ATMOSPHERIC SCIENCES OR GEOLOGY OR VETERINARY SCIENCES OR AGRICULTURE OR MATHEMATICS OR MARINE FRESHWATER BIOLOGY OR PLANT SCIENCES OR INSTRUMENTS INSTRUMENTATION OR PHYSICS OR REMOTE SENSING OR FORESTRY OR HISTORY PHILOSOPHY OF SCIENCE OR ENERGY FUELS OR THERMODYNAMICS OR ENTOMOLOGY OR WATER RESOURCES OR ASTRONOMY ASTROPHYSICS OR AUTOMATION CONTROL SYSTEMS OR ZOOLOGY OR OCEANOGRAPHY OR CRYSTALLOGRAPHY OR CHEMISTRY OR GEOCHEMISTRY GEOPHYSICS OR ANTHROPOLOGY OR CONSTRUCTION BUILDING TECHNOLOGY OR PHYSICAL GEOGRAPHY)

DISASTER TERMS: TS=(terror* OR attack* OR catastrophe* OR disaster* OR crash*) OR TS=(building* NEAR/3 collaps*) OR TS=(tower* NEAR/3 collaps*) OR TS=(building* NEAR/3 burn*) OR TS=(tower* NEAR/3 burn*) OR TS=(building* NEAR/3 fire*) OR TS=(tower* NEAR/3 fire*) OR TS=plane* OR airplane* OR jet* OR aircraft* OR “twin tower*” OR hijack*)

Statement #4: Shanksville & Pentagon Locations and Disaster Terms
SHANKSVILLE & PENTAGON LOCATION TERMS: TS=(Shanksville OR “somerset county” OR stonycreek OR pentagon OR “Washington DC” OR “Washington D.C.” OR “district of Columbia” OR Arlington) [excluding] RESEARCH AREAS: (ACOUSTICS OR ENGINEERING OR MATERIALS SCIENCE OR ENVIRONMENTAL SCIENCES ECOLOGY OR OPTICS OR METEOROLOGY ATMOSPHERIC SCIENCES OR GEOLOGY OR VETERINARY SCIENCES OR AGRICULTURE OR MATHEMATICS OR MARINE FRESHWATER BIOLOGY OR PLANT SCIENCES OR INSTRUMENTS INSTRUMENTATION OR PHYSICS OR REMOTE SENSING OR FORESTRY OR HISTORY PHILOSOPHY OF SCIENCE OR ENERGY FUELS OR THERMODYNAMICS OR ENTOMOLOGY OR WATER RESOURCES OR ASTRONOMY ASTROPHYSICS OR AUTOMATION CONTROL
EMBASE limit 2001-October 31, 2020; humans

**Statement #1: Common References to the Attack**

("world trade center" OR (sept* near/1 “11”) OR (sept* near/1”11th”) OR “ground zero”):ti,ab,kw

**Statement #2: Numerical Date and Disaster Terms**

NUMERICAL DATE TERM: (“9/11”):ti,ab,kw

DISASTER TERMS: (terror* OR attack* OR catastroph* OR disaster* OR collaps* OR tower* OR building* OR fire* OR plane* OR airplane* OR jet* OR aircraft* OR burn* OR crash* OR hijack*):ti,ab,kw

**Statement #3: NYC & NJ Location and Disaster Terms**

NYC & NJ LOCATION TERMS: (“new york” OR NY OR NYC OR “new jersey” OR NJ OR “lower Manhattan”):ti,ab,kw

DISASTER TERMS: (terror* OR attack* OR catastroph* OR disaster* OR crash* OR (building* adj3 collaps*) OR (tower* adj3 collaps*) OR (building* near/3 burn*) OR (tower* near/3 burn*) OR (building* near/3 fire*) OR (tower* near/3 fire*) OR plane* OR airplane* OR jet* OR aircraft* OR “twin tower*” OR hijack*):ti,ab,kw

**Statement #4: Shanksville & Pentagon Locations and Disaster Terms**

SHANKSVILLE & PENTAGON LOCATION TERMS: (Shanksville OR “somerset county” OR stonycreek OR pentagon OR “Washington DC” OR “Washington D.C.” OR “district of Columbia” OR Arlington):ti,ab,kw

DISASTER TERMS: (terror* OR attack* OR catastroph* OR disaster* OR crash* OR (building* near/3 collaps*) OR (tower* near/3 collaps*) OR (building* near/3 burn*) OR (tower* near/3 burn*) OR (building* near/3 fire*) OR (tower* near/3 fire*) OR plane* OR airplane* OR jet* OR aircraft* OR “twin tower*” OR hijack*):ti,ab,kw.
Appendix E. Scoping Review: Data Abstraction Topics

This appendix reports the topics covered in the DistillerSR query form used for article abstraction during the scoping review. The full query form is available on request.

Article Identifying Information

- Title
- Abstract
- Publisher or journal
- Publication data
- Authors
- Authors’ affiliations
- Keywords
- Funder(s)

Article Content

- Clinical conditions studied
- Environmental exposure(s) studied
- Research objectives
- Population(s)
- Intervention or exposure study type
- Comparator
- Outcomes
- Timing
- Study setting
- Study design
- Research findings

Types of Evidence and Application of Translational Research Frameworks

- Evidence type (e.g., generation, synthesis)
- NIEHS Translational Research Framework
- NIH Translational Science Spectrum

Free-Text Capture

- Study objectives
- Findings
- Implications
- Limitations
Appendix F. Scoping Review: Included Articles


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534. Leikauf, John, Clyde B. Schechter, Kathryn Marrone, Faith Ozbay, Alison Rapoport, Vanshdeep Sharma, and Craig L. Katz, “Patient-Clinician Agreement on Treatment Type and Helpfulness: Results from a WTC Rescue and Recovery Worker Cohort,” *Psychiatric Services*, Vol. 64, No. 11, 2013, pp. 1173–1176.


Appendix G. Qualitative Analysis: Codebooks

These codebooks were applied to focus group and interview transcripts, Program documentation, and gray literature. Table G.1 crosswalks the codebooks to demonstrate how they align across the three main data sources that were manually coded. We developed codebooks that logically followed the structure of each data source, with careful attention to alignment across codebooks.

Table G.1. Codebooks Applied to Three Sources of Qualitative Data

<table>
<thead>
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<th>Program Documentation A Priori Codebook</th>
<th>Focus Group Transcripts A Priori Codebook</th>
<th>Interview Transcripts A Priori Codebook</th>
</tr>
</thead>
<tbody>
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<td>HEALTH CONDITIONS</td>
<td>HEALTH CONDITIONS</td>
</tr>
<tr>
<td>• Neuropsychiatric condition</td>
<td>• Cancer</td>
<td>• Neuropsychiatric condition</td>
</tr>
<tr>
<td>(parent code with child codes)</td>
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<td>• Cancer (parent code)</td>
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<td>EXPOSURES (parent code):</td>
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<td>• Chemical hazard (child code)</td>
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<td>• Conditions that function as a hazard</td>
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<td>STAKEHOLDERS/END USERS</td>
<td>STAKEHOLDERS/END USERS</td>
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<td>• Program decisionmakers (parent code)</td>
<td>• Who is using Program research?</td>
<td>• Program policymakers</td>
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<td>• Who should be using Program research?</td>
<td>• Researchers</td>
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<td>code)</td>
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<td>• End users (parent code)</td>
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<td>• External stakeholders (parent code)</td>
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<td>– Researchers (child code)</td>
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<td>– Advisory group member</td>
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<td>(child code)</td>
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<td>– Women (child code)</td>
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<td>– Advocates or family</td>
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<td>– Aging populations (child code)</td>
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<td>members (child code)</td>
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<td>– Historically marginalized</td>
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<td>– Providers and Caregivers (child</td>
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<td>populations (child code)</td>
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<td>code)</td>
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<td>– STAC members (child code)</td>
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<td>• Affected populations</td>
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<td>– Other end users (child code)</td>
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<td>– Responders (child code)</td>
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<td>– Policymakers external to Program</td>
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<td>– WTC youth (child code)</td>
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<td>(child code)</td>
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<tr>
<td>– Aging populations (child code)</td>
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<tr>
<td>– Women (child code)</td>
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<td>Program Documentation A Priori Codebook</td>
<td>Focus Group Transcripts A Priori Codebook</td>
<td>Interview Transcripts A Priori Codebook</td>
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<td>RESEARCH TOPICS, QUESTIONS, PRIORITIES</td>
<td>RESEARCH TOPICS, QUESTIONS, PRIORITIES</td>
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<td>• Perspectives on research topics studied to date by the Program</td>
<td>• Challenges for Program research (parent code)</td>
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<td>• Research priorities for the future</td>
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<td>• Desired Program accomplishments (parent code)</td>
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<td>– Health effects and conditions</td>
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<td>– Recommendations for carrying out Program research mission (parent code)</td>
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<td>– Health services</td>
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<td>– Lessons for future disasters</td>
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<td>– Program planning advice for NIOSH (child code)</td>
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<td>– Occupational outcomes</td>
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<td>– Surveillance and registry</td>
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<td>• Study design (parent code)</td>
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<td>– Exposure characterization (child code)</td>
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<td>– Exposure-outcome linkage (child code)</td>
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<tr>
<td>– Outcome modification (child code)</td>
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<tr>
<td>– Health services research (child code)</td>
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<tr>
<td>– Precision medicine (child code)</td>
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<td>• Perspectives on research topics studied to date by the Program</td>
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<td>• Perspectives on Program outcomes</td>
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<tr>
<td>– Care priorities and impact (child code)</td>
<td>• Comments on conducting research within the Program</td>
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<td>– Other assessments (child code)</td>
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<td>– Stakeholder engagement and transparency (child code)</td>
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<tr>
<th>Program Documentation A Priori Codebook</th>
<th>Focus Group Transcripts A Priori Codebook</th>
<th>Interview Transcripts A Priori Codebook</th>
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<td><strong>USE OF RESEARCH (parent code)</strong></td>
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<td>• How research is being used</td>
<td>• Specific examples of uses of WTC-related research (parent code)</td>
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<td>– Child codes</td>
<td>– Informing clinical care (child code)</td>
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<td>• Environmental exposure activities (child code)</td>
<td>– for program planning</td>
<td>– Advocating for a condition to be covered (child code)</td>
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<td>• Guideline development (child code)</td>
<td>– to advocate</td>
<td>– Determining covered conditions (child code)</td>
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<tr>
<td>• Lived experience (child code)</td>
<td>– to make policy or funding decisions</td>
<td>– Briefing Congress, state and local lawmakers, and advocacy on behalf of the Program (child code)</td>
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<tr>
<td>• Outreach strategies (child code)</td>
<td>– to care for patients</td>
<td>– Informing Program/research planning (child code)</td>
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<td>• Policy changes (child code)</td>
<td>– to make decisions or understand one’s health</td>
<td>– Informing individual health care decisions (child code)</td>
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<td>• Research priority changes (child code)</td>
<td>– to guide future research</td>
<td>– Responding to future health care decisions (child code)</td>
</tr>
<tr>
<td>• Suggestions on how Program research should be used (child code)</td>
<td>– other</td>
<td>– Guiding future research (child code)</td>
</tr>
<tr>
<td></td>
<td><strong>How research should be used</strong></td>
<td>– Other uses (child code)</td>
</tr>
<tr>
<td></td>
<td><strong>COMMUNICATION AND TRANSLATIONAL ACTIVITIES (parent code)</strong></td>
<td><strong>COMMUNICATION AND TRANSLATIONAL ACTIVITIES (parent code)</strong></td>
</tr>
<tr>
<td>• Barriers to translation (child code)</td>
<td>• Barriers to use of research</td>
<td>• Conceptualization of translation (parent code)</td>
</tr>
<tr>
<td>• Facilitators of translation (child code)</td>
<td>• Facilitators of use of research</td>
<td>– Goals of translation (child code)</td>
</tr>
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<td>• Strategies for translation (child code)</td>
<td>• Strategies for communication of research</td>
<td>– Definition of translation (child code)</td>
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<td>• Barriers to communication (child code)</td>
<td>• Barriers to communication of research</td>
<td>– Factors positively influencing translation (child code)</td>
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<td>• Facilitators to communication (child code)</td>
<td>• Facilitators of communication of research</td>
<td>– Barriers to research translation (child code)</td>
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<tr>
<td>• Strategies for communication (child code)</td>
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</table>
Appendix H. Qualitative Analysis: Search Strategy for Gray Literature

Google
Limit 2001–November 2020

Attack Terms
“World Trade Center” OR WTC OR “September 11” OR “ground zero”

Effect Terms
health; exposure; monitoring; health care; risk

Exposure Terms
chemical; asbestos; dust; particle

Response Terms
prepared; preparedness; response; recovery

Population Terms
worker; responder; survivor

Translation Terms
research translation; research impact; research transparency; research communication; research to clinical practice; research relevance; research intervention; research to practice

Searches took the following form:

("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Effect Term*
("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Exposure Term*
("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Response Term*
("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Population Term*
("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Translation Term*

*Terms were searched one at a time

For each search, three separate search conditions were applied: (1) limiting search results to .org; (2) limiting search results to .gov; and (3) no limits.

Homeland Security Digital Library (HSDL)
Limit 2001–present

Attack Terms
“World Trade Center” OR WTC OR “September 11” OR “ground zero”

Effect Terms
health; exposure; monitoring; health care; risk

Exposure Terms
chemical; asbestos; dust; particle

Translation Terms
research translation; research impact; research transparency; research communication; research to clinical practice; research relevance; research intervention; research to practice

Searches took the following form:

("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Effect Term*
("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Exposure Term*
("World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Translation Term*
*Terms were searched one at a time

.govinfo
Limit 2001–present
Attack Terms
“World Trade Center” OR WTC OR “September 11” OR “ground zero”
Effect Terms
health; exposure; monitoring; health care; risk
Exposure Terms
chemical; asbestos; dust; particle

Searches took the following form:
(“World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND (Effect Terms OR Exposure Terms)

Harvard Kennedy School Think Tank Search
Limit 2001–present
Attack Terms
“World Trade Center” OR WTC OR “September 11” OR “ground zero”
Effect Terms
health; exposure; monitoring; health care; risk
Exposure Terms
chemical; asbestos; dust; particle
Response Terms
prepared; preparedness; response; recovery
Population Terms
worker; responder; survivor
Translation Terms
research translation; research impact; research transparency; research communication; research to clinical practice; research relevance; research intervention; research to practice

Searches took the following form:
(“World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Effect Term*  
(“World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Exposure Term*  
(“World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Response Term*  
(“World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Population Term*  
(“World Trade Center” OR WTC OR “September 11” OR “ground zero”) AND Translation Term*

*Terms were searched one at a time
Appendix I. Qualitative Analysis: Stakeholder Views on Future Research Priorities

As shown in Table I.1, stakeholders across various categories had generally aligned views about certain research priorities but diverged in their prioritization of other topics. All stakeholder groups except researchers identified youth as a priority population. However, this result may not reflect the views of all researchers, several of whom exclusively focus on youth. Several of the groups mentioned prioritizing women in Program research, but the FDNY, two researcher focus groups, and the Registry did not explicitly discuss women in the context of research priorities for the Program (although the majority of studies involving the Registry include female survivors). An FDNY focus group participant who was suffering from severe rheumatoid arthritis did, however, express his concern for the health of residents of Lower Manhattan who were continuously exposed for months:

The people in that area that lived down there, the people that were visiting down there in that hotel that hung out and watched for a while. I mean these people just left everything and that dust was coming. So, all those people that have younger kids that were living in that area before they really started to really think about the dust and everything else, cleanup, when young kids are 19, 20 years old now, that’s to me I think about it constantly because I can’t even imagine a juvenile rheumatoid arthritis.

There was general agreement across stakeholder communities about several clinical conditions as priority topics (e.g., cancer came up as a priority in every group, and autoimmune disorders were discussed by almost every group). Notably, the only focus group that did not mention PTSD even in passing was the FDNY responder group. Stakeholder communities agreed that interventional research should be a priority, and there was strong support across the focus groups for the need for health services research.
Table I.1. Selected Research Priorities Explicitly Identified by Focus Group Participants

<table>
<thead>
<tr>
<th>Topic</th>
<th>FDNY</th>
<th>General Responders</th>
<th>Survivors</th>
<th>Representatives of Responder and Survivor Communities</th>
<th>CCE Leadership</th>
<th>CCE Staff</th>
<th>Researchers</th>
<th>Registry</th>
<th>NIOSH</th>
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<tr>
<td><strong>Populations</strong></td>
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<td>Youth</td>
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<td>Women</td>
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<td>Disadvantaged populations</td>
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<td>NPN members</td>
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<tr>
<td><strong>Clinical Conditions</strong></td>
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<td>Cancer</td>
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<tr>
<td>Autoimmune disorders</td>
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<td>Aging</td>
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<td>Comorbidities</td>
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<td>Cognitive impairment</td>
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<td>QOL, functioning</td>
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<td>Neuropathy</td>
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<tr>
<td>Topic</td>
<td>FDNY</td>
<td>General Responders</td>
<td>Survivors</td>
<td>Representatives of Responder and Survivor Communities</td>
<td>CCE Leadership</td>
<td>CCE Staff</td>
<td>Researchers</td>
<td>Registry</td>
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<td>Interventional</td>
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SOURCE: Author analysis of focus group transcripts.

NOTE: NPN = National Provider Network; QOL = quality of life. To create this table, we reviewed all excerpts for the codes related to future research priorities. We then reviewed the 12 transcripts in their entirety to identify any other topics identified as priorities. Green represents a research priority that was identified by all but one or two of the stakeholder types. Yellow represents topics that were not mentioned by at least three of the stakeholder types. Gray represents a topic that was not explicitly mentioned during the focus group.
Criteria for Prioritizing Certain Topics

When asked how they would prioritize the many options, given finite resources, focus group participants’ comments most commonly described three criteria. They would prioritize research according to

- what is most clinically relevant
- who is affected
- the “feasibility of being able to answer the question.”

One researcher described what is meant by *clinical relevance*:

I think obviously, clinical care informs research, and priorities in research have to come from the bedside. So, you take what you locate at the bedside and you go back, and you say what’s the important questions that need to be answered and that’s how you prioritize your research.

Some stakeholders stated, both in the focus groups and in the STAC meeting minutes from 2011 (WTC Health Program Scientific/Technical Advisory Committee, 2011), that conditions that were preventable or could benefit from early detection were highly clinically relevant (e.g., “People are very anxious for answers, in particular with cancer, but with other latent conditions”). Others, such as a stakeholder in the FDNY focus group, would prioritize conditions with the highest mortality (e.g., “for me, the priority is keeping [us] alive . . . certain people are on their deathbed and they should give you whatever help they can do for you”); still others prioritized conditions that affect large numbers of people.

Second, opinions differed on the exact meaning of another criterion: *who is affected*. Some stakeholders felt that conditions that affect Members more or uniquely and that are not being studied well elsewhere should be the focus of future Program research. For instance, an FDNY focus group participant suggested that the Program should support research “that affects the World Trade Center guys more,” rather than what “the general medical community has already been covering” through “billions and billions of dollars going into research.” This view is consistent with the Zadroga Act language that specifies that the Program should study health conditions of enrolled responders and certified-eligible survivors. Other stakeholders, including a Member, felt that the Program should emphasize generalizable research that has “relevance to other populations whose health has been damaged by environmental exposures,” while still conducting research on the populations that it is intended to serve. Finally, representatives of the survivor community who spoke at the 2011 STAC meeting called for future research to prioritize the recruitment of a diverse sample of research participants, both by gender and race/ethnicity.

Third, some stakeholders would prioritize research questions that are potentially answerable. In other words, they would prefer that NIOSH invest its finite resources into answering questions that are feasible to address through research, rather than take risks and
support studies with only a long shot of yielding something actionable and useful for Members. As a CCE leader put it,

It’s not just about the scientific question that’s raised in the grant proposal or the contract proposal. It’s about the feasibility of being able to answer the question. That’s nothing new for the Federal Government or for any funding agency, but it will be of particular importance going forward, especially because of the limited amount of dollars that are present and the numerous really fantastic ideas that are on the table.

Although stakeholders generally agreed that the degree of clinical relevance and characteristics of the affected population(s) should guide the prioritization of research topics, there was little agreement on what specific topics within those broad criteria should be prioritized for funding over others.
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