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Developing Large-Scale Research in Response to an Oil Spill Disaster: a Case Study

Richard K. Kwok[1] · Aubrey K. Miller[2] · Kaitlyn B. Gam[1] · Matthew D. Curry[3] · Steven K. Ramsey[3] · Aaron Blair[4] · Lawrence S. Engel[1,5] · Dale P. Sandler[1]

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Abstract

Research conducted in the wake of a disaster can provide information to help mitigate health consequences, support future recovery efforts, and improve resilience. However, a number of barriers have prevented time-sensitive research responses following previous disasters. Furthermore, large-scale disasters present their own special challenges due to the number of people exposed to disaster conditions, the number of groups engaged in disaster response, and the logistical challenges of rapidly planning and implementing a large study. In this case study, we illustrate the challenges in planning and conducting a large-scale post-disaster research study by drawing on our experience in establishing the Gulf Long-term Follow-up (GuLF) Study following the 2010 Deepwater Horizon disaster. We describe considerations in identifying at-risk populations and appropriate comparison groups, garnering support for the study from different stakeholders, obtaining timely scientific and ethics review, measuring and characterizing complex exposures, and addressing evolving community health concerns and unmet medical needs. We also describe the NIH Disaster Research Response (DR2) Program, which provides a suite of resources, including data collection tools, research protocols, institutional review board guidance, and training materials to enable the development and implementation of time-critical studies following disasters and public health emergencies. In describing our experiences related to the GuLF Study and the ongoing efforts through the NIH DR2 Program, we aim to help improve the timeliness, quality, and value of future disaster-related data collection and research studies.

Keywords Deepwater Horizon · Oil spill · Cohort studies · Epidemiologic research design · Disasters · Research strategy

Introduction

Disasters have increased in frequency and intensity and have short- and long-term effects on human health [1]. In the midst of a typical disaster response, the primary focus is on immediate needs—saving lives and preventing property and environmental damage [2]. Because of this, other health concerns may go unidentified and unaddressed until much later. Currently, information on disaster-related health effects is lacking. This may be attributable to the multiple challenges posed in studying human health risks following large-scale disasters. For example, data collection for research on health effects following the World Trade Center attack in 2001 did not begin until September 2003—a full 2 years after the disaster [3]. It took time for investigators to obtain registry funding, create a protocol, test questionnaires, and obtain institutional review board (IRB) approvals [4]. Such tasks can lead to delays in obtaining data and may limit the ability to characterize primary disaster-related exposures, fully

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✉ Richard K. Kwok
Richard.Kwok@nih.gov

[1] Epidemiology Branch, National Institute of Environmental Health Sciences (NIEHS), NIH, Research Triangle Park, North Carolina, USA

[2] Office of the Director, NIEHS, NIH, Bethesda, Maryland, USA

[3] Social & Scientific Systems, Inc., Durham, North Carolina, USA

[4] Occupational and Environmental Epidemiology Branch, Division of Cancer Epidemiology and Genetics, National Cancer Institute, NIH, Rockville, Maryland, USA

[5] Department of Epidemiology, University of North Carolina Gillings School of Global Public Health, Chapel Hill, North Carolina, USA

enumerate and identify the exposed population, and study short-term health risks.

A growing list of recent US disasters (e.g., World Trade Center 2001, Hurricane Katrina 2005, Deepwater Horizon oil spill 2010, and Hurricane Harvey 2017) underscores the need for disaster research infrastructure, full disaster research integration into public health response efforts, and timely research responses [3, 5, 6]. The importance of researching disaster-related human health effects has been emphasized by both the Assistant Secretary for Preparedness and Response (ASPR) and the National Biodefense Science Board (NBSB), who have called for the inclusion of scientific investigations as an integral component of the disaster planning, response, and recovery cycle [7]. Furthermore, leaders from the US Department of Health and Human Services (DHHS), National Institutes of Health (NIH), and Centers for Disease Control have outlined the critical elements of an effective disaster research response calling for actions before, during, and after a public health emergency to ensure a robust scientific effort in improving our response to future disasters [8].

Information gained from disaster research may lead to interventions to reduce injury, illness, disability, and death and to support recovery efforts and improve resilience [8–10]. However, understanding and effectively addressing environmental health concerns in response to disasters depend on the collection of time-sensitive health and exposure information that is often limited, collected retrospectively, or not collected at all [9, 10]. In addition, disaster response research efforts may require expertise from a multi-disciplinary team, such as experts in toxicology and industrial hygiene, biostatistics, exposure assessment, epidemiology, occupational and environmental medicine, behavioral and mental health, survey methodology, and community engagement. Investigators carrying out disaster research projects need to quickly identify (1) the underlying baseline distribution and determinants of disease in the affected population to help identify risk factors for adverse outcomes and causal associations; (2) efficacy of mitigation strategies; and (3) opportunities for risk communications, critical evaluations, or other interventions to benefit the health and well-being of impacted communities [10, 11]. Furthermore, individuals involved in research response have to collaborate with or work alongside individuals involved in the public health and disaster response. Forming relationships early, before a disaster, can help investigators be better prepared to act quickly and decisively once a disaster occurs [8]. Research conducted during and after a disaster can provide actionable intelligence to policymakers, planners, incident commanders, decision-makers, and impacted community members [8, 10].

According to Malilay et al. [9], the field of disaster epidemiology encompasses "rapid needs assessment, surveillance, tracking, research, and evaluation, executed in response to a large-scale emergency or disaster." However, details on how to design and implement a research study in the midst of a large-scale disaster are not obvious or well specified, and many challenges exist. In this article, we share the challenges we faced while trying to quickly implement the Gulf Long-term Follow-up (GuLF) Study [12, 13••, 14], a prospective cohort study of workers involved in clean-up following the largest marine oil spill in US history. We also discuss steps taken to facilitate rapid implementation and strategies we employed to overcome challenges, many of which are applicable to other types of disasters.

Case Study: the GuLF Study

The Deepwater Horizon Oil Spill

The explosion aboard the Deepwater Horizon drilling rig on April 20, 2010, led to the deaths of eleven workers and subsequent sinking of the vessel which damaged the wellhead and led to the uncontrolled release of crude oil into the Gulf of Mexico. Over 200 million gallons of crude oil flowed into the Gulf of Mexico over a period of 3 months, and tens of thousands of workers and volunteers were involved in oil spill response and clean-up (OSRC) activities [15].

Crude oil is a complex mixture of known and suspected toxicants, including volatile organic compounds (VOCs), polycyclic aromatic hydrocarbons (PAHs), hydrogen sulfide, and heavy metals [16]. VOCs, particularly benzene, have been linked to lymphohematopoietic malignancies [17–21] and kidney dysfunction [22]. VOC exposures can also cause central nervous system (CNS) depression, respiratory irritation, and immune system alterations [23–26]. PAHs include known carcinogens and may alter reproductive and immune function [27]. Hydrogen sulfide can cause acute and chronic CNS effects such as headaches, poor attention span, poor memory, and poor motor function [28]. Heavy metals found in crude oil, including arsenic, cadmium, chromium, manganese, copper, nickel, vanadium, and lead, have a range of adverse health effects, including neurotoxicity and carcinogenicity, renal and cardiovascular toxicity, and immunotoxicity [29–39].

At the time of the Deepwater Horizon disaster, there had been little research on the long-term health effects from oil spills despite the fact that between 1970 and 2009, there were 356 spills of more than 700 tons from oil tankers, with approximately 38 of these spills affecting coastal populations [40–43]. Also, there were a number of key differences between the prior spills studied and the Deepwater Horizon disaster. Foremost were the sheer size and scope of the damage brought on by the disaster—which impacted over 1100 linear miles of shoreline. The release of approximately 200 million gallons of crude oil into the Gulf of Mexico was far larger than any of the other spills studied [15]. Additionally, OSRC activities spanned several states and involved an unprecedented

volume of dispersants, controlled burns, and physical collection of oil and oiled materials, potentially leading to many complex exposure scenarios for OSRC workers and the residents of the surrounding communities [15, 42•, 43–45]. The lack of information on some of these exposures produced considerable uncertainty and concern in the population.

The OSRC following the Deepwater Horizon disaster involved skimming and booming activities, some of which included pooling of the crude oil onto the surface where it was ignited and burned. Burning oil produces particulates and PAHs, which have adverse cardiac and respiratory effects, and may generate dioxins because of incomplete combustion in the presence of chlorine in the sea water [44, 46]. OSRC activities also included the aerial and subsurface application of dispersants to chemically break up the oil. The dispersants used contain potential respiratory and dermal irritants, including 2-butoxyethanol, propylene glycol, and sulfonic acid salts that could lead to adverse physical health symptoms [47•].

In addition to chemical exposures, the widespread social and economic disruption caused by an oil spill may also contribute to adverse mental and physical health outcomes, especially in populations with potentially increased vulnerability due to prior exposures to trauma, financial strain, or social stressors arising from previous disasters [48]. Excess prevalence of generalized anxiety disorder, post-traumatic stress disorder (PTSD), and depressive symptoms was observed among communities affected by the 1989 Exxon Valdez oil spill approximately 1 year after the spill occurred [49]. Similar patterns of higher anxiety and depression scores and worse mental health were observed among communities near the 1996 Sea Empress spill [50]. The 1993 Braer spill was associated with increased somatic symptoms, anxiety, and insomnia, but not personal dysfunction or severe depression [51]. Worse mental health scores were related to proximity to the 2002 Prestige spill [52]. Individuals whose livelihood were impacted by the 2007 Hebei Spirit oil spill also suffered poor mental health outcomes [53].

At the time of the 2010 Deepwater Horizon disaster, the 2002 Prestige and the 2007 Hebei Spirit oil spills had the largest longitudinal datasets available on human health effects. In addition to poorer mental health [53–55] and increased physical health symptoms [56, 57] among residents exposed to the Hebei Sprit oil spill, analyses of urinary and hematologic biospecimens indicated negative changes in oxidative stress, hematologic parameters, and urinary metabolites [58–60]. Results from the Prestige oil spill also indicated decrements in mental health [61, 62] as well as significant decrements in lung function and respiratory health both immediately after the spill and for several years afterwards [63–68]. Biomarker results indicated DNA damage and other genotoxic effects among those exposed [69–73].

The early federal response to the Deepwater Horizon disaster involved both military and civilian federal authorities focused on mitigating the impact of the oil spill. The US government response involved an immediate search and rescue mission, the establishment of a command center, the mobilization of various federal agencies such as the National Oceanic and Atmospheric Administration (NOAA) and the coast guard, and the formation of interagency coordinating committees. In late May 2010, the National Institute for Occupational Safety and Health (NIOSH) was asked to perform a health hazard evaluation, largely in response to reports of the hospitalization of seven fishermen whose symptoms were initially believed to be related to exposures experienced during their involvement in OSRC activities. Other hazard assessments followed along with a voluntary rostering of clean-up workers with an eye towards potential future health research. On June 15, 2010, NIH Director Francis Collins informed Congress that he intended to commit $10 million to initiate research led by the National Institute of Environmental Health Sciences (NIEHS) to investigate short- and long-term health consequences among workers and community volunteers engaged in clean-up activities surrounding the Deepwater Horizon oil spill [74]. Separately, at the request of the Secretary of the DHHS, Kathleen Sebelius, the Institute of Medicine[1] (now known as the National Academy of Medicine (NAM) and will be referred to as such) held a workshop on June 22–23, 2010, to (1) review the current knowledge about oil spills and identify research gaps; (2) consider research efforts addressing the health effects of the Deepwater Horizon disaster; (3) to communicate information concerning these risks to the public; and (4) to make suggestions for creating a monitoring and surveillance system designed to provide "actionable" information regarding emerging health risks [75]. The goal was to optimize resources to high-risk populations for treatment and to foster new approaches for the prevention of adverse health effects [75]. The workshop provided valuable perspective that was used in developing plans for the NIEHS study.

While the potential for health effects of the oil was a concern at the highest levels of the federal government, the highest priority was stopping the spill and mitigating its damage. Multi-agency committees and task forces had been convened, and it was important to ensure that research activities did not interfere with mitigation efforts. At the same time, the NIEHS research team faced intense pressure to design a study and start data collection quickly while OSRC work was ongoing—a mandate that was often at odds with the need to keep a low profile. To ensure coordination, the research team was tasked with involving many layers of governmental experts and oversight bodies in study planning as well as gaining

[1] The Institute of Medicine (IOM) was renamed in 2015 as the National Academy of Medicine (NAM). It is one of three academies that make up the National Academies of Sciences, Engineering, and Medicine (the National Academies) in the USA.

the support and/or concurrence of government leaders for the proposed research plan. The team was also charged with addressing the health concerns of the local communities while carrying out scientifically justified hypothesis driven and peer-reviewed research. This was especially challenging given the lack of evidence for health effects of the ostensibly low levels of chemical exposures likely for OSRC workers and members of the affected communities and the wide range of symptoms and health complaints being reported by affected individuals and covered widely in the media.

The Gulf Long-Term Follow-up (GuLF) Study, led by the NIEHS, was initiated with input from federal, state, and local agencies; local academic institutions; and communities in the Gulf region. Over the summer of 2010, the NIH coordinated many multi-agency meetings involving a range of federal agencies and departments engaged in aspects of oil spill response, seeking insights on clean-up efforts and exposures to aid in study planning, as well as to seek support and concurrence with the proposed research plan. Figure 1 provides an overall timeline for the development and initiation of the study.

Due to heightened concerns surrounding the potential human health impacts from the Deepwater Horizon disaster and the scale of the proposed NIEHS research response, the NIH contracted with the NAM to provide scientific peer review and potentially ongoing study oversight. The NAM convened a panel on September 22, 2010, to review the GuLF Study protocol. The panel included experts from a wide range of relevant disciplines who offered insights on population research methods, disaster research, and community engagement and suggested improvements which were incorporated into study plans [76].

Specific details on the GuLF Study design can be found elsewhere [12, 13••]. Briefly, the GuLF Study was designed to allow prospective investigation of potential short- and long-term health effects associated with response and clean-up efforts. It was designed to address specific hypotheses generated from previous studies of oil spill exposures and, importantly, for an exposure that has not been studied in relation to long-term health outcomes, identify new exposure-related associations, and evaluate the persistence of any observed health effects. The data and the biological and environmental samples that have been collected will allow examination of a wide range of health areas of interest, including respiratory, cardiovascular, hematologic, dermatologic, neurologic, cancer, reproductive, mental health, immunologic, hepatic, and renal outcomes. GuLF Study investigators prioritized research questions based on published epidemiologic analyses following the 2002 Prestige and 2007 Hebei Spirit oil spills as well as studies of petrochemical workers. Standardized questions and procedures were used whenever possible so that study results could be compared with those of other populations [77].

Throughout the planning effort and beyond, GuLF Study investigators held webinars for state and local agencies, community groups, and interested members of the public and met with various academic institutions; local, state, and federal officials; and community stakeholders across the Gulf region to identify their concerns and get input on the proposed study design. At the federal level, in particular, considerable effort was devoted to defining NIH's role in the disaster response; distinguishing the planned research response from the mandated roles of other agencies engaged in rostering, surveillance, and hazard evaluation; and seeking the support of these other agencies.

Over time—including after the study started—study materials were revised to incorporate evolving information on the ORSC efforts as well as to address new concerns raised by workers, the public, and the media. For example, recurring media reports of elevated levels of benzene in the blood of some community members motivated a nested substudy examining blood levels of volatile organic and their predictors [78].

Study Development and Implementation Challenges

Even with the funding, support, and backing of the NIH Director and senior officials within HHS and other federal agencies, data collection did not begin until 11 months after the spill began [13••]. Much of this time was taken up with developing the protocol, consent forms, questionnaire, recruitment materials, test result reporting forms, and other study materials; obtaining scientific peer review and subsequent study modification; establishing collaborations with local and regional partners; developing health and mental health referral procedures and caregiving networks; and hiring and training field staff and interviewers. GuLF Study investigators worked closely with the NIEHS IRB to make sure the study conformed to expectations for human subject protections [14]. Working closely with IRB staff as the study protocol was being developed shortened the time frame for IRB review. Considerable effort was also devoted to obtaining review and authorization from the US Office of Management and Budget which claims authority under the Paperwork Reduction Act of 1980 (amended and broadened in 1995) for review and oversight of federally conducted population surveys.

Community Engagement Challenges

When conducting research in a disaster-impacted community, it is important to establish contacts with local community organizations, representative worker organizations, advocacy groups, and state and local government representatives to identify or confirm the primary health issues of concern locally and to discuss study implementation issues [79]. The groups should span the representative geographical

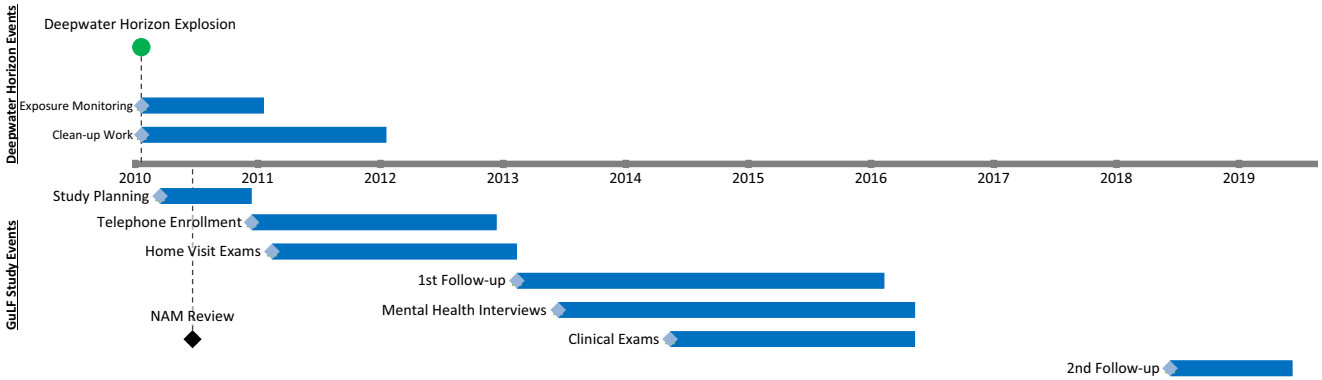

Fig. 1 GuLF Study timeline and significant study events

boundaries, as well as cultural, religious, occupational, and state and local governmental entities that will serve as important links into the community [79–81].

As recommended during the June 2010 NAM meeting, the GuLF Study team sought to include broad input from community leaders and citizens during development of the study to enhance the scientific validity and improve investigator understanding of local concerns to help make the study more broadly relevant and beneficial to the affected communities [13••, 75].

With that said, accomplishing this goal was challenging as the GuLF Study targeted such a large geographic area such that there was no single "community" but many different ones across the impacted areas in the region which included the 5 Gulf states—Alabama, Florida, Louisiana, Mississippi, and Texas [13••]. The GuLF Study cohort included participants from all walks of life, representing many segments of the population across the Gulf region. Although the GuLF Study focused on OSRC workers, it was not a typical occupational cohort. Cohort members did not represent a single or even multiple identifiable industries so there was no obvious union or industry group that represented the entire cohort. Furthermore, the cohort was not drawn to be representative of the affected Gulf state population. However, the majority of workers did come from the surrounding communities, making community concerns relevant to the study design.

In addition to the challenges of geographic size, population diversity, and time pressures, there was a great deal of distrust, frustration, and misinformation swirling throughout the region [13••, 45, 81–83]. Study-specific concerns included the sharing of participant results and data privacy [14]. Many residents were extremely angry at BP, which was the responsible party, and frustrated with what they believed to be a lack of response from the federal government to the Deepwater Horizon disaster and prior disasters in the region [84, 85]. Concerns identified in town hall meetings and individual focus groups were wide-ranging and often contradictory. Boat owners were angry about federal regulations and limits on where and when they could fish, while others were concerned that not enough was being done by the government to monitor seafood contamination. Others complained of lack of access to health care and the lack of federal response in this regard. All of these concerns had implications for participation rates and study design.

Many in the community had also hired lawyers to sue BP for damages or were considering filing for legal remedies [86]. Others were being targeted for inclusion in class action lawsuits. We were unable to collect direct information from participants about their involvement in class action or individual lawsuits. The implications of the legal climate for study response rates and scientific validity are complex. Anecdotally, some participants refused to participate or to complete follow-up activities because of their concerns that participation may undermine their claims. On the other hand, some lawyers were encouraging their clients to participate in the study in hopes it would generate individualized or summary information to strengthen their case. Our experiences mirrored those of other settings such as the Exxon Valdez, where the adversarial legal climate was considered to be responsible for increased psychosocial impacts, intra-community conflict, and a sense of intrusion and loss of privacy thus potentially leading to low response rates and for the difficulty of investigators to carry out long-term follow-up of exposed groups [87–89].

Community Engagement

The GuLF Study investigators embraced recommendations for community engagement through extensive outreach efforts to apprise the community of study activities and maximize transparency. A multi-faceted approach included in-person meetings across the Gulf region; webinars; teleconferences; social media postings; attendance at community events; public service announcements; newspaper, radio and TV campaigns to spread the message about joining the study; meetings with health officials; and even mass mailings to individuals residing in impacted communities. Additionally, we secured endorsements from local celebrities by having them record public service announcements for use in mass media

campaigns within the local communities to promote participation and enroll a more representative sample of those involved in OSRC efforts. The abbreviated time frame and massive scale of the study, however, precluded the GuLF Study investigators from pursuing formal community engagement in the form of a community-based participatory research model which had been recommended by some groups involved in the initial study peer review [76].

The value of these community outreach efforts cannot be overstated, as incorporating the feedback from the meetings with state and local health department and community representatives led to several modifications in the study protocol and questionnaire. For example, based on feedback from community members and key informants, the questionnaire was revised to (1) better define labor categories, (2) better characterize definitions of exposure, (3) improve the workers' ability to recall important dates in their clean-up work history, and (4) include or expand questions about the symptoms of greatest concern to the workers and affected community members. Additionally, discussions with OSRC workers provided critical insight into the processes and procedures occurring at worksites to which study investigators could not gain access. The questionnaires were revised to better reflect "real-world" scenarios rather than idealized protocols established by BP and Federal agencies that may not have been practical to employ in the field.

Privacy and Transparency

GuLF Study investigators tried to be as transparent as possible and to appear neutral and independent. All GuLF Study protocols and questionnaires were posted online and publicly accessible. Written peer review and responses were also made publicly available. Data privacy concerns were addressed in study materials and through the use of a federal Certificate of Confidentiality (CoC). Although no longer required for NIH-funded health research under the 21st Century Cures Act passed by Congress in 2016, the CoC helps protect against disclosures of study-related information by federal, state, or local civil, criminal, administrative, legislative, or other proceedings [90, 91]. Although it does not guarantee that data would never be released, it creates legal hurdles that must be cleared before an order to release data can be issued [91]. The GuLF Study investigators established procedures to share summary study results with participants, community groups, and state and local health officials as the study progressed. A community advisory board was also established to provide oversight and advice; community representatives are also included on the study's scientific advisory board.

Rostering

As may be the case following other disasters, there was no central list of persons involved in OSRC activities [9]. BP contracted with multiple companies to provide needed staff for various OSRC-related efforts. The percentage of OSRC workers that were on the BP payroll was very small. Other workers came from federal and local agencies that maintained their own lists of workers. As noted above, rapid needs assessment and rostering were prioritized as part of the government's response following the Deepwater Horizon disaster. As part of this effort, the National Institute of Occupational Safety and Health (NIOSH) developed a voluntary roster to potentially track OSRC workers by targeting individuals who had just completed mandatory safety training, but before they were assigned to or hired by a specific contractor for clean-up work. Since this OSRC population came from all over the country and was highly mobile, this effort helped larger-scale epidemiologic investigations such as the GuLF Study get established.

The NIOSH roster, worker lists from federal agencies like the coast guard and US Fish and Wildlife Service, and databases tracking completion of NIEHS-developed safety training courses and logging entrance and exits from OSRC worksites were used to develop a master list of names and contact information that was used to enroll individuals into the study. However, because many of these lists were developed for purposes other than future research, key information for contacting workers was often missing, inconsistent, incomplete, or out of date by the time it was needed. Some individuals were on more than one list, but because of incomplete information, it was not always possible to rule out duplicates. Thus, getting an accurate count of how many people were involved in the OSRC was not possible, and different estimates of the workforce size have been reported [13••, 15].

Despite efforts to identify all of the OSRC workers, there were still subgroups missing. Many of the BP employees were not rostered, primarily because they had their own safety training programs and did not badge into clean-up sites at the same locations as other more short-term workers. The names and contact information for BP employees were not made available to the research team. While attempting to obtain contact information for some of these workers, study investigators discovered that workers at the wellhead, where oil exposures were expected to be highest, were not included in the initial rostering efforts and therefore would be left out of the study. An incidental encounter led to the discovery that these potentially highly exposed workers were transported by helicopter to the oil rigs. Therefore, arrangements were made to set up a recruitment kiosk at the main heliport where these workers were transported (Houma, Louisiana) to recruit and enroll these individuals.

While many individuals provided telephone numbers, some of those were mobile numbers linked to "disposable" cell phones, as was the case post-Hurricane Katrina where

residents were found to use "disposable" cell phones only as funds were available. In other cases, multiple workers provided the same contact number—either a single worker with a phone or a number from a boarding house. As such, extensive tracing and locating operations were necessary to reach some study participants. Merging contact information from the study master list with the automated batch tracing databases, such as LexisNexis Accurint and National Change of Address, was often necessary to locate participants.

Future rostering efforts should proactively advocate for a centralized effort with robust contact information for all individual as well as secondary contacts who would know how to get in touch with the individual. The collection of social security numbers (or at least the last 4 digits) would facilitate tracking in large centralized databases such as mortality and cancer registries although this would be problematic in the case of undocumented workers. Efforts by investigators following the World Trade Center attack highlight the importance of establishing a roster quickly as the opportunity to collect this information is limited [92].

Gatekeepers

During the initial peer review, we were strongly advised to work through local community gatekeepers, especially for engaging specific racial/ethnic subgroups of the worker population such as Vietnamese fishermen and other non-English-speaking groups. For some groups, there was no single organization that represented the entire subpopulation of interest, and competing organizations vied to become the focal point of recruitment efforts. Many of the local community service organizations wanted to use their own staff to recruit participants from their communities and even to conduct study interviews. To maintain needed standardization and quality control over the study protocol, however, a more centralized approach was needed. Rather than contracting with multiple small local organizations that served unique population subgroups, research staff were centrally hired and managed but recruited from the local communities in the Gulf of Mexico when feasible. For example, local examiners were hired to carry out in-home and clinic exams.

Balancing between being responsive to community feedback while also following a standardized protocol requires nimbleness and diplomacy to find solutions that foster trust and relationships between the study staff and the community. The ongoing community engagement was important for identifying previously unrecognized health concerns in the affected communities and for increasing the scientific validity of the study by increasing trust and study participation.

Telephone Administration

Because of the need to enroll large numbers of participants quickly and the fact that many workers were no longer in the area by the time the study started, initial enrollment and data collection were done through telephone interviews. We were advised that the diversity of the worker population, especially in the Gulf states, might require an in-person approach. While there were challenges to carrying out telephone interviews with a very mobile population that primarily used cell phones, often without long-term coverage plans, we were able to enroll a diverse cohort, and response rates did not vary substantially by race. A number of Vietnamese fishermen who spoke only Vietnamese took part in clean-up efforts. Most of these were not born in the USA and had little formal education. Reviewers were especially concerned about this subgroup and recommended that we work with community gatekeepers to reach this population. However, a lack of resources and time to devote to developing a tailored strategy for including them kept us targeting this subgroup at the time the rest of the cohort was being enrolled. Our inability to identify a single authority for this group and the unwillingness of the community groups that served the Vietnamese to merely pass on contact information led to a decision to try our centralized telephone approach using Vietnamese-speaking interviewers. Although we preemptively simplified the questionnaire out of concern for concepts that could not be easily translated, we were able to enroll 41% of the Vietnamese-only-speaking persons we had identified from our master list.

Participant Benefits

Input obtained from focus groups and community meetings provided GuLF Study investigators with a better understanding of local barriers to recruitment and enrollment as well as insights useful for identifying strategies designed to overcome these barriers and make it less cumbersome for individuals to participate. Based on feedback from community meetings, the protocol was modified to provide participants with beneficial health information at each encounter. For example, GuLF Study investigators worked with NIEHS-funded community groups to develop easy to understand individual-level reports to return participant results from clinical tests and medical examinations such as blood pressure levels, pulmonary function results, height, weight, body mass index, and urine glucose levels. These reports detailed the normal range of values for each test result along with the information on whether additional medical input might be needed.

For the subset of cohort members participating in a substudy focused on measurement of current levels of chemicals in blood, reports included easy to read graphics of individual participant's results compared with a nationally representative sample from the National Health and Nutrition Examination Survey (NHANES). Summary findings from the GuLF Study are provided via newsletters and are posted on the study website [93]. Study staff also worked to better tailor messages to participants about the purpose of the study, the importance of their participation, and benefits of participation.

Remuneration

Another strong recommendation from the NAM review, other peer reviewers, and community groups was that participants should be compensated for their time [76]. There was no agreement on how much money was appropriate and on what level of compensation would be considered coercive. While the NIH IRB does allow for small, non-coercive financial remuneration, the size of the study precluded offering compensation at the outset. We have no way to know if our response would have been better had we offered payment for completion of the telephone interview. Compensation at other stages of the study—for example, the home and clinic visits—did appear to be helpful but there was no time to formally study the value of these efforts for the telephone interview. Other efforts, such as adding low-level remuneration or drawings for non-responders or for completion of special tasks (e.g., medical record authorization or extra blood sample) had modest success.

Healthcare

During community meetings, it was noted that there was a high prevalence of chronic disease and limited access to health care in the Gulf Region. We found that 49.4% of the GULF Study participants were uninsured and 37.4% did not have a primary care doctor. In addition to the sharing of test results, community groups advocated medical referrals for those in need. While providing health care is beyond the mandate of the NIH, GuLF Study staff worked to enhance access to existing health care services, especially those that were available based on a sliding fee scale, as needed.

GuLF Study investigators worked with federal partners to expand the health care provider referral network to include federally qualified low-or no-cost health care options. Lists of local federally qualified medical and mental health care providers were developed based on input from state and local health care officials, the Health Resources Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and GuLF Study community advisors. Resources varied by state, and there were fewer resources for mental health care or specialty care such as occupational medicine than for primary medical care. The resulting lists were used to offer referral information to participants who had abnormal exam findings or other health concerns. Of the 32,608 enrolled participants, 11,193 completed a home exam which included measurement of blood pressure levels, pulmonary function tests, height, weight, body mass index (BMI), and urinary glucose level measurements [13••]. The most common abnormal findings detected were elevated BMI, urinary glucose, and blood pressure above the normal range and decrements in lung function tests (Table 1). Following or during the home exam, 947 (8.5%) participants requested and received information on medical resources, and 877 (7.8%) received referrals. Mental health needs accounted for 10% of referrals. Mental health referrals were given if participants exhibited signs of distress or upon request during the home visit. During the subsequent clinic exam, we scored responses to depression, post-traumatic stress disorder (PTSD), and anxiety scales in real time and referred participants to clinics in their area as needed. Arrangements were also made to have ready access to poison control centers (for inquiries about chemical exposures), especially when results from chemical testing were mailed, and to suicide prevention hotlines throughout the study. Of all of the home exams conducted, study managers attended to 42 (0.4%) critical health issues that resulted in calls to 911 or referrals to suicide prevention hotlines.

Characterizing Exposures

Many earlier studies based individual level exposure assessment on proximity to the oil spill and/or hours or days of clean-up work performed. These measures would typically be available in other disaster scenarios. For the GuLF Study, we devoted significant resources to developing comprehensive individualized exposure estimates [16, 94–99]. This work involved collecting extensive information from participants about their work experiences during the response and clean-up and incorporating information from exposure monitoring that had been carried out by BP and their contractors during the spill. Although both BP and other agencies that conducted exposure monitoring were very forthcoming in sharing data, the monitoring that was done was to ensure that exposures did not exceed predetermined occupational thresholds rather than for the purpose of future research on health effects at various exposure levels. Thus, monitoring may not have reflected all OSRC work scenarios, and the reported limits of detection were not originally set to capture the lower-level exposures that many workers experienced. As reported elsewhere, it was necessary to recalibrate much of the monitoring data before developing exposure metrics to characterize individual OSRC jobs and tasks [16].

We had originally hoped to identify the location of the individual based on their badging in and out of their worksites. Unfortunately, some of the badging stations served such a wide geographic area that the information was not useful to pinpoint an exact location. For example, a badging station at a marina was used to record individuals coming in and out of the marina. However, there was not a record of where the boats leaving the marina went, leaving us with incomplete information. Additionally, the boats could be out at sea for several days at a time and return to a different marina with different personnel, leaving only partial badging information for study investigators to attempt to piece together.

Table 1 Abnormal clinical findings and referrals in the GuLF Study home visit exams 2011–2013

	Abnormal findings*		Referrals provided	
Measurement	*N*	%	*N*	%
Blood pressure	7415	66.4	310	4.2
Urinary glucose	1318	12.0	97	7.4
Body mass index	8462	76.7	361	4.3
Lung function	2439	25.2	103	4.2
Blood count	570	14.1	20	3.5

*Values outside of the normal range

Early on, we were encouraged to keep a low profile and not interfere with clean-up efforts. Because of the need to get into the field quickly and our inability to visit many of the worksites before the study was launched, some of our information about what was done during the OSRC was incomplete or incorrect. Questionnaires were modified as new information was obtained. However, there were still some instances where the questions we asked did not reflect what was actually done, leading to some potential misclassification or difficulty distinguishing some exposure patterns.

A common concern raised during peer review and in commentaries about the oil spill was that because most of the clean-up work had ended before participants were enrolled, we were unable to collect environmental and biological samples needed to measure exposures [100, 101]. However, given the volatile nature of the VOC's and the day to day variation in jobs and tasks, it is not clear that collecting a single biological sample from participants during clean-up would have allowed us to better characterize exposures. While such samples could have been useful for small validation efforts, the job-exposure matrices we were able to develop allow us to characterize exposures much more completely than has been done before and hopefully serve as a model for future efforts [16].

Comparison Groups

A frequent recommendation from peer reviewers was that we consider adding an unexposed comparison group from outside the affected region. The GuLF Study includes workers with a range of exposures as well as individuals who completed safety training but were not ultimately hired. This latter group generally comes from the same affected communities so, in theory, makes an appropriate comparison group for exposed workers although they were not entirely unexposed because of living in the region. However, it is possible that some were not hired because of various issues including poor health. There is some evidence of a healthy worker effect in the GuLF Study [47, 102, 103]. On the other hand, both workers and non-workers residing in the Gulf states would have been residentially exposed to the effects of the oil spill and have experienced the same media coverage that could have exacerbated mental health concerns [104]. Non-workers from the Gulf region may have experienced spill-related unemployment that was somewhat alleviated for those who were hired, even in the short-term, for OSRC work. Some reviewers suggested including a "similar" but distant community or individuals residing in the same state but further from the Gulf as a comparison population. However, the affected communities were likely to differ in many key ways from distant or out-of-state communities, and no perfect solution was found. Many of the GuLF Study analyses focus only on the workers, with low- or unexposed OSRC workers serving as controls for those with higher OSRC exposures. Choosing appropriate comparison groups is likely to be a challenge in other disaster scenarios.

The NIH Disaster Research Response Program

Based in part on the experiences of the GuLF Study, the NIEHS adopted a forward-leaning approach towards the development, support, and promotion of disaster science in response to disasters and other emerging threats. In 2013, the NIEHS, in collaboration with the National Library of Medicine, led the development of a pilot project which grew into the NIH Disaster Research Response (DR2) Program [10].

The DR2 Program provides data collection tools, research protocols, IRB guidance, and training materials to advance timely research in response to disasters and other public health emergencies. These readily available tools and resources as well as information on trained investigators and funding sources are intended to enhance disaster-related research response. There are currently over 350 research protocols and data collection tools available on the continually expanding and publicly available DR2 website (https://dr2.nlm.nih.gov).

As part of DR2 efforts, NIEHS has held training workshops in Los Angeles (2014), Houston (2015), Boston (2016), and Tucson (2019) to better prepare stakeholders to work together on the development and implementation of disaster-related data collection and research. Of note, the workshop held in Houston in 2015 focused on a hurricane scenario hitting the Houston metropolitan area. When Hurricane Harvey hit Houston in August 2017, academic institutions in the area and across the USA quickly banded together in partnership with local public health officials and impacted communities to quickly form research collaborations utilizing pre-approved DR2 protocols and other resources from the NIH DR2 repository [105, 106].

Conclusion

Implementing a large-scale research study under time restrictions is challenging and resource intensive. Key decisions made under time pressures inherent to disaster response and with missing, incomplete, or erroneous information may threaten data quality and validity. The need to balance research aims with health care needs in underserved populations is an ongoing challenge that requires establishing clear expectations for researchers and health agencies from the start. In the GuLF Study, the number of abnormal test results and requests for medical referrals exceeded our expectations, resulting in increased staffing time and efforts to support effective health care referrals. Despite our best efforts, some participants remained frustrated that they did not receive health care for problems they attributed to the oil spill.

A key aspect to designing the GuLF Study was the establishment of community partners and other key stakeholders that helped investigators understand community issues that might affect study success. In turn, epidemiologic studies can provide critical details to key stakeholders during a disaster and contribute to a better understanding of the risks and hazards involved. This information can be used to provide information to optimize resource allocation and develop policies and procedures such as the use of personal protective equipment when encountering known hazards and recommendations on the duration of work shifts to minimize morbidity and mortality for future disasters.

Following a disaster, surveillance systems may be put in place to collect a variety of information to provide actionable intelligence to decision-makers or decision-makers may rely on surveillance systems already in place, as was the case following the Deepwater Horizon oil spill. However, small to modest revisions of usual data collection efforts may provide more useable information for the benefit of both short- and long-term health studies. Furthermore, broader efforts to characterize populations at greater risk for disasters, before disaster strikes, will provide information that is needed to determine if, for example, spikes in health care utilization following a disaster are real.

Experiences in establishing the GuLF Study can be used as a template in future disaster scenarios to identify the population at risk and work with community partners and local stakeholders and IRBs to address important issues of scientific and community concern. It is vital that ongoing efforts maximize the use of validated data collection approaches and tools to ensure that results can be most useful in informing preparedness, response, and recovery efforts for future situations. Using resources established under such initiatives as the NIH DR2 Program will help investigators be better prepared to quickly respond to future disasters with standardized methods and questionnaires that will provide both "actionable intelligence" and improve public health.

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Compliance With Ethical Standards

Conflict of Interest Aubrey K. Miller and Dale P. Sandler are section editors for *Current Environmental Health Reports*. All other authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent Human studies ethics approval was granted by the Institutional Review Board of the National Institutes of Environmental Health Sciences.

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