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Community Engagement and Research Translation in Puerto Rico's Northern Karst Region: The PROTECT Superfund Research Program

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Abstract

We describe here the social science-environmental health collaboration in PROTECT, the Puerto Rico Testsite for Exploring Contamination Threats, which is one of eighteen Superfund Research Program centers funded by the National Institute of Environmental Health Sciences. This collaboration has multiple facets: (1) create a holistic, unified research program that addresses the complexity of environmental contamination, (2) offer research participants an engaged and respectful interaction with the research team, (3) provide cross-training, in which the team's social scientists learn environmental health and the environmental health scientists learn social science, and (4) provide training for graduate students and post-docs in multiple disciplines in this burgeoning form of collaboration.

Keywords

social science; environmental health; Superfund Research Program; PROTECT

Introduction

NIEHS Center Programs and Their Impact on Social Science-Environmental Health Collaboration

The National Institute of Environmental Health Sciences (NIEHS) has developed multiproject center grant programs that address a range of issues in a certain geographical area, using transdisciplinary teams that bridge environmental health science and social science. These center grants require community engagement and research translation cores (RTCs), in varying formats across center types, and while there is no requirement for social scientists to lead the community engagement and research translation activities, they are

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frequently the ones in that role. More importantly, even if social scientists are not in such positions, the community engagement and research translation activities have a strong social science component by the nature of their work. Center/program grants of this type include the Superfund Research Program, Children's Environmental Health Center Program (jointly funded with the Environmental Protection Agency [EPA]), the Deepwater Horizon Oil Spill Centers, and the Breast Cancer and the Environment Research Program (jointly funded with the National Cancer Institute). Another large NIEHS program, the Environmental Health Science Core Center Program, provides infrastructure support rather than research support, and each center also contains a Community Outreach and Engagement Core.¹

The combined work of these programs, as well as individual grants from NIEHS programs, such as its past Environmental Justice and Community-based Participatory Research Programs and its current Research to Action, has generated considerable social science/environmental health collaboration, resulting in important scholarship that bridges the worlds of environmental justice and community-based participatory research. Research and practice in these collaborations has informed us about key areas such as lay-professional interaction, community discovery of toxic contamination, cumulative impacts, stress-environmental interactions, social networks, community organizing for environmental remediation and prevention, and environmental health literacy.²⁻¹³

Anderson and colleagues integrate research translation and community engagement in an NIEHS' Superfund Research Program in their notion of "interweaving." This encompasses multiple forms of academic-community, academic-government, and academic-entrepreneur partnerships that are geared to rapid dissemination of knowledge into skills for environmental remediation, monitoring, and regulation. At the same time, interweaving involves extensive commitment to understanding community members' expertise in their surroundings and lifescape. Incorporating the diversity of inputs into this approach requires awareness that the nature of these interwoven realities come from journals in many different disciplines that require integration and synthesis. More so, people engaged in interweaving must attend to the vast knowledge and skills available from web sites, brochures, and unpublished activities of community groups and even government agencies which have no incentive or ability to publish in traditional journals. Last, these must be flexible interweavings, amenable to rapid change when needed. As the authors put it, "The widely diverse resources are woven together to create a knowledge fabric that is permeable."¹¹ One way that can be accomplished is by having "knowledge brokers," or team members whose role is to build, maintain, and iteratively refashion connections between academics, regulators, advocates, community groups, professionals, and legislators.¹⁰

While NIEHS and some other federal agencies may be very good colleagues for community groups, there remains a necessity for such groups to conduct their own independent investigations. Citizen science approaches such as pesticide drift monitoring, bucket brigades, balloon mapping, and other community monitoring devices and approaches have been well developed, with many of the reports on these activities coming from the writings of social scientists.¹⁴⁻¹⁸ Social scientists involved in PROTECT have been influenced by such work and have shared it with their environmental health partners.

Geo-political and economic context—Puerto Rico is composed of Isla Grande, Vieques, Culebra, and a series of smaller islands; it is located within the Caribbean archipelago. Puerto Rico, the smallest island of the Greater Antilles, has high biodiversity with unique endemic components.⁷ The archipelago is also in a strategic geopolitical position, making it a source of interest to colonizers for more than five hundred years, having been first occupied by the Spaniards in 1493. After nearly exterminating the native population of approximately 60,000 Tainos, the Spaniards remained for four hundred years. As a result of the Spanish–American War, in 1898, the United States gained control over Puerto Rico, accorded by the Treaty of Paris. In 1917, as the United States entered World War I, Puerto Ricans were granted U.S. citizenship via the Jones Act;^{19,20} since then, Puerto Rican men and women have been a part of the U.S. Armed Forces. Puerto Ricans are citizens of the United States, though they cannot vote for the President of the United States and have one nonvoting Representative in Congress. Multiple plebiscites to address the political status of Puerto Rico have been held over the last few decades. However, they were nonbinding referendums and since the U.S. Congress has ultimate legislative authority, no change has occurred to date. Due to its status as a U.S. territory, Puerto Rico is governed by the same federal agencies, including the EPA, National Parks Service, Department of Agriculture, and so forth.

In 1947, Puerto Rico’s economic policies began to focus on export-led industrialization, known as Operation Bootstrap, a program implanted in Puerto Rico by the U.S. government. These policies were implemented initially with government-run factories, and then via privately owned industry recruited from the U.S. mainland. Agriculture, in the meantime, declined significantly, causing internal migration from rural to urban centers and subsequent mass migrations of Puerto Ricans to the mainland due to high rates of unemployment, extreme poverty, and cheaper air fares.^{21,22} The migration of agriculture workers and their families to the capital city, San Juan, created a need for decent and affordable housing that was not adequately planned or available. This great migration by people of limited economic resources contributed to the creation of clusters of inadequate housing that were built in areas of San Juan that were along channels within mangrove forests and wetland ecosystems, exposing both people and other organisms to contamination due to the lack of adequate infrastructure.^{23,24}

Although promises of increased employment opportunities of Operation Bootstrap did not fully come to fruition, United States based and other foreign owned manufacturers (initially textiles and electronics manufacturers, followed by pharmaceuticals) remained on the island due to significant tax incentives. In 1976, the U.S. Congress amended the Internal Revenue Code and created Section 936 to allow U.S. corporations to establish operations on the island and repatriate their profits without paying federal taxes. Economic growth in Puerto Rico did indeed occur; however, the emphasis on industrialization also left the island open to poorly regulated contamination of the natural environment.

In 1996, under President Bill Clinton’s administration, Section 936 was revoked as an economic policy under the Internal Revenue Code. Many analysts have cited the implementation of the North American Free Trade Agreement of 1994 as a rationale for this policy change, as cheap labor and fewer regulations were available in Mexico. Subsequently,

U.S. industries that had operated in Puerto Rico for decades left the island causing major losses in manufacturing jobs and leaving abandoned factories, many of which included environmental contaminants.^{25,26}

PROTECT as a response to environmental contamination in Puerto Rico—

PROTECT is a multiproject initiative that studies environmental contamination and the resultant exposure threats to pregnant women and infants in Puerto Rico. The primary goal is to examine potential environmental factors, especially phthalates and trichloroethylene, in preterm birth, which has a much higher incidence in Puerto Rico than in the U.S. mainland. The project focuses on Puerto Rico's northern region with dynamic contamination exposure pathways through aquifers in karst regions. Karst is a highly permeable limestone geology that allows contaminants to readily seep into aquifers without the protection of soil and other geological components that might retain some contaminants. PROTECT also seeks to better understand the phenomena affecting fate and transport of hazardous substances in karstic aquifers and to develop green remediation strategies that attenuate and mitigate exposure to protect human health and ecosystems. Through integrated analytical, mechanistic, epidemiological, fate and transport, and remediation studies, along with a centralized, indexed data repository, PROTECT delivers new knowledge and technology in the area of contaminants of interest to the Superfund Research Program as a potential cause of preterm birth. The new knowledge and technology will also be useful more broadly in the overall field of environmental health. PROTECT involves six universities (Northeastern University [NU], University of Puerto Rico Medical Sciences Campus, University of Puerto Rico Mayaguez, University of Michigan, West Virginia University, and University of Georgia), community organizations, state and territorial agencies, federally qualified health centers, and the Manatí Medical Center. As Table 1 shows, there has been a high success rate at recruitment, with nearly 1100 women currently in the cohort.

Puerto Rico has more than two hundred hazardous waste sites.²⁷ Of the total, twenty-two are listed on the National Priorities List (EPA Superfund Program), ten of which are in the PROTECT research area and include (1) unlined landfills, (2) an active paper and plastic bags manufacturer that discharged wastewater containing hazardous chemicals into a local river and surrounding areas, (3) a pesticide warehouse that contaminated soils and groundwater with hazardous chemicals, and (4) a pharmaceutical manufacturing plant operating in a two-acre area that had a leak in an underground storage tank contaminating wells on site, soil, and groundwater with carbon tetrachloride.²⁸ Nearby industrial activity and the construction of stainless steel monitoring wells are believed to release metals into the groundwater.²⁸ The sites are located on top of or near aquifers in highly permeable karst geologic formations that allow contaminants to easily seep into the aquifer.

PROTECT Activities at the Social Science-Environmental Health Interface

A research program that addresses the complexity of environmental contamination—The PROTECT project collects information that helps relate and compare socioeconomic, demographic, and geographic information with data on use and exposure to harmful chemicals as measured in the biological samples donated by the participants. Most women in the cohort live on less than \$20,000 annual income, very much

under the poverty line in Puerto Rico and the United States overall. Many are very young, with low levels of education, and are single parent heads of households living in rural areas with scarce resources.

The conceptual framework and work perspective for PROTECT is founded on key areas that already integrate environmental health and social science, in particular the areas of health inequality research and environmental justice. Social scientists have long collaborated with environmental health scientists in these areas, as detailed extensively in the introduction to this special issue. A number of the PROTECT scientists were moderately familiar with these areas but had not consciously framed their work in such concepts, though they were very receptive to it. Community Engagement Core (CEC) leaders aided this growth by bringing in noted environmental justice and community-based participatory research speakers for the project's webinar series and in making these issues part of regular presentations of PROTECT work made in many venues, ranging from government events to professional conferences. PROTECT is particularly attuned to the growing approach of "reproductive justice" that merges concerns of environmental justice with reproductive health.²⁹ This is especially important in light of Puerto Rico's legacy of unethical contraceptive testing and coerced sterilization.^{21,30} In 1937, the U.S. Congress approved Law 116 which institutionalized a population control program that led to the sterilization of a significant number of women in Puerto Rico. In 1965, about two-thirds of women within the ages of twenty to forty-nine were sterilized.³¹ Additionally, Puerto Rican women were the first on whom the birth control pill and other pregnancy control methods were tested, without informed consent.³²

The PROTECT project is also informed by the "research-right-to-know" approach that holds that just like people's right to their clinical health data from medical visits, they have the right to data from any research in which they are participants (we provide extensive detail on this below in the section on report-back of data).³³ PROTECT scientists were also introduced to water justice issues from two post-docs, an anthropologist whose dissertation on water and sanitation in Latin American had been done in collaboration with environmental engineers, and a sociologist who also had a master of science degree in environmental engineering and had worked on water shutoffs and other access issues. Their presence demonstrated additional forms of social science-environmental health collaborations, showing the team that such collaborations were increasingly common.

PROTECT colleagues further understood the potential of social science-environmental health collaboration when NIEHS awarded a T-32 Training Program, "Transdisciplinary Training at the Intersection of Environmental Health and Social Science," cosponsored by Phil Brown, Director of the Social Science Environmental Health Research Institute (SSEHRI) at NU, and Julia Green Brody, Executive Director of Silent Spring Institute. PROTECT scientists are among the faculty mentors in the program and provide lab visits for the trainees. The Training Program was also opened to the PROTECT trainees as a form of cross-fertilization, providing sociological topics to which they would otherwise not likely be exposed.

PROTECT's CEC and RTC play a relevant role in focusing on the social determinants of health. The CEC and RTC cores focus on understanding how health outcomes of populations are affected by social and economic inequality, gender, the natural and built environment, access to education, employment opportunities, access to health care, political-economic processes, and social capital. This awareness allows the CEC/RTC to conduct its work within a historical and structural framework.

The PROTECT center connects a diversity of disciplines, including engineering, medicine, public health, epidemiology, nutrition, social work, sociology, anthropology, toxicology, and geology. This dynamic provides for integrating social science perspectives with environmental public health research and practice. The transdisciplinary nature of the research team and its overall project plan provide for the interaction between the researchers, clinical staff, student trainees, and the individuals and communities that participate and contribute to the study. Through its tight connections and respectful approach to participants, PROTECT's Human Subjects and Sampling Core (HSSC) team laid the groundwork for the Community Engagement and RTC' activities. The HSSC work created the connection and trust needed for the community engagement, described next.

It is possible that the term "Human Subjects and Sampling Core" may sound traditional and paternalistic to some readers who see this as opposite of the community-based participatory research and community-engaged research approach we take. Indeed, the terminology was used to mirror a typical biomedical recruitment and sampling feature that was central to the research and was intended to assure participating clinics and hospitals that our project was in the mainstream of biomedical research. But the originators of the project had a deep respect for the women as research participants and were very attuned to past abuses of women in Puerto Rico research. This respect and the growing involvement of participants in the project's direction were amplified by the creation of the CEC that was required for the renewal.

Building connections—PROTECT was developed in part as a response to a request from a community organization. The Puerto Rico Chapter of March of Dimes alerted academic researchers about the exceedingly high preterm birth rate, 1.5 times that of the United States, and in an effort to respond, the PROTECT Center was created. March of Dimes continues its engagement as a key adviser and member of both the Community Advisory Board and the External Advisory Committee, which functions as a scientific advisory board.

The establishment of a Community Advisory Board was made possible due to the foundations of collaborative relations established by the PROTECT HSSC during the first three years of the center. The connections made include reaching out to local environmental advocacy groups, including Citizens of the Karst (*Ciudadanos del Karso*) and Citizens for Environmental Defense (COTICAM). Other important collaborators are administrators and clinical staff at the local Federally Qualified Community Health Centers Pry Med in Ciales, Morovis Community Health Center, and Manatí Medical Center. In recognition of the significance of its work, members of the PROTECT research team have been appointed to the Puerto Rico Taskforce for Prematurity.

The role of a health nonprofit, March of Dimes, set the stage for a community-initiated area of concern, as well as for an approach that would take very seriously community needs over solely scientific needs. This did not automatically make it a *participatory* approach, though as will be shown below, there has been an increasing amount of participation. Community-engaged research (CErR) is very much in service to the community, and frequently initiated by community requests, but unlike community-based participatory research, it does not include participants as coresearchers.^{34,35} PROTECT's work has fallen further to that end of the continuum. But the CEC has been planning to work with some of the most active and engaged participants to formulate a community-based participatory research proposal.

Already, one of PROTECT's five research projects, based at UPR-Mayaguez, has had engineering students developing a research project with residents on sampling water. The CEC initiated collaboration to discuss community engagement for a project the students have been independently conducting. These three students have been working with community leaders to monitor well water. The community uses private wells as its water source and the students are helping with monitoring to ensure the wells are up to code and that the water remains safe to consume. The CEC collaboration will assist the students on documenting and publishing the important work they have done engaging community members in the research and reporting the findings to the community on a regular basis. Currently, they are working on a manual of guidelines and regulations. The manual will serve as a tool to protect the community's goal of maintaining their independently owned wells as a healthy and safe water source. As a pilot project, the students hope to replicate this model in other communities and regions of Puerto Rico. Also, as we discuss below, focus groups with participants are playing a central role in how research data will be reported back to participants.

PROTECT's engagement with diverse audiences to create useful resources is exemplified in the production of a documentary film *36 Semanas (36 Weeks)*, involving film students from the University of the Sacred Heart, advocates from the March of Dimes, mothers with preterm babies, and health care professionals. Another example includes working with materials from Silent Spring Institute; the PROTECT team designed a brochure, using common language, to explain to participants and others how to avoid environmental contaminants in household and personal care products. Building on material from Alaska Community Action on Toxics, PROTECT produced a brochure on environmental factors in reproductive health for physicians, nurses, and other health professionals, tailored to local Puerto Rican conditions. Working with physicians' organizations, PROTECT researchers are preparing to launch a survey of physicians' awareness of environmental factors in disease and hope to use the results to promote required continuing medical education in the area.

PROTECT Means Proteger: Offering Research Participants an Engaged and Respectful Interaction With the Research Team

Building trust and capacity—The CEC's main goals are to engage women in northern Puerto Rico participating in the center's epidemiological cohort, and the broader group of residents in PROTECT's groundwater study area, in a bidirectional communication process that enables key stakeholders to offer lay perspectives and information, build trust with the

affected communities, improve study recruitment and retention rates, build capacity for participants and their community organizations, and lay the groundwork for additional community-based participatory research projects. A good deal of the trust stems from the work of the HSSC, whose job is to recruit and maintain the cohort of now nearly 1100 women and to carry out interviews and specimen sampling. The intense engagement with participants at a clinical level offers a stronger connection than many women have experienced in health care settings. The following section examines how the participants are very much part of a community engagement.

The cohort as an engaged community—As noted above, the development of our cohort was centered on building a trusting relationship that would provide valuable resources for participants. Both clinical staff and social science professionals were involved in this work, creating fertile ground for later establishing a CEC, which by the time of PROTECT's first renewal was a requirement rather than an optional core. (PROTECT's first grant was for a four-year period, the standard for first-time Superfund Research Program grantees, but actually came in a little late, effectively making it a 3.5-year funding cycle. The renewal was for the standard five years.) The trust that was established and supported by the PROTECT team has been instrumental to the work of PROTECT. As Table 2 shows, withdrawals from the cohort have declined dramatically over time, indicating a deep trust and interest in remaining involved.

One example which is a result of the engagement of participants in the PROTECT cohort is that the center has gained important collaborators and new team members. In PROTECT's fourth year, three previous PROTECT participants were recruited as new nursing staff members. They made reference to PROTECT as a source of motivation to complete nursing studies. Additionally, in order to ascertain what people would like to hear in report-back of their individual data (to be discussed in the following section), we completed key informant interviews and held focus group meetings in each of the five sites of PROTECT.

For the study with key informant interviews, participants as well as collaborators from the Community Health Centers and environmental community organizations were approached and asked to talk about their concerns with environmental exposure and contamination within the geographical area of the study. Another area of inquiry included their experience with providing information related to environmental exposure and health, and the methods and practices that would be most effective with PROTECT participants. We talked to PROTECT participants in terms of their knowledge, interest, and preferences with regard to getting information on the results of their exposure to chemicals and education on the possible effects and ways to prevent or reduce harm. The study included ten key informants who are either health care providers or environmental community organizations and ten participants from the PROTECT cohort.

For the second study consisting of focus groups with PROTECT participants, the PROTECT project coordinator made contact with participants from each recruitment clinic site via telephone. The study planned for ten participants per focus group session, therefore twelve to fourteen participants were scheduled for each session. The total number of participants was thirty-six. The focus group was guided by the Community Engagement Coleader and a

doctoral trainee. Meetings ranged from one and a half to two hours in total and participation and engagement were active and dynamic.

The research was designed to capture the opinions and preferences of participants in reference to research where biological samples are asked of them and inquired into their understanding of their contribution to research on premature births and exposure to chemicals and to document opinions on what are the best methods to engage participants and provide information that is both useful and clearly understood.

The main question themes asked included:

1. Opinions on researchers/investigators and project staff
2. Reasons to participate
3. Positive outcomes of participating
4. Conditions or factors that would prevent consent to participation
5. Who is best prepared to approach and inform on participation in clinical research that involves donation of biological samples: blood, urine, hair, placenta, etc.
6. What to consent to: Here participants explain what they are willing to consent to and on what terms
7. What should occur if a scientist/researcher discovers something that may affect the participant's and/or participant's child's health
8. Preferred formats of report back
9. Most important information to include in report back discussions of results
10. Best moment and location for report back

Focus groups and interviews were recorded in audio and transcribed, following a content analysis of the texts produced. Results from both methodologies revealed a consistent commitment of participants and collaborators with learning about the effects of environmental exposure on pregnancy and birth outcomes. Participants expressed their trust in the PROTECT study team and stated they wanted to know if their participation in research has produced valuable knowledge. They also insisted they wanted to know and understand what is causing such high rates of premature births. Results for both methods were consistent in terms of information produced. Participants in the PROTECT study expressed looking forward to the report-back process and gave specific recommendations in terms of how this information should be organized and presented. One indication of participants' level of commitment was that, besides offering valuable information on what they wanted to learn, several participants expressed interest in collaborating with the development of educational materials on exposure to harmful chemicals and health. This is a clear indication of the need for more participatory research methodologies. As a result of these interviews and focus groups, a participant advisory board will be coordinated in the fall of 2016 as a method to further obtain feedback on how to successfully and effectively report study results to participants. (Silent Spring Institute's report-back system is discussed below.)

The above examples reveal that the experience of participating and collaborating in PROTECT research activities supports the building of community capacity through educational interventions and participatory activities. We view this as a key contribution of social science-environmental health collaboration in cohorts and note that it occurs in other NIEHS-funded center grants.³⁶ This is very different from traditional cohorts in which people are passive human subjects rather than active participants. Lessons from such engaged cohorts should be widely promoted among environmental epidemiologists in order to provide a more democratized form of research engagement.

Cross-Training of Environmental Health Scientists and Social Scientists: Focus on Report-Back of Personal Environmental Health Data

One of the most significant aspects of cross-training for PROTECT's environmental health scientists is the practice of report-back of data. PROTECT scientists had no prior involvement in such activities, but began learning about them in the year-long process in which PROTECT prepared its first five-year renewal. That renewal brought the CEC into being, with report-back being a major element. Silent Spring Institute, with whom CEC coleader Phil Brown had worked for twelve years on report-back in various projects, was brought in as a partner. The entirety of the report-back approach had been developed by a team of sociologists and environmental health scientists, and the social science colleagues in PROTECT made it a point to emphasize sociological elements, such as the primacy of social stratification, the central role of social movements in advancing human health, the social production of knowledge, and the power imbalances evidenced in struggles over environmental causation of disease. PROTECT researchers for whom this report-back approach was new required additional education and training in order to successfully engage in these research activities. Meetings and webinars arranged by the team's main social scientists—a sociologist and a social worker/population health researcher—addressed the ethical issues, usefulness to participants, and scientific benefits. Environmental health scientists came to realize the ethical responsibility and community-engaged necessity of report-back.

Through the sociological input from the leadership of PROTECT's RTC, the center organized conferences in 2015 and 2016 in collaboration with environmental justice and women's health groups—one on Reproductive Health and the Environment and one on Women of Color and Environmental Health—that advanced the team's awareness of the embodied experience of health and the role of social movements. Most significantly, PROTECT's cosponsorship of the very successful social science-environmental health collaborations conference, from which this special issue derives, showed the whole team the importance of a social science perspective.

At the same time, PROTECT researchers were pleased to see the scientific potential of Silent Spring Institute's new Digital Exposure Report-Back Interface (DERBI) that not only produced print and/or computer report-back for participants but also offers a cluster analysis tool for scientists to investigate groupings of contaminants. DERBI is a hybrid entity—both an advance for the sociological importance of report-back and for the scientific analysis of multiple exposures, and holds promise to be a significant tool for advancing research on

cumulative exposures. Sociology graduate students and sociology and anthropology postdocs learned more about the environmental health science involved by working on the report-back development.

From this preparation for report-back, the whole PROTECT team became familiar with a broader, long-standing social science-environmental health collaboration that included Silent Spring Institute, other universities (Brown, UC–Berkeley, Harvard), and environmental justice groups (Communities for a Better Environment in California, Alternatives for Community and Environment in Boston, Alaska Community Action on Toxics, and Environmental Justice League of Rhode Island). That partnership, with varying members, has emphasized research on how participants understand and use the data given to them, both for individual action and policy change, and the team has published its work in the top journals in environmental health, sociology, science and technology studies, and public health.^{37 39} Environmental health scientists and social scientists worked together to develop a strategy for selecting what contaminants to report and to learn about the techniques of report-back, running focus groups with participants to inform the strategy, and met to discuss the “research right-to-know” and the history of report-back of environmental health data.

In order to design a report-back process that is responsive to participants’ concerns and preferences regarding the process and content for report-back, the CEC ran focus groups with PROTECT participants and also interviewed other stakeholders such as community organization representatives and health care providers. Information produced by this preparatory work revealed a very strong need and interest in knowledge to be obtained by receiving personal results, combined with information on reducing exposures. The focus groups demonstrated a deep desire for learning about exposures but went further in people’s expression of being committed to participating in the PROTECT cohort. They felt their participation helped a greater good—the production of scientific knowledge that can answer the questions of premature births and other health problems. As one participant said: “I want to know if what I did helped science help others in the future.”

A pilot version of report-back materials is presently being constructed to test on a small sample, in order to identify the best approaches and format. Report-back will provide individual data with text and graphs, and the ability to navigate the DERBI interface as much as they want to learn more about contaminant sources, exposure reduction strategies, and broader policy approaches. All participants receiving report-back will have access to researchers and clinicians by phone or in-person to help interpret data. Aggregate data will be presented at community meetings and disseminated via news media and web sources.

PROTECT is the first project in Puerto Rico to deliver the results of individual samples provided by participants from blood, urine, hair, umbilical cord blood, and placenta. In contrast to prior exploitative health research, this approach offers a democratic, participatory model that will yield improved science, as has been the case with report-back in a variety of projects.⁴⁰

Transdisciplinary work in report-back is not specific to only the PROTECT Superfund Research Program. Other NIEHS grantees have found a community-based, social science-environmental science approach useful as well, including individual grantees and Children's Environmental Health Centers.^{3,41,42} The Northeastern/Silent Spring Institute/UC Berkeley team has been using its social science-environmental health collaboration approach to work with eight research teams, including CDC and NIEHS grantees, to further expand the use of right-to-know report-back.

Training Graduate Students and Postdocs From Multiple Disciplines

Knowledge of social science-environmental health collaboration through the lens of environmental justice and CBPR/CEnR does not come automatically to people. Fortunately, NIEHS requires each Superfund Research Program Center to have a Training Core that is tasked with offering a variety of professional training resources to graduate students and postdocs working in the center. Their goal has been to support cross-disciplinary training in fields related to environmental health and environmental science and engineering in order to prepare the next generation of environmental health and science professionals. In addition to typical skills (e.g., grant-writing, poster creation and presentation, conference presentation, and communication/dissemination), PROTECT provides other resources.

To ensure that graduate student and postdoctoral trainees learn enough about the nature of social science-environmental health collaboration, regular webinars provide speakers from within and outside PROTECT discussing topics such as environmental justice, community-based participatory research, and careers in environmental health. Additionally, an annual ethics training session as well as an annual orientation session give trainees an overview of each project and core. These sessions also support learning about the social science aspects of the project. Trainees work with their faculty project leaders and coleaders on presenting material on research translation of their science to diverse audiences, ranging from community organizations to government agencies. Trainees have also learned about social science/environmental health collaboration from attending conferences at NU, such as a May 2015 conference on Social Science-Environmental Health Research Collaborations, a December 2015 conference on Reproductive Health and the Environment, and a 2015 conference in Puerto Rico on Citizen Science. These training activities provide a lived experience of working in a setting that has strong social components for trainees in environmental epidemiology, toxicology, and environmental engineering. This is how the project enhances their discipline-specific training through exposure to social science theories, methods, and tools that can increase their scientific impact in the field.

Trainees include graduate students in the social science-oriented public health doctoral program in Social Determinants of Health that is run by the Department of Social Science at the University of Puerto Rico—School of Public Health (UPR-SP). Those trainees' education is enhanced by a strong background in environmental health science that prepares them for the interdisciplinary work of the center. One of these students is currently developing her dissertation proposal to explore lived experiences of PROTECT participants and the process by which report-back data potentially influences community involvement and environmental justice movements. Another UPR-SP doctoral student, whose

concentration is Environmental Health, is working with PROTECT to analyze socioeconomic and demographic variables related to an increased risk of differential exposure to contaminants by means of personal and household products during pregnancy. Collaboration among these doctoral students, whose backgrounds are in social science or environmental health sciences, has enhanced each student's research proposals and the interdisciplinary nature of public health.

Northeastern's SSEHRI is the only graduate training program in the United States that specializes in social science-environmental health collaboration, and its director is also coleader of the PROTECT CEC and leader of the RTC. SSEHRI is a successor to the Contested Illness Research Group started in 1999 at Brown University with funds from the Robert Wood Johnson Foundation and the National Science Foundation. As a multidisciplinary working group that began by looking at disputes over environmental factors in asthma, breast cancer, and Gulf War Illnesses, it expanded to other areas, including biomonitoring and household exposure in collaboration with Silent Spring Institute and involvement with the Brown Superfund Research Program. After moving from Brown University to NU, Contested Illness Research Group director Phil Brown created SSEHRI as an interdisciplinary group of graduate students, postdoctoral researchers, and faculty members from Sociology-Anthropology and Health Sciences, funded by research and training grants from National Science Foundation and NIEHS. Research efforts have expanded to include data privacy issues in environmental health data sets, citizen science approaches to low-cost community environmental monitoring, brownfields redevelopment policy, and chemical policy on flame retardants and highly fluorinated compounds.

SSEHRI and PROTECT interact in multiple ways—research, education, and community engagement. SSEHRI scientists and trainees learn the ways they can participate in social science-environmental health collaboration and work with community organizations dealing with environmental justice and citizen science. PROTECT provides presentations to SSEHRI's thirteen students (ten Sociology PhD students, one Sociology MA student, one Population Health doctoral student, and one MPH student) and runs lab tours of toxicology and environmental remediation. SSEHRI students and postdocs participate in PROTECT activities such as surveys of physician awareness of environmental factors in disease and in writing grant proposals for extending PROTECT's efforts.

In addition to SSEHRI trainees, students at Northeastern who are not PROTECT trainees also benefit from the opportunities offered by the center. They include Northeastern students in the MPH program; the PhD program in Population Health, run by the Department of Health Sciences; and the PhD program in Personal Health Informatics, jointly run by the Department of Health Sciences and the College of Computer and Information Science. Those students work on projects with PROTECT faculty and attend PROTECT events and campus conferences that provide education on social science-environmental health collaboration.

Conclusion

We have shown how PROTECT's collaboration of social science and environmental health science forms a rich, complex approach to the study of environmental factors in disease, along with approaches for remediation and a strong community engagement element. We have also pointed out that other NIEHS programs have similar transdisciplinary approaches, which taken together have provided leadership to the environmental health field and to the broader public health field. Community engagement is a multifaceted phenomenon: It is a communication approach which provides the best way to inform affected people and communities about environmental hazards; it is an educational approach in which colearning takes place; and it is a redistributive approach in which the equitability of resource distribution is at play.

While increasing numbers of environmental health researchers are involved in community engagement, such engagement is very much a facet in which social science has led. Social science involvement in multiproject environmental health research centers strengthens such engagement and explores it in a sociological manner. Our perspective sees it as a central element to not only carry out transdisciplinary, community-engaged research but also to study the entirety of the process of that research.

Discussing the importance of report-back of participant data, and preparing to carry out that work, is probably the most significant outcome of social science-environmental health collaboration, as we described above. The research team as a whole benefits from many of the training activities, which are attended by project scientists as well. As noted in the discussion of training for graduate student and postdoctoral trainees, the social scientists were central in designing webinars with speakers on environmental justice, research ethics, and community-based participatory research. In helping design the series on careers in environmental health, the social scientists brought in scientists who had a deep understanding of CBPR and community-engaged research and who had experience collaborating with social scientists. By extensively engaging in team discussions about citizen science, along with information presented at an EPA citizen science conference, the social scientists showed the entire team the value of such work.

Our case study offers more general lessons for research translation as well. While we may consider community engagement as a form of research translation, there are various other forms of research translation, as we pointed out in the description of "interweaving" in the Introduction section. Beyond research translation, we find citizen science and the politics of expertise to be significant inputs, as we wrote in that same section. Significantly, much of that work is the product of social science-environmental health collaboration.

PROTECT researchers from all ends of the disciplinary spectrum have been able to inform each other of their own science and to learn much about the science of the other side. The transdisciplinary approach used in PROTECT and other environmental health centers and projects offers researchers a way to understand the multiple ways in which environmental contamination affects individuals and communities. Community engagement and research translation provide knowledge and tools for these individuals and communities to better

protect their health in collaboration with researchers who have become more informed through the community collaborative process.

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Biographies

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Phil Brown is university distinguished professor of Sociology and Health Sciences, and director of the Social Science Environmental Health Research Institute at Northeastern University. His current research includes social policy and regulation of flame retardant chemicals and perfluorinated compounds, and techniques and ethics of reporting data to study participants in biomonitoring and household exposure studies. He codirects the Community Engagement Core and directs the Research Translation Core of Northeastern University's Superfund Research Program, PROTECT.

Colleen Murphy is a third-year doctoral student in the DrPH program at the University of Puerto Rico-Medical Sciences Campus, School of Public Health, with a concentration in Social Determinants of Health. She has a master in public health from the University of North Carolina-Chapel Hill, Gillings School of Global Public Health. She has been working as a trainee with the Community Engagement Core of the PROTECT (Puerto Rico Testsite for Exploring Contamination Threats) project for the past year and will continue this work throughout the remainder of her program.

Abigail Figueroa has been a research nurse for the PROTECT project since 2011. She has a bachelor's degree in Nursing from the University of Puerto Rico, Medical Science Campus. Currently, she is the Campus Activity Coordinator of the PROTECT/CRECE projects.

Jóse Cordero is a pediatrician, epidemiologist, teratologist, and former Dean of the Graduate School of Public Health at the University of Puerto Rico. He is the codirector of the "Puerto Rico Testsite for Exploring Contamination Threats (PROTECT)," an NIH P42 Center. His work has been published in many national and international scientific and medical journals.

Akram Alshawabkeh is the George A. Snell Professor of Engineering and the codirector of the "Puerto Rico Testsite for Exploring Contamination Threats (PROTECT)," an NIH P42 Center. He is a civil and environmental engineer with expertise in environmental restoration and health impacts, contaminant fate and transport, geochemistry, geomechanics, and

electrokinetic and electrochemical processes. As the PI and codirector of PROTECT, Dr Alshawabkeh leads a team that includes toxicologists, epidemiologists, chemists and civil, environmental, chemical, computer, and electrical engineers. Together, this multidisciplinary collaboration studies environmental and water contamination in Puerto Rico and its effects on preterm birth and other adverse pregnancy outcomes to develop prevention and remediation strategies.

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Table 1

Cumulative Recruitment, as of 1 June 2016.

Status	Number
Screened	1651
Eligible	1362
Recruited	1181
Pregnancy completed	825
Livebirths	780

Table 2

Eligibility, Recruitment, and Withdrawals by Year, 2011–2016.

Year	Eligible	Recruited	Withdrawals
2011	68%	70%	21%
2012	83%	86%	22%
2013	85%	93%	21%
2014	91%	93%	13%
2015	89%	90%	6%
2016	85%	91%	4%

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