COMMUNITY ENGAGEMENT CORE

SUMMARY/ABSTRACT

The Community Engagement Core (CEC) will build bidirectional partnerships with target communities to enhance their ability to understand the health risks posed by emergent water contaminants in the environment (specifically 1,4-dioxane (1,4-DX)), and to provide interventional strategies that will improve public health and inform health policy. In the first phase of the project, the CEC will focus on communities in Nassau and Suffolk counties of Long Island, New York. These communities include residents whose public drinking water wells are impacted by nearby EPA Superfund sites. The CEC will work with the Research Translation Coordinator (in the Administrative Core) to develop replicable tools and resources to provide data and generate knowledge among stakeholders who are invested in addressing water-related issues in the State of New York, especially in areas near Superfund sites. To accomplish this, we will identify effective methods to communicate risk information to each stakeholder group, including the economically-disadvantaged and environmental justice communities proximal to these sites. The specter of emerging contaminants in drinking water is fraught with uncertainty about risk and appropriate courses of action, creating an atmosphere of confusion, blame, anxiety and, most importantly, mistrust. The CEC will address these challenges through facilitation of engagement and information exchange among the diverse and relevant constituencies in NY State. We will create opportunities for constituent groups, including federal, state and local governmental agencies, to learn from each other and share information. We will encourage and facilitate multi-directional interactions among communities and experts to complement and support the Yale Superfund Research and Training Program's (YSRTP's) overarching objective of fostering research that improves the detection, toxicological evaluation, risk assessment, and mitigation of emerging contaminants to address genuine health issues that may result from consuming contaminants in drinking water in EPA Regions 1 (New England) and 2 (New York, New Jersey, Puerto Rico, US Virgin Islands and eight Tribal Nations). In addition, we will collaborate with the Research Experience and Training Coordination Core (RETCC) to educate and train the next generation of scientists to conduct citizen science and develop skills for advocating for environmental justice and equity. The initiatives implemented in this proposal will be transferable to other communities facing similar challenges including the State of New Hampshire which will be the second targeted area for CEC activities. The overarching goal of the CEC is to engage, educate and empower residents in impacted communities so they may understand and inform public health policy, and participate in the improvement of public health. Results of this collaborative effort will have a significant impact on the health of human populations in New York and New Hampshire, aid the resolution of similar challenges at Superfund sites throughout the U.S.A., and enhance global efforts to monitor, remediate and determine the impact of water contaminants.

PROJECT NARRATIVE

The uncertainty about risk and appropriate courses of action surrounding emerging contaminants in drinking water, such as 1,4-DX, creates an atmosphere of confusion, blame, anxiety and mistrust in communities impacted by these issues. The focus of the Community Engagement Core (CEC) in the Yale Superfund Research and Training Program (YSRTP) is to address these challenges through facilitation of engagement and information exchange among diverse constituencies in two states currently impacted by 1,4-DX issues (i.e., New York and New Hampshire). The CEC will create opportunities for stakeholders – including residents, government agencies, community and educational organizations – to learn from each other, and by utilizing multilateral partnerships among the projects in the YSRTP, will strengthen relationships across stakeholder groups, foster educational opportunities, and promote active and sustained community engagement.

INTRODUCTION

Following are comments that respond to reviewer concerns about the Community Engagement Core (CEC) section in our first P42 submission, and how we have addressed the concerns in this revision.

Core director effort level/commitment: The newly-proposed director for the CEC, Andrea Boissevain, possesses both the credentials and the time to fully meet the expectations of this role. As evidence of her commitment, she has contributed hundreds of hours to the development of the current P42 application, including significant efforts to identify and build collaborations with the proposed communities of interest. Moreover, she is supported in her role by Elaine O'Keefe, a faculty member of the Yale School of Public Health (YSPH) with extensive experience in community engagement, teaching, applied research and evaluation and management. An assistant director, Alivia Coleman, will manage the on-the-ground operations for the CEC. Together, Ms. O'Keefe and Ms. Coleman will enhance the leadership and management capacity in the CEC providing ongoing professional support for the Core Director.

Lack of management / evaluation plans: The CEC will be managed by the Core Director and other key CEC personnel with additional oversight from the CEC Steering Committee and the Administrative Core as we have described in the Core Structure and Profile section of the CEC narrative. The Core Director will ensure that CEC protocols and activities are effectively implemented and evaluated with guidance from Ms. O'Keefe who has successfully designed and implemented a comprehensive evaluation system for an NIMH funded research center at Yale where she serves as Executive Director. To assess the CEC's progress in achieving its stated aims, and ensure accountability, Ms. O'Keefe developed a detailed evaluation plan for the Core with process and impact measures that will be monitored using annual work plans and continuous quality improvement approaches.

<u>Insufficient Letters of Support (LOS) from key stakeholders in targeted communities</u>: We have spent the last year building relationships with key stakeholders (including government agencies and community advocacy organizations) and enlisting their guidance in developing the aims of the YSRTP and the CEC, as evidenced in the LOS detailed in this revised application.

<u>Need to better identify roles and responsibilities</u>: We have articulated roles and responsibilities of CEC members in each of the CEC aims and also described anticipated roles of community stakeholders.

Need to involve trainees/students/post-docs in CEC activities: Trainees/students are an integral part of the CEC plan and community engagement activities. The CEC will provide a vehicle for experiential learning opportunities to foster skills in community engagement and CBPR. In addition to utilizing post-docs who are part of the Research Experience and Training Coordination Core (RETCC), the CEC plan and budget provides for graduate or undergraduate level intern(s) to work specifically on CEC aims each year of the project.

There was no explicit intent in the CEC plan to study and learn from and share what works in community engagement so that other researchers and communities can benefit from the planned activity: We have included a new specific aim (#4) that focuses on transferring knowledge and best practices from our initial target area in New York to another state heavily impacted by 1-4-DX, New Hampshire. The CEC plan now includes development, testing, and launch of community-level engagement interventions that could benefit communities as outputs of activity. The CEC plan also embodies a commitment to create learning communities to foster dynamic two-way communication and sustained, trusting relationships.

<u>Dissemination activities should have included the conduct of regional/statewide workshops where Yale and stakeholders share lessons learned</u>: We have included a variety of dissemination and bidirectional sharing methods in our CEC plan and we will collaborate with the YSRTP Translation Research Coordinator on communication and dissemination approaches to optimize reach and to evaluate the merits of different tools and modalities. These are described in the CEC narrative.

SPECIFIC AIMS

The Community Engagement Core (CEC) will support the YSRTP's overarching focus on community-based concerns about water contaminants that exist at sites in EPA regions 1 and 2 and implement strategies for monitoring, intervention and prevention of exposure to emerging contaminants. Working with target communities in New York (NY) and New Hampshire (NH), we will build bi-directional partnerships to enhance their ability to understand and reduce (or eliminate) health risks posed by 1,4-DX and its combined effects with other common co-occurring contaminants. Many sites where solvents were used or disposed of in northeastern states were remediated prior to 2008, i.e., before sensitive testing for 1,4-DX became available. Long Island (LI) NY is home to many already-mitigated sites (e.g., Old Roosevelt Field Contaminated Groundwater Area Superfund site in Garden City, NY) with impacted public drinking water wells that are now being revisited to determine and mitigate the impact of 1,4-DX contamination. Meanwhile, the NY State Drinking Water Quality Council is in the process of establishing drinking water maximum contaminant levels (MCLs) for 1,4-DX and other emerging contaminants. This combination of increased testing activity and detections in LI, together with the prospect of a new 1,4-DX MCL, will create a large community interest in drinking water quality in general, and in 1,4-DX in particular. Thus, LI will serve as the initial community for our engagement. Despite the presence of Superfund sites and contaminated groundwater on LI, there are no Superfund-associated community advisory groups (CAGs). This is a large unmet need that will become more acute as communities' grapple with the possibility that their drinking water may be affected by 1,4-DX. The CEC will establish one or more CAGs on LI to engage stakeholders in an ongoing two-way dialogue, and in creating and evaluating educational materials to explain testing, health risks and treatment technologies to diverse groups within the community. New research on 1,4-DX conducted by the YSRTP and other researchers will be translated for the community. This community engagement model for 1,4-DX will then be adapted for use in communities in NH impacted by 1,4-DX. The NH Department of Environmental Services (NHDES) is testing groundwater proximate to 150 unlined landfills and in previously investigated sites to evaluate 1,4-DX drinking water contamination. Walpole and Greenland (Coakley Landfill Superfund site) are examples of communities in NH with 1,4-DX contamination in drinking water in need of effective community engagement strategies and tools. Working in both NY and NH, the CEC will support multiple communities affected by 1,4-DX by crafting optimal community engagement approaches and evaluating the transferability of methods and materials developed for different populations/areas impacted by 1,4-DX. The overarching goals of the CEC will be to (i) identify, educate and empower communities to actively participate in public health improvement efforts, and (ii) inform public policy that enhances protection of the public water supply from 1,4-DX at local, state and national levels. To accomplish these goals, the CEC will develop effective stakeholderdirected tools and resources that provide data and generate knowledge among stakeholders, including the economically-disadvantaged and environmental justice communities. The CEC will also facilitate engagement and information exchange among diverse and relevant constituencies and create opportunities for constituent groups (including government and state agencies, and experts) to learn from each other. Andrea Boissevain, MPH, (CEC Director) and Elaine O'Keefe, MS, represent an outstanding leadership team with extensive backgrounds in community health assessment, risk communication and community mobilization efforts involving diverse constituencies. This team has a history of successful collaboration on community engagement and remediation efforts at state and federal Superfund sites. Under their guidance, the CEC will establish CAG(s) and facilitate outreach and education that is inclusive of vulnerable communities. The following specific aims are proposed:

- **Specific Aim 1**: Develop and facilitate the work of one or more CAGs on LI impacted by 1,4-DX to ensure representation and engagement of all key groups (community members, governmental and other stakeholders) in the YSRTP research agenda and process.
- **Specific Aim 2:** Engage CAG members in developing educational and research translation materials generated from research Projects 1-5 that address key concerns and empower impacted communities to identify and request solutions to outstanding drinking water contaminant issues.
- Specific Aim 3: Promote informed health policy change by facilitating active and sustained input from diverse stakeholders (including state regulators and legislators) which can form the basis for better safeguards of drinking water quality and help impacted individuals and communities understand ways in which health risks can be mitigated.
- **Specific Aim 4:** Apply the lessons learned from community engagement efforts in NY to other communities in NH with 1-4 DX contamination issues in which the outreach effort and educational materials developed for LI can be adjusted to meet the specific needs of other communities.

RESEARCH STRATEGY

A. SIGNIFICANCE

The YSRTP will focus on addressing emerging water contaminants in drinking water, with emphasis on 1,4-DX in EPA regions 1 and 2. This is a highly significant public health concern in these geographic areas as well as other parts of the U.S.A. and the world. New Hampshire is in process of establishing more stringent standards for 1,4-DX in drinking water; at least one community, North Walpole, is currently drinking well water that exceeds permissible levels. New York State is also in the deliberation process regarding establishing drinking water standards for a suite of emerging contaminants, including 1,4-DX. The majority of Long Island's (LI's) public water supplies have detections of 1,4-DX that exceed the risk level. Based upon screening detections from large public supplies on LI and elsewhere in the EPA's third Unregulated Contaminant Monitoring Rule (UCMR3) database, a potential for elevated cancer risk from water ingestion is a concern in certain communities. One investigation found that 66% of supplies on LI were above the lower end of EPA's reference range, 0.35 ppb, in comparison to 6.9% of overall US supplies that exceeded this reference level (1).

The problems associated with 1,4-DX are many-fold. Only recently has technology been developed that detects 1,4-DX with sufficient sensitivity (2). As such, Superfund sites that were considered to have been effectively remediated may reveal 1,4-DX contamination in their 5-year reviews by state and federal regulatory agencies. Moreover, there is evidence that 1,4-DX may co-occur with other industrial solvents that may aggravate the adverse health effects of 1,4-DX; furthermore, groundwater remediation technology currently in place may not be adequate to remove 1,4-DX. Finally, neighboring states vary by orders of magnitude in their standards for permissible 1,4-DX levels (3).

Addressing the complex issues around emerging water contaminants, such as 1.4-DX, requires scientific research be combined with actions to address public health and policy concerns. Meaningful involvement of affected communities is key. The CEC is an important component of the YSRTP with a highly significant role in assuring the overall aims of the program are achieved, including the provision to communities of intervention tools that they need to reduce or eliminate exposure, e.g., information about relative risk, detection and treatment technologies. The CEC team functions as the base for facilitating involvement of diverse stakeholders in meaningful bidirectional communication to (i) engage the community in a participatory process, (ii) appropriately inform the public regarding public health outcomes, (iii) facilitate linkages between researchers and those who may be eligible to participate in studies in the YSRTP and/or serve as community advisors and (iv) provide the community with tools they need to mitigate their risk of exposure. The CEC provides important infrastructure services that link the YSRTP to the communities it serves including actively supporting YSRTP investigators to conduct and disseminate their research. It also provides a vehicle for students and trainees to build skills in community engagement and research translation processes. An overarching goal of the CEC is to engage, educate and empower the targeted communities so they may participate in the improvement of public health and inform public health policy. This collaborative effort will have a significant impact on the health of human populations in the States of NY and NH, provide replicable tools and processes to assist Superfund and other identified sites throughout the U.S.A., and enhance global efforts to monitor, remediate and determine the impact of emerging contaminants in drinking water.

B. <u>INNOVATIO</u>N

Confronting and resolving environmental contamination issues that threaten the health of the public, ecosystems, and the socioeconomic milieu of communities is an infinitely complex and fraught process. The interactions between technical experts, researchers, regulatory agencies and authorities and impacted communities are often problematic and challenging. Yet these interactions are essential to the successful design and execution of viable approaches to mitigate risks to human health and the environment while also minimizing adverse impacts on the social, psychological and economic health of individuals and communities.

The "discovery" of 1,4-DX in drinking water, a contaminant that was not previously detectable and one without definitive or consistent health or remediation standards, adds a layer of complexity to the process of engaging impacted communities while establishing and maintaining trust and credibility, especially if the sites have been acknowledged as having been previously cleaned up. This emergent issue in NY and NH provides the opportunity to pilot and evaluate approaches that will actively engage (rather than passively involve) stakeholders

- all in the interest of giving voice to decisions that impact their lives. By developing community-driven methods of engagement in the research and policy setting process, and in the creation of information materials, systems, and tools to effectively communicate risks in communities/areas with different situations, the CEC offers the potential to generate best practices and innovative approaches that can be replicated in other places experiencing issues with 1,4-DX and its co-occurring contaminants. While community engagement and outreach education with residents and stakeholders around Superfund sites are not new approaches, the innovation of the YSRTP is its focus on 1,4-DX and other emerging contaminants, and the development of effective methods to communicate to diverse stakeholder groups how that science is evolving, and how to assess and mitigate health risks. Ultimately, the process will empower residents to know the risks, and take appropriate steps to reduce the risk—interventions and preventions intended to improve public health.

C. BACKGROUND

Communities of Interest: There are 122 active or closed NY State Superfund sites in Suffolk County (on LI) and 89 in Nassau County (on LI); an additional 16 and 18 Federal Superfund sites are in Suffolk and Nassau Counties, respectively (4). Given that Long Island's (LI's) sole source of drinking water comes from three aquifers which may be subject to groundwater contamination, LI residents have reason to be concerned. Public drinking water wells have been impacted in several communities. The Village of Garden City, NY (Garden City) public drinking water supply wells at the Old Roosevelt Contaminated Well Superfund Site have been found to be contaminated with the chlorinated solvents tetrachloroethene (PCE) and trichloroethene (TCE) (5) and are now being tested for the commonly found co-occurring contaminant, 1,4-DX. The public water supply for Garden City, serving 22,371 residents, is routinely tested by the Garden City water district to ensure that all federal and state drinking water standards are being met. The challenge is a standard for 1,4-DX that has not been established. Garden City is located in Nassau County and will be our initial target community. We will also work with other community-based advocacy organizations on LI (e.g., the Citizens' Campaign for the Environment and the Group for the East End) to identify and convene other stakeholders who would be appropriate to serve on a regional or county-wide community advisory group (CAG). A map developed by the Citizens' Campaign for the Environment shows public drinking water supplies that are below or above the current EPA cancer risk guideline of 3.5 ug/l is depicted in Figure 1., highlighting the magnitude of the impact 1,4-DX has on LI.

The secondary population of interest is residents of New Hampshire (NH) with private drinking well water impacted by known or potential 1,4-DX contamination, including residents in proximity to NH-state listed sites, primarily those previously-closed unlined landfills that are now being revisited to assess for emerging contaminants. The NH Department of Environmental Services (NHDES) is testing groundwater proximate to 150 unlined landfills and previously investigated sites to evaluate 1,4-DX drinking water exposures. Walpole and Greenland (Coakley Landfill Superfund site) are examples of NH communities with 1,4-DX contamination in drinking water in need of effective community engagement strategies and tools. The YSRTP will maintain communications with NH partner agencies during the initial phase of the project, sharing our progress in NY with the implementation of research studies from the YSRTP, and as appropriate, other pertinent information on the process of forming a CAG and issues identified by communities in LI around 1,4-DX that result from our assessment. Following the development and evaluation of community engagement initiatives on LI, the CEC will focus efforts on translating methods and approaches used in NY to NH.

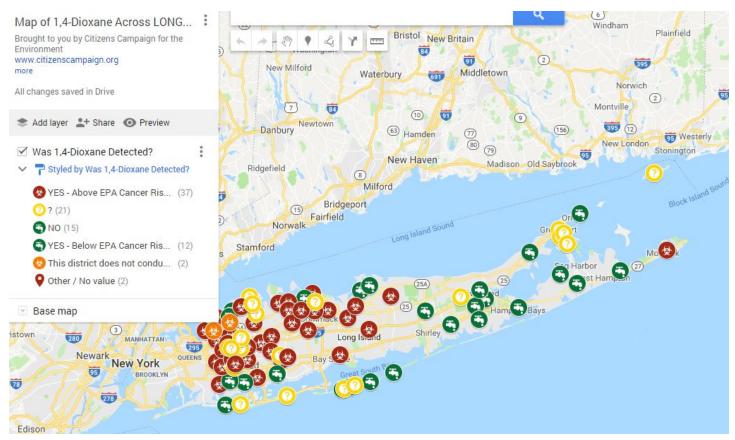


Figure 1: Map of Test Results where 1,4-DX was sampled from public drinking water supplies (Long Island, NY).

Involvement of Participating Communities and Identification of Research Priorities: The involvement of impacted communities and public health officials in the remediation of water contamination issues and threats in NY and NH has been central to the development of the YSRTP application. Dr. Vasiliou (Director of this P42 and Chair of the Environmental Health Science Department at the Yale School of Public Health), Andrea Boissevain and Elaine O'Keefe (Leaders of the CEC), and other members of the YSRTP research team have initiated partnerships with state public health and environmental agencies and affected communities in both NY and NH. Through a series of meetings and consultations over the past year, these parties have developed priority research and community engagement foci for the YSRTP that are reflected in this application. Thus, this program proposal has been developed in direct response to (i) the articulated needs of these two states that are within EPA Regions 1 and 2, and (ii) the acute emergent concerns relative to 1,4-DX and co-occurring contaminants of the most impacted communities within these states.

While the YSRTP will initially focus on defined studies addressing specific scientific questions of importance to our understanding of the impacts of 1,4-DX and co-occurring contaminants on human health, over the life of the YSRTP there will be opportunities to identify additional research priorities defined by community stakeholders that could be carried out with the support of post-doctoral students, community members and Yale researchers. Dr. Vasiliou (Program Director) and his project research teams and cores will collaborate with Ms. Boissevain and other members of the CEC to engage the EPA, NY State Department of Health, NH Department of Health and Human Services and NH Department of Environmental Sciences, community advocacy/action groups, and other governmental and nongovernmental entities to develop such additional research priorities and optimize stakeholder engagement in the YSRTP's research, training and community engagement endeavors. The YSRTP (specifically Project 5 focusing on advanced oxidation treatment) will partner with the NY State Center for Clean Water Technology at Stony Brook University, exploring ways to collaborate to develop and commercialize innovative solutions to address 1,4-DX contamination of drinking water through enhanced treatment technology thereby reducing consumer exposure. The CEC will facilitate the transfer of information resulting from all research projects (Projects 1 – 5) in the YSRTP by working in concert with the Translation Research Coordinator (P. Anastas) to identify community priorities for drinking water-related research and foster bidirectional knowledge exchange between researchers and community stakeholders. The CEC will engage community

stakeholders in identifying and designing effective and accessible tools for collection and dissemination of appropriate information. There will be a focus on engagement of economically and otherwise marginalized groups in and around the identified project sites of LI to promote environmental and health equity for all affected citizens and residents. Building on current efforts in the community to remediate contaminants and improve public health, the program developed by the YSRTP will lead to greater public understanding of the importance of remediation and the capacity of the community to lead those efforts.

Community Stakeholder and YSRTP Roles:

The roles of community stakeholders would include (but not be limited to):

- Actively engage in bi- and multi-lateral communications with all community, governmental, and YSRTP stakeholders.
- Assist the YSRTP to foster opportunities for economically- and linguistically- marginalized communities/residents to participate in the educational and decision-making processes.
- Participate in and assist with:
 - the creation of one or more Community Advisory Groups (CAGs) to assure balanced representation of community and other stakeholders
 - ensuring educational seminars related to environmental- and health-related issues are accessible to the community.
 - nomination of key representatives from identified community stakeholder groups to encourage community participation and action as members of the CAG (that will be formed by the CEC) and in other activities of the YSRTP.
 - o provision of community forums to communicate stakeholder needs, concerns, and current information.
 - o conveying individual and collective advice regarding the water contamination-related research priorities and information needs and priorities for each stakeholder group.
 - o Reviewing and pilot testing educational materials and approaches, including research dissemination materials developed by and with the YSRTP.

The roles of CEC members are delineated in each of the Specific Aim statements for the CEC. As the community relationships strengthen and vital feedback from the communities is sought and integrated into the research plan, the list of roles and related stakeholders are expected to evolve and expand.

Topics of Interest to Community Stakeholders: The interests of the various communities will be determined by comprehensive community assessment utilizing multiple tools and methodologies, community forums and educational seminars. The following are topics that we anticipate will be of interest to Long Islanders and have also been raised as potential areas of interest in discussions with agencies in New Hampshire:

- Remediation of contaminants in the drinking water now and in the future
- Assessment of ongoing adverse health effects of exposure
- How stakeholders can leverage partnerships with other interest groups to improve public health
- Collaboration to address water quality by applying rigorous scientific methodology.

Community Acceptance and Involvement: Letters of support for the YSRTP and this project (included with this application) demonstrate the high level of acceptance and involvement of key local and state stakeholders in efforts to remediate current and prevent future contamination of the area's drinking water supply. Support from these stakeholders will leverage involvement of key community partners on a local level and foster the collaborative efforts of the CEC and overall YSRTP team. The multidirectional communication and sharing of knowledge and resources among these key stakeholders are paramount in the development of a replicable and scientifically-rigorous project model and associated tools. Acceptance and involvement of the following entities have been secured at the time of proposal submission:

- New York State Department of Health, Bureau of Environmental Exposure
- New York State Department of Environmental Conservation
- NY State Center for Clean Water Technology at Stony Brook University
- Suffolk County Department of Health Services, Water Quality Division

- The Group for the East End
- Citizens' Campaign for the Environment
- New Hampshire Department of Health and Human Services, Division of Public Health Services
- New Hampshire Department of Environmental Sciences

D. APPROACH

Theoretical Framework for Community Engagement: The National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and its Agency for Toxic Substances and Disease Registry (ATSDR) have been refining the science and practice of community engagement (6) for over two decades. The working definition of community engagement developed by the CDC in its first edition of the Principles of Community Engagement (7) was "the process of working collaboratively with the groups of people affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being" (7). Using that as a foundation, the Access, Quality, and Use in Reproductive Health (ACQUIRE) Project (8) developed the Active Community Engagement (ACE) Continuum (9) which consists of three levels of engagement: consultative, cooperative, and collaborative, each with a varying level of participation and empowerment. Active Community Engagement is characterized by five components: 1) community involvement in assessment; 2) access to information; 3) decision-making; 4) advocacy to institutions or governing structures; and 5) accountability of institutions to the community/public.

Working with impacted communities around emerging contaminants, such as 1,4-DX, presents some unique challenges. The diversity of sources of drinking water supplies, remediation difficulties, variety of standards/targets for 1,4-DX levels in drinking water, and lack of scientific data on the cancer potential/mechanism of 1,4-DX in humans, and other health effects, are among the issues that affect risk interpretation and sound policy on human health protection measures for this contaminant. A participatory approach is critical to promote meaningful community engagement and environmental justice. This requires democratizing the inquiry and decision-making process to enable full participation of all parties and combining the scientific knowledge of professionals with the local contextual intelligence of affected communities (10). Examples of these approaches are public participation in defining questions for research studies and in contributing observations/knowledge of health effects and pollutants, the use of community-based participatory research (CBPR) methods, supportive actions to build community capacity to engage fully in the process, community-driven research activities, and applying a "learning community" model that engages community members and other stakeholders as active participants rather than passive recipients in educational activities (10). Participatory action research (PAR) is a particularly useful framework for democratizing the process and fostering meaningful collaborations with individuals and groups who are most impacted by contamination issues (10). The community engagement methods employed by the YSRTP will reflect aspects of each of these theoretical models and evidence-based approaches, encompassing the CDC's fundamental principles of community engagement, the ACE continuum, and elements of CBPR and PAR.

Core Structure and Profile: This YSRTP application is driven by community-based concerns about emerging contaminants in drinking water in NY and NH, and the lack of (i) consistent standards on "safe" exposure levels, (ii) understanding about human health effects of exposure to these contaminants, and (iii) effective methods of detection and remediation. In collaboration with community and government organizations in the affected communities, the NY State Department of Health (NYSDOH), the NY State Department of Environmental Conservation (NYSDEC), Suffolk County Department of Health (SCDH), NH Department of Environmental Sciences (NHDES), and the NH Department of Health and Human Services (NHDHHS), the CEC will actively engage community and other stakeholders in multilateral discussions to inform problem-based, solution-focused research. The Core will continue to pursue the Nassau County Health Department as a partner, especially given the prevalence of sites in Nassau County that have 1,4-DX contamination and related problems. The Core will strive for effective information exchange, appropriate communication, and increased participation and education that will enhance public understanding on emergent water contaminant issues. Through such activities, the CEC will establish a model that can be used by other communities facing similar issues. The Core will be structured to incorporate research, teaching, and practice-based expertise.

The CEC Director, **Andrea Boissevain**, **M.P.H.**, is currently Health Director for Stratford, CT, home of a large and highly complex federal Superfund site. Ms. Boissevain is an adjunct faculty member of the Yale School of Public Health (YSPH) Department of Environmental Health Sciences (DEHS). She has more than 25 years of multi-agency experience in addressing public health issues, evaluating human health risks, and communicating

the associated complexities to a wide variety of audiences. Prior to becoming Health Director in Stratford, Ms. Boissevain served as the Stratford Health Department's technical advisor for nearly 13 years on a myriad of issues pertaining to the federal Raymark Superfund clean-up project. She provided crisis management planning and execution in the early phases of the project, reviewed technical documents and drafted comments on behalf of the health department. She also instituted communication and outreach strategies to residents regarding the project's progress and its impact on public health. Ms. Boissevain has played a central role in identifying the communities of interest for the YSRTP, and she has established strategic relationships with public health and environmental services government officials in key areas and partnerships with citizens' advocacy groups on LI and in NH. As CEC Director, she will provide overall leadership and management for the Core, including fiscal and reporting responsibilities, and oversight, implementation and evaluation of the CEC aims. She will serve as an active member of the YSRTP leadership team, and act as the primary liaison among the program project Cores, specifically coordinating activities with the Administrative Core and its Research Translation Coordinator, and with the Research Experience and Training Coordination Core (RETCC).

Elaine O'Keefe, M.S., is Executive Director of both the Office of Public Health Practice and the Center for Interdisciplinary Research on AIDS (CIRA) at the YSPH. She will be a faculty member of the CEC and serve in an advisory capacity on community engagement approaches, evaluation methods, research dissemination, and utilization of students/trainees in the work of the Core. Ms. O'Keefe has worked in governmental public health for 25 years, including 14 years as a local Health Director. She brings extensive experience with Superfund sites and community engagement methods. Her work has focused on academic-practice partnerships encompassing public health workforce development and applied research initiatives, including advising and mentoring graduate students on practicum placements and projects. She is co-director of the Connecticut Public Health Practice Based Research Network and an investigator on affiliated studies. She is also actively engaged in fostering community-based implementation research focused on HIV treatment and care through a New England HIV Implementation Science Network that was created by CIRA and has successfully generated multiple collaborative research partnerships involving diverse stakeholders (including Yale research scientists, government and community agencies. HIV consumers and advocates). Ms. O'Keefe built and maintained a successful model of collaboration among local, state and federal agencies, impacted residents, community groups, and elected officials in order to address a highly complex and widespread environmental contamination situation that evolved into one of the largest federal Superfund sites in New England. She has received national recognition for her leadership in confronting challenging environmental and health issues and was awarded a lifetime achievement award by the US Environmental Protection Agency in 2007.

Alivia Coleman, B.S., will serve as Assistant Director providing coordination, operational and logistic support. Ms. Coleman is an experienced professional with a combination of education in environmental science and community engagement, research experience, and proven skills and knowledge related to project management and evaluation. She will be responsible for developing and implementing the services and activities of the CEC. This will include administrative, operational, community outreach tasks, planning and facilitating community educational activities and monitoring the annual work plan for the Core. Acting as a field-based liaison to the community, the Assistant Director will be responsible for facilitating the bidirectional communication between the YSRTP researchers and community stakeholders. Additionally, the Assistant Director will support the CEC Director in facilitating coordination among the project Cores relative to their community engagements, specifically coordinating activities with the Administrative Core and its Research Translation Coordinator, and with the RETCC.

A CEC Steering Committee will augment the expertise of the CEC leadership/staff team and facilitate ongoing collaborations with investigators from Projects 3, 4, and in the YSRTP that require active participation of residents from the target communities, and with other YSRTP Cores with overlapping and interdependent aims. Research project investigators who will serve on the CEC Steering Committee include: Yawei Zhang, M.D., Ph.D., M.P.H., (Project 3: Exposure Assessments); Drew Gentner, Ph.D., (Project 4: Contaminant Detection Sensors); Jaehong Kim, Ph.D. (Project 5: Advanced Oxidation Treatment Technology); Jordan Peccia, Ph.D., (RETCC), and Paul Anastas, Ph.D., (Administrative Core, Translation Research Coordinator). Debbie Humphries, Ph.D., M.P.H., a YSPH faculty member with expertise in CBPR will also serve on the Steering Committee. In addition, we will invite an EPA Community Involvement staff member from Region 2, and 2-3 representatives from community/agency stakeholder organizations and/or the LI Community Advisory Group that CEC aims to develop

in the first year of the program of the YSRTP, to join the Committee. The Steering Committee will meet monthly and be facilitated by the CEC Director.

Relation to the Overall Center: The CEC will work in tandem with the Administrative Core and its Research Translation Coordinator to promote the success of the YSRTP in advancing public health, developing replicable research tools and methodologies, and empowering communities to advocate for environmental justice and equity. Specifically, the CEC will coordinate its community outreach, education and communications activities with the Administrative Core (and its Research Translation Coordinator) to (i) successfully achieve Specific Aims 2, 3, and 4, (ii) foster interdisciplinary collaboration between YSRTP investigators, and (iii) promote distribution and utilization of YSRTP findings to stakeholders. The CEC will assist the Research Translation Coordinator in designing tools and processes that are accessible to impacted communities, and in utilizing these tools to deliver information to community stakeholders. The CEC will also facilitate active engagement of community members and CAGs in the process of developing materials and tools. The CEC Director will act as the primary liaison with the Administrative Core and its Research Translation Coordinator to ensure bidirectional communication between the YSRTP Cores and community stakeholders. In addition, the CEC Director will collaborate with the Administrative Core and its Research Translation Coordinator to (i) provide appropriate and accessible information and education to community stakeholders, (ii) summarize and disseminate community needs information gathered through community assessments and other tools across the YSRTP, (iii) provide multiple and diverse modes of communicating research findings to the community stakeholders, and (iv) support the collaborative efforts of academic, community and government stakeholders. In collaboration with the Research Experience and Training Coordination Core (RETCC), trainees will be engaged in the development of outreach tools, and in the gathering and dissemination of information within communities served. Trainees will work with the CEC and the Research Translation Coordinator in the creation of accessible and pertinent educational forums and printed materials for specific stakeholder groups (e.g., physicians, school -based groups, business developers, homeowners, advocacy groups). The CEC will also provide opportunities for trainees to develop skills in community engagement through joint educational sessions and workshops organized with the RETCC, and field-based work to apply theoretical constructs of community engagement within a real-life context. Utilizing the efforts of the trainees expands the project's capacity to reach and engage multiple community stakeholders, enhances the trainees' learning experience, and creates the next generation of environmentally-focused researchers who are adept at communicating with lay audiences. The CEC will also remain abreast of the progress and results of the research projects in the YSRTP and provide a vehicle for investigators to disseminate their research aims and progress to community stakeholders, and, where appropriate, help to facilitate study recruitment efforts and engagement of community members in the research process. This includes research Projects 3, 4, and 5, each of which may directly involve participation of residents and/or public health and environmental agencies on LI.

Proposed Aims and Activities: The CEC will achieve its goals through the activities and methods outlined in this section with ongoing evaluation of progress utilizing continuous quality improvement (CQI) approaches to allow for timely, strategic adjustments.

Specific Aim 1: Develop and facilitate the work of one or more Community Advisory Groups on LI in areas impacted by 1,4-DX to ensure representation and engagement of all key groups (community members, governmental, and other stakeholders) in the YSRTP research agenda and process.

Sub-Aim 1.a The CEC has already established connections with locally-based groups whose foci are water-protection and 1,4-DX is a source of concern. Starting with the Village of Garden City's Environmental Advisory Board (an eight-member board that includes up to three high school students), we will also connect with leadership at the Long Island <u>Clean Water Partnership</u> (a comprehensive collaborative comprised of over 90 local environmental and civic organizations and more than 600 individual members). Two of the Partnership's managing entities have provided letters of support: the <u>Citizen's Campaign for the Environment</u>; a citizen's advocacy organization that has raised awareness of emerging contaminants, among other pressing environmental concerns); and the Group for the East End, also a citizen's advocacy group that focuses on education and "policing policies". CEC members will:

- a. Create (with assistance from CEC trainees) a baseline profile of the different communities and their residents to assess who is already actively involved, what their capacity is for involvement, and enumerate concerns and issues.
- b. Identify potentially impacted resident communities (as well as local government, business and community organizations that serve those affected by 1,4-DX exposure issues and/or in proximity to contamination sites) to gauge interest in serving on a county-wide or LI-wide (serving Nassau and Suffolk counties) CAG focused on 1,4-DX.
- c. Work with EPA Community Involvement Coordinators and Citizen's Campaign for the Environment CCE to identify additional partners to explore their interest in forming and participating in a CAG and working with the CEC.
- d. Invite communities to appoint a representative (with the time and commitment) to participate in a CAG for sustained dialogue and engagement.
- e. Facilitate inclusion of and provide opportunities for economically- and linguistically- marginalized communities/community members to participate on the CAG and fully engage in the educational and decision-making processes.
- f. Examine existing government agency health risk documents, policies, and programs regarding water contamination, and provide feedback on policy and programmatic issues.
- g. In conjunction with EPA's regional Community Involvement Coordinators, establish operating guidelines and protocols for and with the CAG.

Sub-Aim 1.b. Following the formation of the CAG, CEC members will:

- a. Organize and support CAG leadership and members to conduct meetings and other activities.
- b. Serve as the primary liaison between researchers and staff in the YSRTP and the CAG, to assure bidirectional communications and engagement in decisions regarding research priorities, and other critical matters.
- **Specific Aim 2:** Engage CAG members in developing educational and research translation materials generated from research projects 1-5 that address key concerns and empower impacted communities to identify and request solutions to outstanding drinking water contaminant issues.

Sub-Aim 2.a. The CEC will utilize CAG members to identify areas of interest and concern and involve them in the process of developing materials that reflect their needs and the needs of the impacted communities represented by the CAG. We will assist in identifying water contamination-related information priorities for the various members by conducting a series of in-depth, semi-structured interviews with members and opinion leaders from each of the participating stakeholder groups. This "hands-on" approach will allow for the collection of information needs in relation to water contamination and its risks, as well as areas of uncertainty. As research priorities of communities change over time (and especially as new information becomes available), re-surveying of stakeholder groups will occur to keep abreast of changes in some (or all) of the community constituencies. CEC members will:

- a. Survey community members and stakeholders to gain insight into current levels of knowledge, awareness, risk perception, prioritization, and interest in topics regarding delivery, consumption and treatment of drinking water, as well as gather questions and responses regarding site exposures and health.
- b. Determine preferred methods and venues for communication for each stakeholder group.
- c. Provide community forums for the generation of hypotheses for additional research that the YSRTP might support (e.g. additional studies to demonstrate the effectiveness of in-home treatment technologies), discuss progress and scientific findings of studies managed by the YSRTP and their relevance, and gather ideas for (and assistance in) the transmission of such findings to the communities.
- d. Develop avenues for expression of the needs and perspectives of different stakeholder groups to the community-at-large to facilitate constructive understanding of different points of view.
- e. Assist in the outreach and advertising for the recruitment of households to participate in research Project 3 (Exposure Assessment). CEC will serve as the interface between participants and investigators to facilitate feedback on study participation, expectations, etc., as well as promoting understanding of the

- data generated from the study.
- f. Disseminate water testing and exposure study results for those LI residents participating in research Project 3 (Exposure Assessment), and work in concert with the Research Translation Coordinator and area health officials to provide context and meaning to the information being provided to the stakeholders.
- g. Recruit households to participate in research Project 4 (Contaminant Detection Sensor technology). The CEC will serve as the interface between participants and investigators to facilitate feedback on the deployed sensor equipment, as well as promoting understanding of the data generated from the sensors.
- h. Recruit households to participate in research Project 5 (Advanced Oxidation Treatment technology). The CEC will serve as the interface between participants and investigators to facilitate feedback on in-home treatment equipment deployed as an intervention strategy, as well as ensuring participants understand how the intervention is health-protective.

Sub-Aim 2.b. It will be essential that the relationships and community participation fueled by these stakeholder partnerships be built and maintained to ensure bidirectional communication, as well as transparency and engagement. To do so, proper tools and processes (and their evaluation) for maintaining communication with the community will be employed. CEC members will:

- a. Create a comprehensive plan for educating diverse community stakeholders involved in this project.
- b. Provide a variety of accessible and relevant informational products through a number of platforms, e.g., the YSRTP website, a CEC blog chronicling activities monthly, maintain social media presence (also a way to monitor and engage community reaction, e.g. using Facebook, Instagram, Twitter, etc.), an electronic quarterly newsletter produced by the CEC, and a yearly report produced in collaboration with stakeholders.
- c. Respond to speaking engagement requests at community events and gatherings and to health care provider groups serving at-risk populations and communities (e.g. Federally Qualified Health Centers).
- d. Investigate participating in the annual "Water We Going to do?" conference, an annual meeting designed to assess current status and promote strategies to protect and manage LI's drinking water and surface water resources.
- e. Introduce community members from other impacted communities to share their stories, their lessons learned and their assessment of how their voices were heard (or not).
- f. Establish a feedback process to engage stakeholders in the development and operational testing of the above-mentioned materials and their delivery methods (e.g. print, public forums, social media, etc.)
- g. Conduct an evaluation to measure the reach of each of the communication channels to assess effectiveness and impact.
- h. Evaluate impact of community level engagement interventions using post-doctoral students and report findings back to stakeholders.

Specific Aim 3: Promote informed health policy change by facilitating active and sustained input from diverse stakeholders (including state regulators and legislators) which can form the basis for better safeguards of drinking water quality and help impacted individuals and communities understand ways in which health risks can be mitigated.

Sub-aim 3.a. Environmental justice encourages fair treatment and meaningful involvement of all community members, without prejudice or privilege, with respect to the development, implementation, and enforcement of environmental laws, regulations, policies, and programs. In collaboration with linguistically-diverse and culturally-informed leaders in the community, the CEC will ensure that all community members have the capacity to provide meaningful input and gain adequate knowledge about each of the five research projects and their potential role. Equity emphasizes the importance of equal protection from environmental and health hazards among community members, as well as equal access to the decision-making process to have a healthy environment in which to live, learn, and work, especially within marginalized communities. The YSRTP will work with the communities and governmental stakeholders to secure environmental equity for affected citizens/residents, adhering to principles and practices that align with health equity, including (but not limited to): encourage fair treatment and meaningful involvement of all community members, without prejudice or privilege, with respect to the development, implementation, and enforcement of environmental laws, regulations, policies, and programs; emphasize the importance of equal protection from environmental and health hazards among community

members, as well as promote equal access to the decision-making process to have a healthy environment in which to live, learn, and work, especially within marginalized communities; address current structural and foundational barriers that lead to the exclusion of minority subpopulations in biomedical research and program development and implementation; and strive for ecological unity and interdependence, focusing on public policy, cessation and investigation of contaminants, and holding past and current producers accountable to the people for the decontamination and treatment of polluted water sources. CEC members will:

- a. Actively recruit economically and linguistically marginalized communities/community members to participate in the educational and decision-making processes.
- b. Involve CEC student interns and RETCC post-doc and graduate trainees in activities to promote and support engagement of marginalized communities in the mission of the YSRTP, including policy change efforts around standards for 1,4-DX and other emerging contaminants in drinking water.
- c. Provide advocacy and policy development skills training for affected communities.

Sub-Aim 3.b. The CEC will utilize a broad range of communication methods to reach the most diverse and largest percentage of the affected populations. In addition to direct meetings with community members, the CEC will utilize a web-based communications model for interacting with the community, including social and traditional media. These tools, as the overall project products, will be replicable and sustainable. Quarterly community forums will ensure/promote active bidirectional communication between the community stakeholders and researchers in the YSRTP, allowing parties to become familiar with each other's perspectives and need for information. CEC members will:

- a. Present active research projects in the YSRTP, progress and research results, followed by open discussion to allow for the understanding of the context and implications of the-scientific work.
- b. Share scientific findings with the communities and educate stakeholders about how to make informed decisions regarding reducing or mitigating exposure to drinking water contaminants.
- c. Offer CEC student interns, post-docs, and graduate students opportunities to gain research and teaching experience by working with the CEC to present scientific findings, engage in discussions, and foster dialogue.
- d. Publish presentations and supporting documents from the investigators on the YSRTP/CEC website to facilitate distribution of new findings.
- e. Work with partners (e.g., Citizens Campaign for the Environment) to reach the larger LI audience and thereby more effectively disseminate progress updates, findings, etc.
- f. Create a portal on the YSRTP website and invite members of the public to submit comments, questions, and concerns to project and program core investigators.
- g. Work with agency partners (e.g. SCDHS, NYSDOH, NYSDEC), leveraging their already existing reach into the community to organize public forum(s) to foster robust dialogue and share what the needs and perspectives of different stakeholder groups are and foster constructive understanding of differing points of view.
- h. Seek to gain better insights into community differences with regard to water contamination knowledge and risk assessment. This will be accomplished through community meetings, panel discussions, surveys and discussions established to examine different perspectives on risk and to provide relevant scientific information.
- **Specific Aim 4:** Apply the lessons learned from community engagement efforts in NY to other communities in NH with 1-4 DX contamination issues in which the outreach effort and educational materials developed for LI can be adjusted to meet the specific needs of other communities.

Sub-Aim 4.a. To achieve Aim 4 CEC members will:

- a. Rigorously document and evaluate processes, methodologies and outcomes of community engagement interventions in LI.
- b. Conduct regional and/or national workshop(s) to ensure that the evaluative results and lessons learned are shared with communities, and our regional and national counterparts.
- c. Publish workshop proceedings to allow others to learn from our work.

- d. Generate and operationally test best practices of community-driven methods of engagement in the research and policy setting process for emerging contaminants (specifically 1,4-DX and its co-contaminants).
- e. Work with established partners in NH and NH community stakeholders to discuss the most useful means of adapting approaches found to be effective in LI for use in NH.
- f. Replicate communication materials, systems, and tools to effectively communicate with and engage stakeholders in communities in NH where emerging water contaminants and particularly 1,4-DX are an issue.

Evaluation and Management Plan

The CEC has developed a comprehensive evaluation plan to monitor progress and impact over the five-year project period for the YSRTP that is too detailed to include in this narrative. The plan identifies process and outcome measures for all core aims and activities. Illustrative process measures contained in the CEC evaluation plan include: records of CEC outreach to engage stakeholders including meetings with individuals and agencies; records of outreach to recruit CAG members; inclusion of marginalized groups in outreach and recruitment; documentation/lists of all engaged individuals and agencies; records on community forums, requested speaking engagements, and workshops facilitated by CEC; diversity and volume of stakeholder participation in CEC sponsored forums, workshops, trainings; development and piloting of community assessment and other survey tools; creation of a LI CAG; records of CAG meetings/activities and YSRTP participation; documentation of input from stakeholders on communication methods and materials; completion, piloting and dissemination of educational materials; diversity of YSRTP informational platforms employed; community policy and advocacy training curriculum and participation; involvement of interns and trainees; existence of YSRTP portal for stakeholder interactions/comments; role of CEC in recruitment for research studies; and completed analyses/reports identifying best practices for dissemination and replication. Examples of outcome measures include: findings and utilization of community assessment; levels of engagement of stakeholders; representation and sustained input of marginalized groups; communication methods and tools that reflect stakeholder input; stakeholder evaluation of dissemination approaches, tools and penetration; functionality of the CAG; recruitment/retention of local participants for research studies in the YSRTP; participant/consumer evaluation of workshops, forums, website, trainings; integration of interns and trainees and evidence of their knowledge/skill gains; documentation and dissemination of best practices of community engagement on LI; and level of interest/uptake in replicating approaches in other settings. A corresponding annual work plan will be developed each year to detail action steps and timelines for completing core activities, identify responsible parties, and specify metrics to track and evaluate progress drawn from the CEC evaluation plan. The CEC Director will oversee the implementation of the evaluation process, supported by other Core personnel, incorporating continuous quality improvement approaches to allow for timely, strategic adjustments in procedures and foci.

Table 1. CEC Timetable

Table 1. CEC Timetable	Year 1	Year 2	Year 3	Year 4	Year 5
Aim 1					
Connect with EPA, and existing groups like CCE and Clean Water Partnership to promote the YSRTP and recruit diverse members to participate in a CAG.	Х				
Establish the CAG.	Х				
Identify forums to present the overall YSRTP program and the 5 research projects, highlighting community role(s).	Х				
Engage post-docs and student interns to create a baseline profile of the different communities and capacity for involvement	Х				
Initiate CAG meetings with members directing frequency and topics, including presentations of and feedback for all 5 research projects.	Х				
Aim 2					
Conduct community survey of knowledge, perceptions.	Х				
Assess stakeholder preferences for communication and develop education/communication plan.	Х	Х			
Develop and operationally test various platforms to encourage bidirectional communication (e.g., interactive portals).		Х	Х	Х	
Organize forums, workshops, listening sessions with stakeholders related to the study projects in the YSRTP and recruitment efforts.		Х	Х	Х	Х
Recruit households/participants for Project 3 (Y1); Projects 4 & 5 (Y3, Y4 depending on progress with developing technologies).	Х		Х	X	
Establish a feedback process with stakeholders to pilot and evaluate educational materials and dissemination approaches.		Х	Х		
Evaluate community engagement interventions with post-docs and report to stakeholders.		Х	Х	Х	Х
Disseminate study findings and results.		Х	Х	Х	Х
Aim 3					
Establish principles and practices that align with health equity.	Х				
Conduct targeted recruitment of marginalized communities.	Х	Х	Х	Х	Χ
Determine if additional stakeholders should be brought into the process.		Х	Х	Х	
Organize community forums with agencies and community organizations to elicit perspectives of different stakeholders on health risks, ways to communicate risk, regulatory issues related to emerging water contaminants, etc.		Х	Х	Х	
Provide training on advocacy and policy development.		Х	Х	Х	
Involve post-docs and student interns in outreach to marginalized communities and presentations at community forums/trainings					
Create policy tracker to assess impact of community capacity building and engagement on policy development.		Х	Х	Х	Х
Aim 4					
Conduct regional, national workshops to disseminate findings and publish proceedings.				Х	Х
Conduct comprehensive, cumulative review and evaluation of engagement, reach and impact of interventions.					Х
Publish a 5-year compilation (complete with infographics) of research findings from all 5 projects.					Х
Maintain communications with NH health and environmental agencies relative to their water sampling program and when it would be appropriate to transfer lessons learned in LI to communities impacted in NH. Identify how replication of community engagement in LI would be accomplished (and if it is applicable) in NH.	Х	Х	Х	Х	Х

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