ABSTRACT

MAY, KATLYN. Exploring Environmental Health Literacy Among Communities Impacted by PFAS Exposure: A Mixed Methods Study (Under the direction of Dr. KC Busch).

Environmental health sciences research investigates the ways in which the environment interacts with human health, in the hopes of reducing and preventing negative health outcomes. Some such research relies on the voluntary participation of members of the public to characterize environmental exposures and document health effects over time. It has become increasingly common for researchers conducting these studies to share data and results with participants. This process, often called report back, is thought to build participants' environmental health literacy (EHL)—the combination of knowledge, efficacy, and behaviors needed to reduce environmental exposures. Report back and EHL are both relatively new concepts, however, and there is still limited research that systematically evaluates the relationship between the two. Moreover, because environmental exposures and the process of responding to them are such context specific phenomena, each instance in which research, report back, and EHL are explored is inherently unique, and helps provide a more nuanced understanding.

The purpose of this research was to contribute to this growing body of literature by exploring the relationship between research participation, report back, and EHL in a community impacted by per- and polyfluoroalkyl substances (PFAS) contamination. Participants were all residents of the Cape Fear River basin, which has elevated concentrations of PFAS in the environment, including in surface, ground, and drinking water supplies. Additionally, all participants are currently enrolled in an ongoing PFAS health study, the GenX Exposure Study. In the first study, a survey questionnaire was sent to all households currently enrolled in the GenX Study to measure knowledge, attitudes, beliefs, and behaviors among participants. Linear regression models were used to determine significant predictors of risk reduction behaviors, and thematic analysis of

open-ended responses was used to characterize participants' motivation and satisfaction related to research participation. Results showed the importance of report back as a benefit to participants, and the role that affective constructs play in predicting behaviors.

In the second study, in-depth interviews were conducted with 33 participants from the Cape Fear River basin. Participants were asked about their experiences learning about and living with PFAS contamination, including the role of research and report back in how they make decisions in response to PFAS exposure. Interview transcripts were inductively coded, and results highlighted the ways in which living with chronic contamination is broader than what is measured in an environmental or biological sample, and impacts the broader lived experience of each participant.

Both studies underscore the importance of report back for demonstrating reciprocity to participants and its ability to contribute to participants' EHL, including their knowledge and self-efficacy. Results also provided insight into the lived experience of PFAS contamination, and how participants make sense of what knowledge, skills, and actions are needed to address exposure. These findings highlight an opportunity for intentionally designing report back to better support participants' information needs, as well as their capacity to enact individual and collective behaviors that ultimately reduce and prevent negative health outcomes.

Exploring Environmental Health Literacy Among Communities Impacted by PFAS Exposure: A Mixed Methods Study

by
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APPROVED BY:

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DEDICATION

This work is dedicated to each person who graciously took the time to participate in these studies; I could not have done this without you. To all residents of the Cape Fear River basin, you have made me a better scientist. Your stories have instilled in me a commitment to conduct and communicate research in ways that are meaningful for your and any other communities facing unjust exposure to understudied, underregulated environmental contaminants.

BIOGRAPHY

Katy May is co-Director of the Community Engagement Core (CEC) for the Center for Human Health and the Environment (CHHE), an environmental health science research center at North Carolina State University. Her work focuses on sharing environmental health research with communities impacted by environmental contamination, working with educators to translate research for formal and informal learning contexts, and helping researchers engage with and be responsive to the public's environmental health concerns. She holds a B.A. in environmental studies from Franklin & Marshall College and a master's in environmental management from Duke University. She lives with her two adorable dogs in Raleigh, NC.

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spirit and trusting me with your participants for this research. The positive things people said in their survey responses and during interviews are a testament to your team's dedication to people in the Cape Fear River basin. To my water warriors, Dana, Emily, and Kemp, thank you for sharing your time, expertise, and unending badassery with me.

Finally, thank you to my human and canine loved ones. As it turns out, finishing this degree while working, coaching, fostering, bridesmaiding, and all my other ventures was indeed quite difficult. So, thank you to my parents and friends for oscillating between fervent support and patient tolerance during this process. I love you. Relatedly, thank you to Jake and Rosie (and the rotating cast of adoptable SPCA dogs in my home) for your moral support, snoring under my desk and keeping my feet warm at all hours of the day and night. I also love you.

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CHAPTER 1:

INTRODUCTION

Environmental health literacy (EHL) draws on the underlying principles of science, health, and environmental literacies to frame how people understand and respond to hazardous environmental exposures and contamination (Finn & Fallon, 2017). EHL has been conceptualized as a combination of knowledge, efficacy, and behaviors that reduce risk and improve health (Finn & Fallon, 2017; K. Gray, 2018). Some literature suggests that sharing data from exposure and health studies with participants, also known as report back, can build EHL among study participants (Perovich et al., 2018; Ramirez-Andreotta et al., 2016a; Sandhaus et al., 2018). Many environmental issues are unique to the communities in which they occur (K. M. Gray & Lindsey, 2019; Lindsey et al., 2021b), and the lived experience of environmental contamination can be complex and nuanced even within a community (Edelstein, 2018; Vyner, 1988). Moreover, many environmental issues require collective action and policy change to ensure longer-term remediation and solutions (L. F. Davis & Ramírez-Andreotta, 2021; Korfmacher & Brody, 2023; Oksas et al., 2022). This dissertation research explores the relationship between research participation, report back, and EHL—including individual and collective behaviors—in the context of contaminated drinking water. Data were collected through survey questionnaires and in-depth interviews to understand how people experience long-term environmental contamination, and the role of research and report back as they make sense of and respond to it.

Science, Environmental, and Health Literacies

The establishment of science literacy in the early 20th century as a measure of broad scientific knowledge, attitudes, and behaviors has since led to various domain-specific subfields of scientific literacies. The broader theoretical concept of science literacy, the notion that practicing and understanding science should support societal wellbeing, has existed for hundreds of years (P. D. Hurd, 1998). It was not until the 1950s, however, that the term "scientific literacy" first appeared in the education literature, encouraging the field of science education to more explicitly emphasize the connections between science and the public interest (P. Hurd, 1958; P. D. Hurd, 1998). While science literacy has roots in classroom-based education to increase general science knowledge among the public (Allum et al., 2018; DeBoer, 2000; Feinstein, 2011a; Liu, 2009), it has evolved to reflect a broader understanding of science and its connection to society (P. D. Hurd, 1998). Some authors have articulated a view of science literacy that hinges on improving the public's attitudes towards science for the purposes of civic engagement around collective scientific issues, which ultimately leads to improved public policies, "better economic returns," and a "more ethical world" (Liu, 2009; Snow & Dibner, 2016).

During the 1960s, environmental awareness was increasing throughout the United States, and culminated in the first Earth Day, creation of the National Institute for Environmental Health Sciences, and establishment of the US Environmental Protection Agency (Finn & O'Fallon, 2017; North American Association for Environmental Education, 2021). Globally, the 1970s saw the world's first international meeting on environmental education, large-scale, multistate assessments of environmental literacy, and a new global commitment to formal and informal education for environmental literacy (Marcinkowski et al., 2012; UNESCO, 1978). Today,

environmental literacy is comprised of knowledge of environmental issues and pro-environmental behaviors, a distinction from the initial knowledge-centric focus of science literacy (Disinger & Roth, 1992; McBride et al., 2013a).

The term "health literacy" was first used in 1974 in a report about formal, classroom-based health education (Ratzan, 2000; Simonds, 1974), and it has traditionally put more emphasis on foundational literacy—reading, writing, and numeracy—than science and environmental literacies, citing associations between improved basic literacy and improved health outcomes (Rudd, 2010). Like science literacy, health literacy is based on a transfer of knowledge and recommendations from the expert, the prescriber, to the non-expert, the patient (Nutbeam et al., 2018), but current definitions also emphasize a broader ability to seek out and understand health information and make informed decisions for health promotion (Institute Of Medicine| Board On Neuroscience And Behavioral Health| Committee On Health Literacy, 2004; Lindsey et al., 2021a; Nutbeam, 2008, 2009; Nutbeam et al., 2018; Okan et al., 2019; Roundtable on Health Literacy et al., 2013; Sørensen et al., 2012).

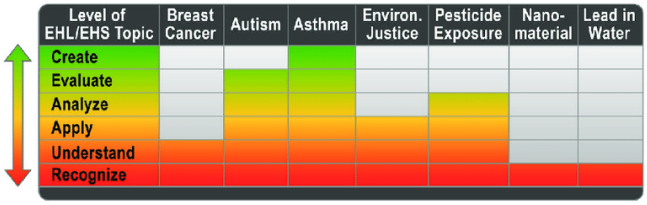
Development of Environmental Health Literacy

Drawing from the decades of literature on science, environmental, and health literacies, environmental health literacy (EHL) was first proposed by program officers from the National Institute for Environmental Health Sciences (NIEHS) as a framework for knowledge, skills, and behaviors in response to environmental hazards (Finn & O'Fallon, 2017). NIEHs is one of the largest funders of environmental health science (EHS) research, which seeks to understand the ways in which the environment impacts human health, exploring how chemical and non-chemical stressors impact cell or tissue function, disease pathways, and population health outcomes (Olden & Klein, 1995; Wilson & Schwartz, 2006). Most EHS research questions are

prompted by environmental hazards to which people are already acutely or chronically exposed (Finn & O'Fallon, 2017; Lioy, 2010; Wilson & Schwartz, 2006). EHS uses a range of approaches to measure and quantify exposures, determine the mechanistic impacts on biological systems, and improve human health outcomes over time (Brody et al., 2007; Lioy, 2010; Schulte, n.d.; Wilson & Schwartz, 2006). As such, EHL was introduced as a multidisciplinary framework that draws on education, communication, and exposure science to describe how EHS information might be translated into health-protective knowledge, capacity, and behaviors (Finn & O'Fallon, 2017; K. Gray, 2018).

Initially, EHL was depicted as an adaptation of Bloom's Taxonomy, with levels of EHL that vary depending on the environmental issue (e.g., asthma, pesticides, lead), and one's capacity to respond to it as seen in Figure 1.1 (Finn & O'Fallon, 2017).

Figure 1.1. *Bloom's Taxonomy of EHL*



Note. Finn and O'Fallon (2017).

Gray (2018) builds on this, creating a concentric model of EHL with three overarching dimensions—knowledge and awareness, skills and self-efficacy, and community change—which are driven by behaviors that reduce exposure and protect health (See Figure 1.2).

EHL draws on the conceptual underpinnings of science literacy, and the health-protective and pro-environmental behavioral goals of health and environmental literacies (Finn & O'Fallon, 2017), emphasizing informed decision making to reduce individual and collective exposures to environmental hazards (K. M. Gray et al., 2021; Hoover, 2019). Indeed, Finn & O'Fallon assert

that EHL "represents a philosophical perspective, a public health policy to improve literacy and health literacy in the general public, and a set of strategies to empower individuals and communities to exert control over the environmental exposures that may lead to adverse health outcomes"(Finn & O'Fallon, 2017). Ultimately, EHL is the range of capabilities needed to understand environmental exposures and their impacts on human health, the self-efficacy to address exposures, and the actions that improve individual and collective health outcomes (Finn & O'Fallon, 2017, 2018; K. Gray, 2018; Hoover, 2019).

Figure 1.2. *Conceptual Model of EHL*

Note. Gray (2018).

Environmental Health Sciences and Literacy

In the last ten years, EHL has become increasingly prevalent in research funded by NIEHS, appearing in presentations (National Institute of Environmental Health Sciences, 2014; Valdez et al., 2014), peer-reviewed literature (e.g., D. Brewer et al., 2019; L. Davis et al., 2018; Garzón-Galvis et al., 2019; K. Gray, 2018; K. M. Gray et al., 2020, 2021; Irvin et al., 2019; Kim et al., 2024; Koester et al., 2021; Lebow-Skelley et al., 2022; Lichtveld et al., 2019; Lindsey et al., 2021b, 2022; Miller et al., 2016; Perovich et al., 2018; Ramirez-Andreotta, 2016; Ramirez-

Andreotta et al., 2016a; Ramos et al., 2012; Raufman et al., 2020; Rohlman et al., 2022; Sandhaus et al., 2018; B. M. White et al., 2014), and directives and guidance from the agency (Department of Health and Human Services & National Institutes of Health, 2022b, 2022a). Finn and O'Fallon (2017) believed that EHL might have first emerged as its own "distinct subfield" because of the increase in EHS research happening directly in/with impacted communities, largely supported by NIEHS funding. Indeed, many papers published on EHL are generated from larger EHS studies funded to investigate specific types of exposures or environmental contaminants and their impact on human health (e.g., K. M. Gray et al., 2021; Lebow-Skelley et al., 2022; Madrigal et al., 2016; Ramirez-Andreotta et al., 2016a, 2016b; Sandhaus et al., 2018). One reason for this may be the alignment between EHL and the process of returning and disseminating results from EHS studies.

Many EHS researchers that aim to characterize human exposure to environmental hazards rely on members of the public to participate in their studies, to submit environmental or biological samples (e.g., tap water, house dust, blood, urine), or answer questions about their medical history and lifestyle habits (Calafat et al., 2007; Creager, 2018; Ladeira & Viegas, 2016; Quigley, 2012; Ramirez-Andreotta et al., 2014, 2016a). These data help researchers understand sources and routes of exposure, and studies that are able to retain participants' ongoing engagement are better able to identify links between exposure and health outcomes over time (Lioy, 2010). One strategy that is purported to encourage participant retention is sharing research results back with participants (Brody et al., 2014a; Dunagan et al., 2013). Although initially met with skepticism by some researchers and university institutional review boards for fear of causing undue worry (Brody et al., 2018; Morello-Frosch et al., 2009, 2015), this process of reporting back research results (report back) has since become increasingly common, even when

there is a lack of scientific, regulatory, or medical guidance in which to couch the data (R. G. Altman et al., 2008; Brody et al., 2014a Brody et al., 2009, 2014a; Brown et al., 2010; Morello-Frosch et al., 2009; Ramirez-Andreotta et al., 2016a, 2016b).

The increase in report back efforts is one of the reasons that the public has more access than ever to EHS data (Altman et al., 2008; Brody et al., 2007), including personal data and measurements to which they may not have otherwise had access (Sandhaus et al., 2018; Soleri, D., Long, J.W., Ramirez-Andreotta, M.D., Eitemiller, R. and Pandya, 2016). Thus, a promise of report back is that providing this information supports EHL by increasing their knowledge and capacity to make informed health-protective decisions in response (L. Davis et al., 2018; Lindsey et al., 2022; Tomsho et al., 2022). For example, some EHS researchers have documented changes to information seeking and purchasing behaviors among participants after receiving their report back materials (Brody et al., 2014a, 2018; Brown et al., 2012; Perovich et al., 2018; Ramirez-Andreotta et al., 2016a). Given the relative nascence of EHL, however, there is limited consistency in how EHL is measured across the literature, including EHL in the context of report back, which can make it difficult to draw comparisons across the field, or to assess impacts beyond knowledge (K. M. Gray & Lindsey, 2019; Lindsey et al., 2021b). For instance, there have been a variety of studies that used survey instruments to measure constructs associated with EHL, like knowledge and self-efficacy, but each one operationalized those constructs differently, varying in scope, type of hazard, and choice of indicators and metrics, or (Binder et al., 2022; K. Gray, 2018; K. M. Gray & Lindsey, 2019; Irvin et al., 2019; Kim et al., 2024; Lichtveld et al., 2019; Lindsey et al., 2021b; Madrigal et al., 2016; Ratnapradipa et al., 2015; Raufman et al., 2020; Rohlman et al., 2022). Indeed, in their initial paper, Finn and O'Fallon (2017) acknowledged that "as EHL evolves, it will be measured and applied in many ways depending

on the disciplinary lens, the aim, and the audience." Given the community-specific nature of environmental exposures and mitigation options, and therefore EHL itself, it might be expected that assessments of EHL would inherently vary as such (K. M. Gray & Lindsey, 2019).

Still, reducing exposure to environmental hazards requires action (Finn & Fallon, 2017; K. Gray, 2018), and permanent, long-term exposure reduction—the outermost "community change" circle of Gray's concentric model of EHL—requires people to take public actions that create structural changes and have collective impacts (Ardoin et al., 2023; L. F. Davis & Ramírez-Andreotta, 2021; Gibson et al., 2024; K. Gray, 2018; Stern, 2000). Thus, there is a need to understand if and when people choose to take private and public exposure reduction behaviors. That is, if EHL is ultimately leading to individual and collective exposure reduction, and report back is one way to build EHL, then report back should theoretically have some relationship to these private and public behaviors. This research was designed to investigate this relationship, by looking holistically at exposure, research participation, receiving report back, behaviors, and community change. In the future, a way to operationalize and do this consistently across EHS studies, may be informative for ultimately understanding the impact of EHS research—and the data shared through report back—on communities impacted by environmental hazards.

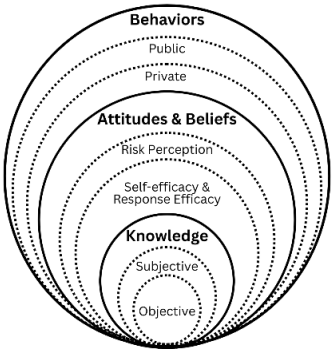
Conceptual Framework

Both studies in this dissertation used EHL as an overarching theoretical framework; they were each grounded in the assumption that a combination of knowledge, capacity, and behaviors are needed to reduce environmental hazards at individual and collective scales. The first study used this three-part conceptualization of EHL as a foundation from which to explore how other

constructs might be antecedents to exposure reduction behaviors, either fitting within or expanding the existing concentric model (See Figure 1.3).

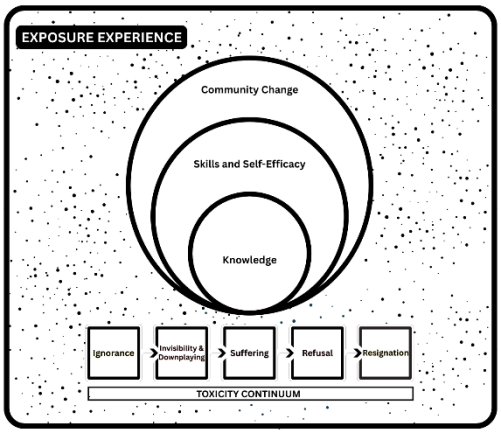
The second study added Exposure Experience (Adams et al., 2011; Brown, 1992, 1995a) and the Toxicity Continuum (Renfrew & Pearson, 2021), creating a conceptual framework in which EHL exists (See Figure 1.4). The toxicity continuum represents the heterogeneity of risk perception, the range along which members of impacted communities can perceive and make sense of an environmental hazard. Exposure experience comes from the field of medical sociology, and emphasizes the interconnectedness of one's lived experience and their understanding of environmental exposures.(Adams et al., 2011; Altman et al., 2008; Brody et al., 2007). Study 2 was based on a conceptual model that EHL exists relative to one's emotions along the toxicity continuum and their overall exposure experience, acknowledging the nuance and contextual nature of environmental contamination. This research was an important opportunity to investigate how report back relates to EHL and how EHL manifests within the context of contaminated communities' exposure experiences.

Figure 1.3. *Conceptual Framework for Study 1*



Note. Adapted from Gray (2018).

Figure 1.4. *Conceptual Framework for Study 2*



Research Context

This research took place within North Carolina's Cape Fear River basin, due to their widespread exposure to per- and polyfluoroalkyl substances (PFAS) and an ongoing PFAS health study that provides report back to participants (Hoppin, 2023; Kotlarz et al., 2020). PFAS are a class of over 14,000 chemicals with a unique molecular structure that makes them water, stain, and fire resistant (Agency for Toxic Substances and Disease Registry, 2023; Fenton et al., 2021; Richter et al., 2018). As such, PFAS have been used for decades to make waterproof clothing, non-stick cookware, firefighting foams, furniture coatings, and food packaging (Richter et al., 2018). Often called "forever chemicals," PFAS are ubiquitous, environmentally and biologically persistent, and are present in the serum of more than 99% of Americans (Kwiatkowski et al., 2020; Sunderland et al., 2019; National Academies of Sciences, 2022; Richter et al., 2018). Current data suggest that even low levels of PFAS exposure can contribute to a range of negative human health outcomes (Blum et al., 2015; National Academies of Sciences, 2022). The most common ways for PFAS to enter the environment are industrial manufacturers discharging PFAS in wastewater or through air emissions, the use of PFAS-

containing firefighting foams that run off into surface or groundwater, and the land application of PFAS-containing biosolids (DeSilva & Elmelech, 2012; Kwiatkowski et al., 2020; Sunderland et al., 2019).

Despite the ubiquity of PFAS in today's society, communities in North Carolina's Cape Fear River Basin have been uniquely exposed to elevated levels of PFAS contamination, likely over the course of decades, despite only beginning to receive public attention within the last eight years (Cahoon, 2019, 2020; Hagerty, 2017; Sun et al., 2016). In the upper part of the river basin, decades of textile manufacturing and the application of PFAS-containing sludge to agricultural fields has impacted the drinking water of communities like Pittsboro, NC. In Fayetteville, NC, a fluorochemical manufacturing company affiliated with DuPont has been discharging PFAS into the air and water since the 19080s (Cahoon, 2019, 2020; Hagerty, 2017; Wagner & Buckland, 2017). Air and surface water emissions have contaminated the groundwater, river water, and therefore drinking water for communities in the middle and lower Cape Fear River basin. In 2016, researchers discovered the presence of multiple PFAS in the Cape Fear River—North Carolina's largest drinking water source—and documented the inability of municipal water treatment systems to remove PFAS from finished drinking water (Sun et al., 2016). Within six months, local media outlets reported the findings, (Hagerty, 2017; Wagner & Buckland, 2017) generating attention from both concerned residents and research funding agencies (Calloway et al., 2020; Obeng-Gyasi, 2022). In response, researchers from NC State began meetings with concerned residents to help answer questions and understand the extent of the issue. In November 2017, NC State researchers received NIEHS funding for the GenX Exposure Study (GenX Study), designed largely in response to the questions generated by initial meetings with concerned residents (Hoppin, 2023; Kotlarz et al., 2020).

Today, the GenX Study is a longitudinal health study that has been collecting biological, health, and questionnaire data from residents in the upper (e.g., Pittsboro), middle (e.g., Fayetteville), and lower (e.g., Wilmington) portions of the river basin. Each time participants provide samples, analytical results are reported back to participants in multiple ways. Each participant receives individual letters with their individual measurements and reference values, and community meetings are hosted by the research team to present aggregate community-level results are presented and answer participant questions as needed. The study's report back materials were not originally designed using an EHL framework and have not previously been systematically evaluated by the GenX Study team. Ultimately, the GenX Study was designed to answer questions about chemical exposures and long-term health outcomes, not explicitly to influence EHL or change the knowledge, capacity, or behaviors of its participants. Still, because the literature emphasizes report back's relationship to EHL, the GenX Study and its participants present an interesting case study to explore EHL as a set of individual constructs (e.g., knowledge, capacity, behaviors), and EHL as an overarching framework for EHS research in impacted communities.

Since the news of PFAS in the Cape Fear River first broke in 2017, data from continued EHS research efforts in conjunction with consistent pressure from residents of impacted communities has led to a variety of actions at the state, national, and international levels (See Figure 1.5). This dynamic policy landscape, in addition to documented widespread PFAS contamination and the ongoing PFAS health study in the Cape Fear River basin created a unique context in which to study EHL, report back, the nuanced lived experience of environmental exposures.

Figure 1.5. *Timeline of Important Events Related to PFAS in the Cape Fear River Basin*

Research Questions and Description of Papers

This research aimed to make valuable contributions to the literature by using mixed methods to explore the relationship between EHL and report back, specifically how receiving personal PFAS measurements relates to how people make sense of exposure, enact protective behaviors, and perceive community change. It is organized into two stand-alone but complementary studies that incorporate aspects of an explanatory sequential design, where the quantitative data generated in the first study helped identify patterns that qualitative data from the second study helped explain and contextualize (J. W. Creswell, 2013; DeCuir-Gunby, 2008). Moreover, this mixed method design supported a pragmatic, outcome-oriented approach to research that aimed to generate actionable findings for the field (Feilzer, 2010). Participants in both studies are from the same geographic area with chronic, widespread environmental contamination, are all currently enrolled in the GenX Study, and have all received individual report back materials.

Paper 1

The first study used a survey questionnaire with closed- and open-ended responses to measure motivations, knowledge, attitudes, and behaviors among GenX Study participants. Each household currently enrolled in the GenX Study (N = 634) was mailed a 24-item questionnaire to complete and return. Results from the 345 survey responses (53.7% response rate) were analyzed using linear regression and thematic analysis to answer the following research questions:

1. After receiving results from a PFAS exposure study, how does participants' knowledge, motivation, perceptions, and beliefs relate to their capacity for and intended actions?
2. How do participants describe their motivations and experience participating in a PFAS exposure study?

Results from three step-wise linear regression models showed that no factors—including sociodemographics—were consistent predictors of private and public behaviors. However, the significance of constructs like risk perception, subjective knowledge, and efficacy highlighted how a broader conceptualization of EHL might better predict or explain behaviors more robustly. Results from thematic analyses of three open-ended survey questions reiterated participants' desire to learn their personal PFAS levels through report back and the importance of risk perception as behavioral antecedents for both research participation and exposure reduction actions. This study also highlighted an underlying sentiment among participants that they lacked efficacy to act beyond a small set of private behaviors. Results from this study outlined trends among GenX Study participants that the second study used to explore in-depth through interviews.

Paper 2

The second study builds upon the first by using in-depth interviews to investigate how people experience PFAS exposure, how they describe their knowledge, efficacy, and behaviors related to PFAS, and what structural changes they think are needed to ultimately solve PFAS contamination in their communities. All adult GenX Study participants (n=994) were invited via email to participate in an interview; 134 people (13.5%) responded and completed the consent process, and 33 were ultimately selected and able to participate. Each participant took part in an interview via Zoom that lasted 37 minutes on average, generating 261 pages of transcribed data to answer the following research questions:

1. How do people experience living with PFAS contamination?
2. What does EHL look like in PFAS impacted communities?
3. What do residents perceive is needed to address their PFAS contamination?

Data were analyzed using inductive thematic coding, allowing for intra-community and cross-case comparisons among the three communities. Results highlighted the nuanced, personal experience of PFAS exposure in the Cape Fear River basin, including the emotional and physical burdens felt by residents. This study also reiterated participants' feelings of limited efficacy and capacity relative to PFAS that the first study highlighted. Both studies underscore potential opportunities for report back to better account for participants' EHL—what participants perceive as necessary information and resources to enact PFAS risk reduction behaviors.

Research Worldview

As a researcher, I situated this work within a pragmatic worldview (Dewey, 1903; Morgan, 2014), and intended for both studies to generate data and practical recommendations for research, report back, and community engagement processes (J. Creswell, 2013; Feilzer, 2010). In acknowledging my positionality and the broader sociopolitical contexts in which the research was embedded, my time spent in NIEHS-funded research centers and with residents working on PFAS in the Cape Fear River basin is inherently reflected in how I approached this research and the methodology therein (J. Creswell, 2013; Feilzer, 2010; Mertens & Wilson, 2012). As with many phenomena of academic research interest, the complexity of understanding and evaluating EHL in PFAS impacted communities was well suited to a mixed methods design that allowed for exploration of knowledge, attitudes, beliefs, and actions at multiple levels (DeCuir-Gunby, 2008). This research was designed to produce results that are meaningful to current environmental health science researchers and practitioners, to inform current practices related to report back, and to contribute to a larger conversation about supporting individual and collective exposure reduction in contaminated communities.

CHAPTER 2:

UNDERSTANDING ENVIRONMENTAL HEALTH LITERACY IN THE CONTEXT OF REPORTING BACK RESEARCH RESULTS TO STUDY PARTICIPANTS

Abstract

Environmental Health Literacy (EHL) frames the knowledge, skills, and behaviors necessary for addressing individual and collective exposures to environmental hazards. While it is assumed that there is a relationship between receiving environmental health science data and EHL, there is limited evaluation of it. This study investigated the dimensions of EHL and exposure reduction in the context of receiving report back materials from the GenX Exposure Study, a longitudinal study investigating the health effects of exposure to per- and polyfluoroalkyl substances (PFAS). Using a 24-item questionnaire, current participants in the GenX Study responded to items measuring knowledge, attitudes, efficacy, and behaviors. Results from three linear regression models and qualitative thematic analyses provided insight into which variables may be significant predictors of risk reduction behaviors, the importance of accounting for affective constructs like risk perception and subjective knowledge within EHL, and opportunities to improve report back letters to support behavior change.

Introduction

Environmental health science (EHS) research seeks to understand the ways in which the environment impacts human health, exploring how chemical and non-chemical stressors impact cell or tissue function, disease pathways, and population health outcomes (Olden & Klein, 1995; Wilson & Schwartz, 2006). Today, most EHS studies that collect biological or environmental samples from members of the public have some element of report back—sharing individual measurements, summary statistics, or regulatory guidance back to participants (Brody et al., 2021). This process has been purported to build environmental health literacy (EHL), reduce environmental exposures and risk, and improve health (Perovich et al., 2018; Ramirez-Andreotta, 2016; Ramirez-Andreotta et al., 2016b; Sandhaus et al., 2018). Still, work to explicitly characterize EHL in the context of report back is limited; it tends to focus on objective knowledge, and may fail to capture the broader multidimensional nature of EHL (K. Gray, 2018; K. M. Gray & Lindsey, 2019). This limits the claims and comparisons that can be made about the relationship between participating in EHS research, receiving personal results, and EHL.

This study used EHL as a lens through which to examine the report back process for participants currently enrolled in a longitudinal health study. A 24-item questionnaire was sent to all households currently enrolled in the GenX Exposure Study (GenX Study), a health study exploring exposure to per- and poly-fluoroalkyl substances (PFAS) among residents of North Carolina's Cape Fear River basin. Survey items measured participants' knowledge efficacy, attitudes, perceptions, and behaviors related to report back and PFAS more broadly. By intentionally looking at multiple dimensions of EHL in the context of an understudied class of chemicals, this study fills an important gap in the literature on report back and has practical implications for the GenX Study's ongoing engagement with its participants.

Environmental Health Science Research and Reporting

Sources of chemical and non-chemical stressors are ubiquitous throughout our environment (Centers for Disease Control and Prevention, 2022; US Environmental Protection Agency, 2023). Many of these stressors are investigated by EHS research, which attempts to understand the links between environmental exposures and human disease to ultimately reduce, prevent, or mitigate negative health outcomes (Lioy, 2010; National Institute of Environmental Health Sciences, n.d.; Olden & Klein, 1995; Schulte, n.d.; Wilson & Schwartz, 2006). EHS research questions are prompted by environmental hazards to which many individuals and communities are acutely or chronically exposed (Finn & O'Fallon, 2017; Lioy, 2010; Wilson & Schwartz, 2006) and aim to understand and ultimately prevent human disease. (Lioy, 2010; National Institute of Environmental Health Sciences, n.d.; Schulte, n.d.; Wilson & Schwartz, 2006) Traditionally, EHS has investigated disease outcomes after exposure to a single environmental hazard, focusing on the unidirectional relationship from one exposure to one health effect. (Lioy, 2010) But humans face myriad potential exposures through air, water, food, soil, and household products, (US Environmental Protection Agency, 2023) and characterizing the severity and impact of a contaminant requires more than an understanding of its chemistry (Hoover, 2019). As such, biomonitoring studies collect environmental (e.g., garden soil, tap water, house dust, ambient air), biological (e.g., skin, blood, urine), and behavior information (e.g., occupation, lifestyle habits) to better understand how people may be exposed to environmental contaminants in the first place (Lioy, 2010; Schulte, n.d.). By integrating these data, biomonitoring studies can explore relationships between concentrations of chemicals in the body and cases of human disease (Ladeira & Viegas, 2016; Schulte, n.d.).

Biomonitoring and exposure studies identify routes of exposure, and can inform proactive strategies for exposure mitigation and prevention (Schulte, n.d.). To do this, they inherently rely on participation from members of the public, requiring biological specimens, environmental samples, or questionnaire responses to build their datasets (Creager, 2018; Ladeira & Viegas, 2016; National Resource Council, 2006). Oftentimes, these studies need long-term, continued participation; longitudinal data are needed to reveal trends in environmental conditions, chemical concentrations, or health outcomes over time (Creager, 2018). There are purported best practices for maintaining participant retention in these studies, including making the participation process as accessible as possible (Salazar et al., 2016; Teague et al., 2018), offering financial and non-monetary incentives like childcare or transportation, (Salazar et al., 2016) tailoring communication strategies to participants' needs, (Abshire et al., 2017) emphasizing the personal benefits of participation, (Abshire et al., 2017) and ongoing engagement by researchers in participants' communities (Frew et al., 2014).

Another such strategy is to share individual measurements and summary data with participants in a timely, accessible manner (Brody et al., 2014a). Initially, some researchers and university institutional review boards were worried about the implications of individually reporting back research results to participants, especially in cases where results were complex, had scientific uncertainty, lacked clinical guidance, or had no relevant regulatory guidelines (Brody et al., 2014a; Brown et al., 2010; Ohayon et al., 2017). However, in studies where participants were asked about these issues, they overwhelmingly reported a desire to receive their results regardless of scientific complexity or uncertainty (Altman et al., 2008; Brody et al., 2014a). Moreover, participants generally report understanding uncertainty and appreciate the ability to use new knowledge to inform risk reduction strategies for themselves and their

families(Adams et al., 2011; Boronow et al., 2019; Brody et al., 2007, 2021; Brown et al., 2012; Huntington-Moskos et al., 2021; Lebow-Skelley et al., 2020; Morello-Frosch et al., 2009; Perovich et al., 2018; Quigley, 2012). Over the last 20 years, the paradigm has shifted accordingly, and it is now widely expected and becoming more common that researchers return results and other relevant information to participants after analysis (Brody et al., 2009, 2014a; Brown et al., 2010; Morello-Frosch et al., 2009; Ramirez-Andreotta et al., 2016a, 2016b). For researchers, the reciprocity they demonstrate through report back can generate increased trust and long-term participation, ultimately improving data collection and the study overall (Sandhaus et al., 2018; Soleri, D., Long, J.W., Ramirez-Andreotta, M.D., Eitemiller, R. and Pandya, 2016). For participants, report back may support aspects of their science literacy—how they understand and respond to environmental health issues.

Environmental Health Literacy

The origins of science literacy emphasized the importance of an informed society that understands scientific concepts and practices and applies them towards a fruitful democratic society (Dewey, 1903) and first appeared in the education literature in 1958 (P. D. Hurd, 1998). Over time, science literacy expanded to include more than formal education of domain-specific science concepts (DeBoer, 2000; P. D. Hurd, 1998). Indeed, today the concept of science literacy includes both the fundamental aspects of reading and writing science (Norris & Phillips, 2003), as well as the ways individuals and communities understand scientific concepts and processes, their ability to evaluate scientific evidence, and the ways in which they participate in civic engagement related to scientific issues (Snow & Dibner, 2016). There is an underlying premise that increased science literacy leads to better decision making, better public policy, and by extension a better society (Snow & Dibner, 2016).

Throughout the 21st century, domain-specific sub-branches have grown out of science literacy, including environmental literacy and health literacy. Environmental disasters and the environmental movement of the 1960s and 1970s led to the formalization of environmental literacy (Disinger & Roth, 1992; Marcinkowski et al., 2012; McBride et al., 2013b; Roth, 1968). In contrast to science literacy, environmental literacy was rooted in outdoor education and highlights the role that free choice learning and informal education contexts play in understanding, protecting, and promoting environmental quality (Disinger & Roth, 1992; Marcinkowski et al., 2012; McBride et al., 2013b). Like science literacy, environmental literacy encompasses knowledge, attitudes, and skills, but it distinctly emphasizes individual and collective pro-environmental behaviors (Disinger & Roth, 1992; Hollweg et al., 2011).

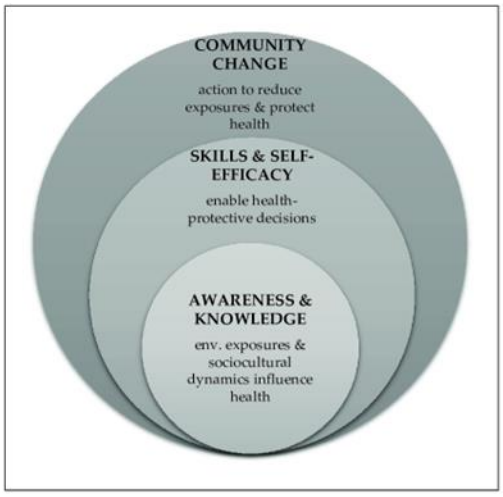
For the last 40 years, a majority of Americans report some type of health problem each month but only a fraction seeks out and receives medical care (Green L et al., 2001; K. White et al., 1961). As such, there has been an increased effort to better understand the role of health literacy in decision making (Nutbeam, 2008; Okan et al., 2019). Whereas science and environmental literacies can include larger societal goals, health literacy has a very individualistic framing—an emphasis on a person's understanding of their own illness, their ability to seek out and understand health information, and if/how they make decisions related to health protective behaviors (Lindsey et al., 2021a; Nutbeam, 2008, 2009; Nutbeam et al., 2018; Okan et al., 2019; Roundtable on Health Literacy et al., 2013). It is represented as a top-down transfer of knowledge from expert (prescriber) to non-expert (patient), and an individual's ability to follow medical recommendations (Nutbeam et al., 2018). Health literacy also emphasizes the foundational competencies of literacy— reading, writing, and numeracy—citing associations between improved basic literacy and improved health outcomes (Rudd, 2010).

Environmental and health literacies highlight the precedent for building on the foundational concepts of literacy (reading, writing, speaking) to define and operationalize more specific sub-branches. Drawing on the tenets of science, environmental, and health literacies, program officers at the National Institute of Environmental Health Sciences (NIEHS) proposed environmental health literacy (EHL) as an adaptation of Bloom's Taxonomy of educational objectives to frame how people understand and respond to environmental hazards (Finn & O'Fallon, 2017). The Society for Public Health Education defined EHL as merging "concepts from both environmental literacy and health literacy" to seek, process, and respond to information about human health and the environment (Finn & O'Fallon, 2017). NIEHS believed that the "distinct subfield" of EHL was a result of increased EHS research, largely supported by NIEHS, happening directly in/with communities impacted by environmental hazards (Finn & O'Fallon, 2017). Indeed, EHL has been gaining traction in the world of environmental health science research and engagement as a guiding framework and is cited frequently in NIEHS funding announcements and publications from NIEHS grantees (Binder et al., 2022; K. M. Gray et al., 2021; Lebow-Skelley et al., 2022; Valdez et al., 2014).

Broadly, EHL is the knowledge, skills, and actions relevant for responding to an environmental hazard and improving health outcomes (Finn & O'Fallon, 2017; K. Gray, 2018; Hoover, 2019; Valdez et al., 2014). EHL has underlying elements of free choice and contextual learning—as people choose how to engage with information about environmental exposures in their homes and communities (L. Davis et al., 2018; Falk & Dierking, 2002; Falk & Storksdieck, 2005)—and behavior theories (Ajzen, 1991; Fishbein & Azjen, 2011)—knowledge about a hazard does not singularly cause or explain individual or collective exposure reduction behaviors. Gray (K. Gray, 2018) depicts EHL as a series of concentric circles of the knowledge,

skills, and exposure reduction actions needed to protect health (See Figure 2.1). EHL is multidimensional and not a proxy for knowledge. It frames the range of capabilities needed to understand environmental exposures and their impacts on human health, the efficacy needed to address exposures, and the behaviors taken to improve health at individual and collective levels (Finn & O'Fallon, 2017, 2018; K. Gray, 2018; Hoover, 2019).

Figure 2.1. *Conceptual Model of EHL*



Note: Gray (2018)

EHL and Report Back of Research to Participants

EHL appears in the literature alongside community-engaged EHS research, participatory EHS methods, and returning EHS research results to participants (Brody et al., 2014b; L. F. Davis et al., 2018; Ohayon et al., 2017; Perovich et al., 2018; Ramirez-Andreotta et al., 2016a, 2016b; Rohlman et al., 2016). Over the last decade, the notion that report back can build knowledge and support exposure reduction behaviors has led to the assertion that report back is thus related to or increases EHL (L. Davis et al., 2018; Lindsey et al., 2022; Tomsho et al., 2022). Using Gray's model, it is logical to assume that if report back supports participants' knowledge of their exposures and/or options for exposure reduction, it may also support their

capacity to reduce these exposures for themselves, their families, or even their communities (L. Davis et al., 2018; Lindsey et al., 2022; Samon et al., 2023; Tomsho et al., 2022). Indeed, some studies have qualitative data that suggests report back drove changes in information seeking and purchasing habits to reduce exposure to certain chemicals (Brody et al., 2014a, 2018; Brown et al., 2012; Ramirez-Andreotta et al., 2016a).

Still, assessments of report back or EHL in EHS studies are limited and lack uniformity. There are no universal instruments for measuring EHL, and to date, the bulk of EHL assessment relies only on quantitative measures of knowledge, 7, 10, 39 often using scales that are specific to a single issue (K. M. Gray et al., 2021; Raufman et al., 2020) or broad scales that try to capture everything potentially related to EHL (Irvin et al., 2019; Lichtveld et al., 2019; Rohlman et al., 2022). The literature emphasizes the context-specific nature of EHL, including how environmental hazards, community capacity, and mitigation options may vary widely among communities (K. M. Gray et al., 2021; Hoover, 2019; Lebow-Skelley et al., 2022). This, in addition to the multidimensional model of EHL discussed above, highlights a flaw in an overreliance on quantitative measures of knowledge or scales that inherently cannot capture the nuance of understanding and responding to local environmental health issues (L. Davis et al., 2018; Ramirez-Andreotta et al., 2016a). Other studies have used focus groups and informal conversations or observations with participants (Tomsho et al., 2019, 2022), which can be useful for exploring self-efficacy, beliefs, attitudes, and behavioral intentions. But these may not capture the actual behaviors and structural changes needed to reduce exposures and the "community change" of Gray's (K. Gray, 2018) third dimension of EHL. While these assessments of EHL provide information on individual dimensions (e.g., changes in knowledge or efficacy), they may misrepresent EHL as an outcome in and of itself instead of a

multidimensional framework guiding the work. Gray and Lindsey acknowledge that EHL scholarship is "in an early stage" and there are gaps still to address, including how to assess EHL to understand how people move along the knowledge-skills-actions "continuum" (K. M. Gray & Lindsey, 2019). This presents an opportunity for those of us in the EHS field to be more intentional with how we evaluate EHL and how we use the findings to inform our work.

Conceptual Framework

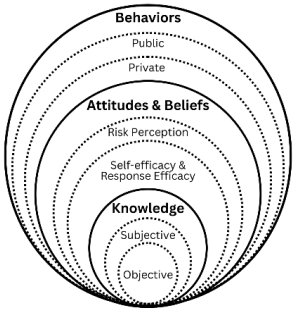
Drawing from the conceptual knowledge of science literacy, the personal decision making of health literacy, and the collective impacts of environmental literacy, EHL provides an overarching framework for this research. As seen in Figure 1.4, EHL is multidimensional and is the combination of knowledge, skills, capacity, and behaviors related to understanding and responding to an environmental exposure (K. Gray, 2018; K. M. Gray & Lindsey, 2019; Hoover, 2019). The innermost circle represents conceptual knowledge of an environmental hazard, including its routes of human exposure and potential health impacts (Finn & O'Fallon, 2018; Hoover, 2019; Lindsey et al., 2021b). The middle circle of skills and self-efficacy represents one's ability to enact strategies that reduce their exposure to the environmental hazard (K. Gray, 2018). Finally, the outermost circle that Gray calls "community change" represents the various behaviors that can promote improved health outcomes (Finn & O'Fallon, 2018; K. Gray, 2018).

Theoretically, the culmination of these three constructs are what ultimately contribute to the reduction or prevention of environmental hazards at individual (e.g, installing a water filter in one's home) and community (e.g., upgrades to municipal water treatment systems) scales. In practice, however, there is limited literature on how the three constructs interact or how EHL relates to reduced exposures and community change. This study intended to help fill that gap by

looking at relationships between these constructs, with a particular interest in health-protective behaviors.

Previous studies have shown that quantitative measures of knowledge as proxies environmental or health literacy did not correlate with an individual's environmental- or health-protective behaviors, (Snow & Dibner, 2016) highlighting the importance of using a range of constructs to understand environmental health literacy and related behaviors. Thus, this study used the original three-construct conceptualization of EHL (Figure 2.1) as an overarching framework for this study and intentionally incorporated additional constructs to explore if they might create a more comprehensive description of how participants understood, made sense of, and respond to PFAS exposures (Figure 2.2). For instance, measures of attitudes and beliefs related to subjective knowledge, risk perception, and response efficacy were added. Additionally, behaviors were further distinguished based on Stern's (Stern, 2000) private and public spheres of behaviors, and included private, individual exposure reduction actions as well as public behaviors with the potential for contributing to community change through advocacy-based and non-advocacy collective actions. This study intentionally used the multidimensional nature of EHL's knowledge-to-exposure reduction continuum to consider how a range of factors related to participants' understanding and response to PFAS exposures in their community.

Figure 2.2. *Conceptual Framework of Expanded EHL*



Note: Adapted from Gray (2018)

Research Questions

The entire field of EHS is based on the premise that the environment can have negative effects on human health and lead to disease (Lioy, 2010; National Institute of Environmental Health Sciences, n.d.; Olden & Klein, 1995; Schulte, n.d.; Wilson & Schwartz, 2006). Biomonitoring and exposure studies are one avenue for exploring the relationship between peoples' exposure to environmental hazards and their disease incidence (Creager, 2018; Ladeira & Viegas, 2016; National Resource Council, 2006). Over the last two decades, the paradigm has shifted such that most of these studies provide at least some level of data back to participants (Brody et al., 2007, 2014a, 2021). Increasingly, this process of report back has been thought to increase EHL among a study's participants, (L. Davis et al., 2018; Ohayon et al., 2017; Perovich et al., 2018) and EHL is how many NIEHS grantees frame the ability to respond to and reduce an environmental hazard (Finn & O'Fallon, 2017; K. Gray, 2018; K. M. Gray & Lindsey, 2019). Yet there is little research that systematically evaluates if/how participating in biomonitoring studies broadly, and receiving report back more specifically, relates to the multiple constructs of EHL or its broader goal of community change. As such, this study aimed to answer the overarching questions:

1. After receiving results from a PFAS exposure study, what factors—demographics, knowledge, capacity, risk perception, perceived benefits—relate to exposure reduction behaviors?
    a. How do these factors relate to past individual, private behaviors?
    b. How do these factors relate to past public advocacy behaviors?
    c. How do these factors relate to future public non-advocacy behaviors?

2. How do participants describe their motivations for and experience during participation in a PFAS exposure study?

Methods

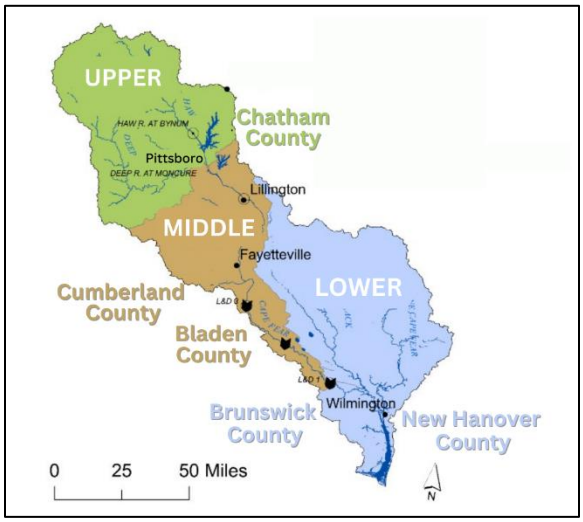
The overarching goal of this correlational study (D. Mertens & McLaughlin, 2004) is to understand how the report back of the GenX Study relates to the dimensions of EHL in order to understand how participating in the GenX Study and receiving individual-level data relates to participants' knowledge, efficacy, and various behaviors. This survey research collected numerical and qualitative data from a large sample of people to investigate the dimensions of EHL among participants (J. W. Creswell & Miller, 2000; D. Mertens & McLaughlin, 2004). This was predominantly a simple descriptive design, as data were collected at one time point using one instrument, though participants from different geographic areas and demographic groups allowed for some cross-section comparison (Mertens 2003).

Research Context

This research took place in three smaller geographic areas within a larger contaminated community that is bounded by a common exposure (Edelstein, 2018) to per- and polyfluoroalkyl substances (PFAS). One of the first projects funded in response to residents' concerns about PFAS in the Cape Fear River was the GenX Exposure Study (GenX Study) out of NC State University. The GenX Study is an ongoing biomonitoring study that has been collecting biological samples and questionnaire data from residents age six and older who live in the upper (e.g., surface water users in Pittsboro, Chatham County), middle (e.g., residents on well water in Cumberland and Bladen Counties), and lower (e.g., surface water users in New Hanover and Brunswick Counties) parts of the Cape Fear River basin since 2017 (Kotlarz et al., 2020; Rosen

et al., 2022; Wallis et al., 2023). As results become available, individual measurements are shared in letters mailed to participants, and GenX Study researchers share aggregate results and answer questions at community meetings throughout the river basin. All report back materials were designed by the GenX Study researchers and reviewed with their community science advisory panel (Hoppin, 2023). This study focused on the individual letter component of the GenX Study's report back process, as every GenX Study participant received a letter and not every participant chose to attend a community meeting. Given this context, PFAS contamination in North Carolina has presented a specific case study in which to explore EHL, participation in an exposure study, and report back.

Figure 2.3. *Map of Cape Fear River Basin and Counties*



Note. Adapted from DeMeester et al. (2019).

Participants

All adult participants for this study were also members of the GenX Study (N = 1,091) who currently live in the Cape Fear River basin. Note that the GenX Study has used different recruitment strategies and sampling frames for the three sections of the river basin. Anyone in New Hanover or Brunswick County could voluntarily enroll if they received drinking water from

Cape Fear Public Utility Authority. Residents near Fayetteville in Bladen and Cumberland Counties that had their private wells tested for PFAS by the Department of Environmental Quality or Chemours were invited to participate (Hoppin, 2023). All residents in the town of Pittsboro on municipal drinking water were allowed to enroll.

Still, the GenX Study is inherently a nonprobability convenience sample that relies on the voluntary participation of residents from three communities (Vaske, 2019). The population for this study is all adult participants currently enrolled in the GenX Study, but due to resource constraints and IRB limitations as to what information the GenX Study team was allowed to share, this study's sampling frame was each household with at least one adult participant currently enrolled in the GenX Study (n = 634). When households had more than one adult GenX Study participant, a sampling strategy (Vaske, 2019) invited the adult with the most recent birthday to participate in this study. As seen in Table 3, participants in both this study and the GenX Study were more likely to be female, White, more educated, and older than the 2023 averages for North Carolina overall, (US Census Bureau, 2020) which inherently limits the conclusions that can be drawn from this study.

Table 1. *Demographic Characteristics of Participants and the Surrounding Geographic Areas*

			Upper	Middle		Lower	
	This Study	GenX Study	Chatham	Cumberland	Bladen	New Hanover	Brunswick
Female	67.2%	59%	51.6%	50.3%	52.1%	52.2%	51.9%
Male	32.8%	41%	48.4%	49.7%	47.9%	47.8%	48.1%
Age (median)	61y	54y	48.3y	31.7y	45y	40y	56.3y
High School +	100%	89%	89.4%	92.3%	88.2%	93.5%	93.5%
Bachelors +	72.4%	56%	46.5%	26.9%	20.3%	43.4%	32.4%
White	93.3%	81%	72.3%	40.5%	54.7%	77.4%	82.6%
Black or African American	2.9%	9%	11.7%	39.9%	33.1%	12.7%	9.3%

Table 1 (continued).

AIAN*	1.5%	n/a	1.2%	2%	3.4%	0.6%	0.8%
Asian*	0	n/a	2.6%	2.8%	0.5%	1.6%	0.8%
NHOPI*	0	n/a	0.2%	0.4%	0.1%	0.1%	0%
Two or more*	1.7%	n/a	2%	5.2%	2.1%	2.4%	1.9%
Hispanic	2.9%	7%	12.1%	13%	8.6%	6.4%	5.3%
Other*	n/a	3%*	n/a*	n/a*	n/a*	n/a*	n/a*
Median Household Income*	$70,000	n/a	$84,222	$55,551	$40,476	$67,515	$71,193

Note. + Categories denote at least that level of education, meaning high school or higher, and bachelor's degree or higher.
*This study and the GenX Study used slightly different categories for race and ethnicity, and the GenX Study did not collect data on household income. N/A indicates that category was not used for that study.

Data Collection

The printed instrument had ample white space, was four pages in length (two legal-sized pages folded in half), and took less than ten minutes to complete so as to reduce cognitive load on participants and ensure a strong response rate (Dillman et al., 2014; Peytchev, 2009; Vaske, 2019). Per Institutional Review Board (IRB) guidance, the GenX Study could share mailing addresses but not individuals' identities with us. As such, the sampling frame for our study is all households currently enrolled in the GenX Study. In November 2022, each household was sent one survey packet, which included one invitation letter that explained the survey and informed consent, one questionnaire, one prepaid and addressed envelope in which to return the survey, and one $2 bill as a small incentive (Peytchev, 2009; Vaske, 2019). Completing and returning the survey indicated a participant's consent. When relying on a single mailing, mail surveys tend to receive at best a 20-40% response rate (Dillman et al., 2014; Vaske, 2019). As such, we sent an additional survey packet to nonrespondents two and four weeks after the initial mailing

(American Association for Public Opinion Research, 2023; Dillman et al., 2014). In total, we received 345 responses for a 53.7% response rate.

Survey Instrument

Following best practices in survey design (DeVellis, 2021; Fowler & Cosenza, 2009; Peytchev, 2009; Vaske, 2019), a 24-item questionnaire was developed to collect information from GenX Study participants, including measures of knowledge, efficacy, attitudes, and behaviors, as well as demographic information and questions specific to the GenX Study report back letters (Appendix A). When possible, items were adapted from existing validated instruments, including those on semantic differential (Babbie, 2016; Osgood, 1952), knowledge sufficiency (Griffin et al., 2004), religiosity (Brossard et al., 2009), and other demographics (Binder et al., 2011; Brossard et al., 2009). Notably, the questionnaire was not designed solely to explore EHL, and items were included that reflect the interest and expertise of the GenX Study team and interdisciplinary collaborators. Survey items were iteratively reviewed by both content experts (GenX Study team) and naive audiences (students) to ensure face validity and clarity (Dillman et al., 2014; Vaske, 2019).

As seen in Appendix B, questionnaire items were used to measure the dimensions of EHL as outlined by the theoretical framework. One item measured objective, conceptual knowledge about PFAS, six items assessed subjective perceptions of knowledge and efficacy, one item asked about past behaviors related to individual and collective PFAS exposure reduction, and one item asked about future behaviors with potential collective impact. To improve predictive potential (Vaske, 2019), items were specific to PFAS rather than broader environmental knowledge or behaviors. In addition, the questionnaire contained three open-

ended questions about participants' motivations for participating in the GenX Study and their dis/satisfaction with the experience.

Table 2. *Mapping EHL Constructs onto Survey Items*

Factual Knowledge	
	13A. But can you tell us if each of the following statements about PFAS is true or false, or if you don't know? ... All PFAS chemicals (including PFOS, PFOA, GenX) act the same way in humans and the environment.
	13B PFAS are substances that do not exist naturally and are only man-made.
	13C The National Academies report made recommendations about seven (7) PFAS found in people's blood.
	13D If GenX was not detected in my blood sample, then GenX was never in my body.
	13E By participating in a study like this one, people can learn if certain health conditions are caused by PFAS.
Subjective Knowledge	
1	How much new information did the letter provide for you?
9A	Could you tell us how much you agree or disagree with these other statements? ... I understand the risks and benefits of contributing to the GenX Exposure Study.
9B	I feel that the objectives of the study have been clearly communicated by the researchers.
9C	The study provides answers to the questions I have about PFAS contamination.
Self Efficacy	
2	Whether it was new or not, how useful was the information presented in the letter?
3A	Based on the letter you received with your PFAS blood results, how much were you able to... Identify the sum of PFAS from your blood sample?
3B	Learn about new medical recommendations for different levels of PFAS in blood?
3C	Understand the blood results provided in the stripcharts?
3D	Describe the objectives of the GenX Exposure Study?
3E	Find answers to the questions you have about PFAS and their health effects?
Response Efficacy	
	14A How effective do you think each of the following activities is at preventing PFAS exposure? ... Not using unfiltered tap water for drinking and cooking.
	14B Avoiding food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)
	14C Not buying waterproof or nonstick products manufactured with PFAS.
	14D Contacting elected officials to reduce PFAS inputs to the environment
	14E Working with local organizations to do something about PFAS in your community.
Risk Perception	

Table 2 (continued).

10A How much risk do you think PFAS presents to you and your health?
10B the health of residents in your community?
Past Private Behaviors
15A Regardless of how effective you think they are, how often have you done any of the following to prevent exposure to PFAS? ... Stopped using unfiltered tap water for drinking and cooking.
15B Avoided food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)
15C Quit buying waterproof or nonstick products manufactured with PFAS.
Past Public Activist Behaviors
15D Contacted elected officials to reduce PFAS inputs to the environment
15E Worked with local organizations to do something about PFAS in your community.
Future Public Non-Activist Behaviors
16A Based on your experience as a participant in the GenX Exposure Study, how willing would you be to sign up for ... Another health study related to PFAS?
16B Another health study conducted by researchers at NC State University?

Validity

Principal Component Analysis (PCA) was used to determine the construct validity of the questionnaire items (DeVellis 2016; Cohen 1988; Vaske). First, an initial round of exploratory factor analysis was conducted using all items among all the constructs (See Appendix C). Informed by the literature and results from the exploratory factor analysis, items were grouped and tested using confirmatory factor analysis. In general, factor loadings above 0.45 were considered fair, above 0.55 good, and above 0.6 very good (Gibson, 2024). In some cases, an item's factor loading did not align with logic or the literature, in which case the item was moved to the appropriate category, either manually or by setting an upper limit on the number of components at two. For example, as seen in Table 2, Q1 is not an objective, factual knowledge item, while all five items in Q13 are. Q1 was manually moved to the subjective knowledge construct. All factor analyses were run with Varimax rotation. Once the items in each construct were finalized according to the PCA results, averages for each construct were used to calculate

their composite values. These composite values are what were ultimately used in the regression analyses.

Measuring the effect size of correlations between each construct confirms that each is a standalone concept, and the level of discriminant or convergent validity (DeVellis 2016; Cohen 1988). In general, each construct appears to have discriminant validity from the other constructs, with effect sizes ranging from -0.002 to 0.449. Notably, Self Efficacy and Subjective Knowledge showed a degree of convergent validity with an effect size of 0.607. Although each is a standalone construct in this analysis, they have conceptual overlap regarding what people *feel they know* and what they feel they *know how to do* as result of participation in the GenX Study.

Table 3. *Correlations Between Survey Constructs*

	1	2	3	4	5	6	7	8
1. Factual Knowledge	1							
2. Subjective Knowledge	.266**	1						
3. Self Efficacy	.449**	.607**	1					
4. Risk Perception	-0.004	0.079	0.064	1				
5. Response Efficacy	0.035	.173**	.118*	.120*	1			
6. Private Past Behaviors	-0.002	0.07	0.084	.341**	.323**	1		
7. Public Past Behaviors	.158**	0.097	0.09	.225**	.136*	.325**	1	
8. Public Future Behaviors	0.084	.345**	.345**	0.091	0.097	.115*	0.096	1

Note. $*p < .05$, $**p < .01$, $***p < .001$

Reliability

After calculating the composites, to see how consistently participants responded to individual items within each construct, reliability was measured using Cronbach's alpha. Alpha values closer to 1 indicate greater internal consistency within the construct, though

there is debate over the exact threshold value for Alpha (Vaske, 2019). All alpha values were greater than 0.65, aside from Factual knowledge, which will be discussed below.

Table 4. *Internal Consistency of Each Construct Measured by Cronbach's Alpha Values*

Construct	Alpha
Factual Knowledge	0.316
Subjective Knowledge	0.751
Self-Efficacy	0.869
Response Efficacy	0.669
Past Private	0.684
Future Public	0.824
Future Public	0.873

Variables

Dependent Variables

Reducing one's exposure to environmental hazards, including PFAS, requires people to enact a range of behaviors. Some actions are taken to reduce personal exposure and have limited impact on the exposure of others, like installing a water filter in one's home. Other behaviors—like participating in EHS research or working with local advocacy groups—while done by individuals can contribute to structural changes that may reduce the collective's exposure (Ardoin et al., 2023; L. F. Davis & Ramírez-Andreotta, 2021; Stern, 2000). These reflect Stern's (2000) spheres of environmental behaviors: private, public non-activist, and activist. As such, the overarching dependent behavior variable distinguished between private and public actions that have individual and collective impacts on exposure reduction.

Past Private and Public Behaviors. These five items were not adapted from an existing instrument; they were created and iteratively revised for construct validity with feedback from PFAS researchers. Each item asked people how often they *have done* an exposure reduction behavior, meaning they are self-reported past behaviors. Each item had five-point Likert scale response options ranging from "not at all" to "all the time." The three items for private actions and personal exposure reduction were chosen based on the known contamination of drinking water, known contamination of local soils and environment, and known ubiquity of PFAS in consumer goods. The two items representing public activist behaviors reflect actions related to structural environmental health changes (L. F. Davis & Ramírez-Andreotta, 2021) and the prominent role played by local advocacy and nonprofit organizations in the Cape Fear River basin (Cahoon, 2019; Mindock, 2023; Perkins, 2023; Severance & McLaughlin, 2023).

Future Public Behaviors. A large portion of this questionnaire was designed to understand participants' feelings and attitudes towards participation in the GenX Study. Participant retention is important for longitudinal EHS studies, and report back is purported to be a strategy for maintaining retention among participants (Abshire et al., 2017; Adams et al., 2011; Brody et al., 2014a; Ohayon et al., 2017; Teague et al., 2018). As such, two items asked about willingness to participate in future EHS research. As public, non-activist behaviors (Stern, 2000), contributing to research studies can be an altruistic service to one's community that helps contribute to a greater good or to solving a problem (Ardoin et al., 2023; Bongartz et al., 2017; Sheridan et al., 2020; Slegers et al., 2015). These two items asked about people's willingness to participate in another health study related to PFAS and another health study conducted by NC State researchers. Importantly, these are items asking about potential future behaviors, rather than the past behaviors described above. Each item had five-point Likert scale response options

ranging from “not willing at all” to “completely willing.” Confirmatory PCA showed the distinction between public and private, and non/activist behaviors. A composite for each of the three behaviors was created by averaging across each participants’ responses all the items in each construct.

Table 5. *Confirmatory Factory Analysis for Dependent Behavior Variables*

	Factor Loadings		
Past Private Behaviors			
Stopped using unfiltered water	.790		
Avoided locally grown food	.781		
Quit buying waterproof products	.744		
Future Public Behaviors			
Another health study by NCSU		0.945	
Another PFAS study		0.936	
Past Public Behaviors			
Contacted elected officials			.910
Worked with local organizations			.900
Initial Eigen Value	2.484	1.688	1.172
% Variance	35.492	24.116	59.607
Cronbach’s Alpha	0.684	0.873	0.824

Independent Variables.

Sociodemographics. At the end of the questionnaire, participants were asked to provide demographic information, including age, race, income, sex, religiosity, political ideology, education, and geographic location. As these were believed to be potentially related to exposure

reduction behaviors, they were included in the regression analyses. New variables were created to serve as dummy and controls for these demographic categories. In most cases, these new variables were binary dummy coded based on the study median value (e.g., age), the state median (e.g., income), or logical breaking point based on the response options ("very" or "somewhat" liberal vs. "moderate," "somewhat conservative" or "very conservative"). For location, Wilmington was treated as the control variable, while Pittsboro and Fayetteville were the two dummy groups. In this case, the control represents a younger non-white woman, with lower than average income, lower education, conservative political ideologies, who is not religious and lives in Wilmington (See Appendix D). Numerical responses for each item were averaged and standard deviations calculated (See Table 9).

Knowing about PFAS. The GenX Study team and our research team were interested in what people objectively did or did not know about PFAS and results from the GenX Study, as well as what they *felt* they knew or did not know about PFAS and the GenX Study. There is a known distinction between objective knowledge of factual concepts and subjective measures of one's own knowledge, which should be treated as two separate constructs (J. P. Carlson et al., 2009; Edelstein, 2018; Goebel & Wardropper, 2023).

Objective Knowledge. Factual knowledge of PFAS and the GenX Study was measured through a series of questions created in collaboration with GenX Study and other PFAS researchers. Items to measure objective, factual knowledge were created based on what researchers considered the most fundamental concepts about PFAS in general and about results from the GenX Study that had objective correct and incorrect responses. Two items asked about the chemical and environmental properties of PFAS. Three items asked about concepts the GenX Study team intended for participants to have learned as a result of their participation. Each of

these five items had three response options- True, False, I don't know. Responses of "I don't know" were marked as incorrect during the coding process.

Subjective Knowledge. Given the conceptual distinction between objective and subjective knowledge, it was important that the survey capture participants' perceptions of their own knowledge in addition to what researchers deemed as sufficient knowledge. These questions asked participants about information in the letters they received with their results and their thoughts on the GenX Study. One question asked how much new information the results letter provided them. The five response options ranged from "no new information at all" to "a lot of new information." Three items asked participants if they understood the objective and risks of participation, and if study provided answers to their questions about PFAS. Five-point Likert scale response options ranged from "strongly disagree" to "strongly agree." Each of these four items relate to what a person feels they do or do not know about PFAS and the GenX Study and cannot be marked as objectively true or false.

PCA of all knowledge items confirm that objective and subjective knowledge items represent different constructs. Importantly, people's factual knowledge about PFAS was inconsistent, and one item (Q1) needed to be manually moved with the other subjective knowledge items to address the low Alpha value.

Table 6. *Confirmatory Factory Analysis for Independent Knowledge Variables*

KNOWLEDGE	
	Factor Loadings
Subjective Knowledge	
I feel that the objectives of the study have been clearly communicated by the researchers.	0.88
The study provides answers to the questions I have about PFAS contamination.	0.81
I understand the risks and benefits of contributing to the GenX Exposure Study.	0.802

Table 6 (continued).

Objective Knowledge		
T/F: PFAS are substances that do not exist naturally and are only man-made.		0.618
T/F: By participating in a study like this one, people can learn if certain health conditions are caused by PFAS.		0.56
T/F: The National Academies report made recommendations about seven (7) PFAS found in people's blood.		0.431
T/F: PFAS chemicals (including PFOS, PFOA, GenX) act the same way in humans and the environment.		0.427
How much new information did the letter provide for you?	0.411	0.412
T/F: If GenX was not detected in my blood sample, then GenX was never in my body.		0.37
Initial Eigen Value	2.586	1.248
% Variance	28.73	13.863
Cronbach's Alpha	0.807 with Q1 = 0.751	0.365 without Q1= 0.316

Feeling capable of responding to PFAS. In addition to what people objectively and subjectively know, the research teams were interested in what people *felt* they could *use* the information for. In alignment with Gray's (2018) second circle of EHL, we also measured self-efficacy and response efficacy.

Self-Efficacy. Self-efficacy is more than knowing what to do, it impacts how people think, respond, and ultimately act in a given situation (Bandura, 2001, 2006a). We followed Bandura's guidance for determining people's assessment of their own capabilities (Bandura, 2006a) within the specific context of participating in research. These items asked what people felt they could do as result of having participated and received their results from the GenX Study. Five items asked if people were able to identify, find, and describe various types of information related to their results. Five-point response options ranged from "not at all" to "completely." One item asked how *useful* people found the information presented in the results

letter. The word "useful" was emphasized on the survey to distinguish it conceptually from subjective knowledge measures. Response options ranged from "not useful at all" to "extremely useful."

Response Efficacy. People's actions are related to perceptions of their own abilities and perceptions an action's effectiveness at reducing risk (Conner and Sparks 2005). The concept of response efficacy was measured by five items that asked participants how effective they felt each of the behaviors in the previous question are at preventing PFAS exposure. Five-point response options ranged from "not effective at all" to "completely effective." PCA shows the distinction between self-efficacy—what participants feel *they* are able to do—and response efficacy—what participants think will *work* if they do it.

Table 7. *Confirmatory Factory Analysis for Independent Efficacy Variables*

	Factor Loadings
Self-Efficacy	
Understand the blood results provided in the stripcharts?	.871
Describe the objectives of the GenX Exposure Study?	.820
Learn about new medical recommendations for different levels of PFAS in blood?	.785
Find answers to the questions you have about PFAS and their health effects?	.782
Identify the sum of PFAS from your blood sample?	.771
Whether it was new or not, how useful was the information presented in the letter?	.642
Response Efficacy	
Working with local organizations to do something about PFAS in your community.	.776
Contacting elected officials to reduce PFAS inputs to the environment	.765
Not buying waterproof or nonstick products manufactured with PFAS.	.622
Avoiding food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)	.610

Table 7 (continued).

Not using unfiltered tap water for drinking and cooking.		.508
Initial Eigen Value	3.79	2.177
% Variance	34.455	19.794
Cronbach's Alpha	.869	.669

Knowledge Sufficiency. Two items were used to measure participants' perceived knowledge sufficiency (Griffin 2004). One item asked participants to identify on a scale from 0 to 100 how much they currently know about PFAS. The next item asked participants on the same scale from 0 to 100 how much they feel they *need to know to make a decision* about PFAS. While the first question on its own represents a person's subjective knowledge, the difference between the two values indicates if they feel ready to respond to PFAS—their knowledge sufficiency threshold (Binder and May 2022). A new binary variable was created to indicate having or not having enough information about PFAS to make health-related decisions (See Appendix D for coding).

Risk Perception. Throughout the literature, there are associations cited between a person's perception of a risk and their behaviors related to it (N. T. Brewer et al., 2007) though the exact relationship between perception and action may vary based on type of threat and accuracy of one's perception (Ferrer 2015). Two items asked how much risk participants think PFAS presents to themselves and to their community. The five response options ranged from "none" to "a lot." Because responses to each item correlated so strongly to one another (alpha = .913), and because this study was not focused on the distinctions between different types of risk

perceptions, a new variable was created to represent a person's total average risk perception, and a composite was created from all participants' averages.

Benefits of research participation. Participant retention is important for longitudinal EHS studies like the GenX Study, and report back is thought to be a strategy to retain participants (Abshire et al., 2017; Dunagan et al., 2013; Frew et al., 2014; Teague et al., 2018). Moreover, report back can demonstrate the study's value to individual participants by providing them with individual measurements and information to which they might not otherwise have access (Sandhaus et al., 2018; Soleri, D., Long, J.W., Ramirez-Andreotta, M.D., Eitemiller, R. and Pandya, 2016). Two items were used to assess how participants perceive the benefits of the GenX Study. Participants were asked to what degree they agreed with statements about the Study's personal benefit to them and benefit to the researchers. Five-point response options ranged from "strongly disagree" to "strongly agree."

Data Analysis

Each questionnaire returned by mail was manually entered into an excel spreadsheet located on a secure Google Drive. All questions except the open-ended items were coded numerically based on the response options, and any items left blank by participants were left blank in the dataset (See Appendix D). All data entry was completed by one researcher, and a random subset was checked for accuracy by two research assistants. The final .csv file as uploaded into SPSS for statistical analysis.

Regression Analyses

To answer RQ1, the three types of behaviors- private, public advocacy, and public non-advocacy- were used as the dependent variable in three separate linear regression models.

Ordinary least squares (OLS) regression is used to measure linear relationships between multiple independent variables and the dependent variable of interest (Denham, 2010; Pohlmann & Leitner, 2003). This study used stepwise OLS to measure the relationship between each of the three types of behaviors and a suite of independent variables. Each model was ran in the following sequence: step 1- demographic control variables, step 2- strict EHL (factual knowledge, self-efficacy, response efficacy), and step 3- other relevant independent variables. In model 3 looking at future research behaviors, a fourth step was added to include perceptions of personal and scientist benefit of research. For each of the three models, statistical power is achieved (n = 342, $\alpha = 0.05$, DF = 322, $1 - \beta = 1.00$) for any effect size, including > 0.35. The regression coefficients, standard error, *VIF*, *F* value, and model fit are reported for each of the three models below.

Thematic Coding

To answer RQ2, open-ended items collected qualitative data and allowed participants to provide more detailed descriptions about their experience. The questions asked what motivated people to participate in the GenX Study, what they were most satisfied with, and what they were least satisfied with (Q4, 5, 6). Handwritten responses were manually typed verbatim into the excel spreadsheet with the quantitative responses for each participant, and a random subset was checked for accuracy by two research assistants. Responses were grouped thematically according to a list of a priori codes that align with the independent variables used in the regressions: factual knowledge, subjective knowledge, self-efficacy, response efficacy, risk perception, private behaviors, and public behaviors (Braun & Clarke, 2006; DeCuir-Gunby, 2008; Guest et al., 2014). Responses could be simultaneously coded as some people addressed multiple constructs

in one response (Huberman, & Saldan, 2014b). Table 8 summarizes the coding scheme for each question.

Per the consent forms that participants received, no direct quotes from the three open-ended questions are reported. Instead, the frequency of themes and demonstrative quotes created for each one are reported below. Integrating this qualitative data into the study's overall analysis served to complement, support, and in some cases contradict the numerical data (Bazeley, 2012). As discussed above, given the tendency to over rely on quantitative data to assess EHL, these qualitative responses allowed for a more holistic description of the dimensions of EHL among participants and their experience participating in the GenX study. This integration of quantitative and qualitative measures on the same questionnaire allowed for exploration of report back and EHL simultaneously from different perspectives (DeCuir-Gunby, 2008). Additionally, while the quantitative items allowed for statistical analysis of relationships between variables, the qualitative responses allowed for exploration of broader themes and sentiments among participants (Tashakkori & Teddlie, 2003). See Appendix K for the full codebook.

Table 8. *Coding Scheme for Open-Ended Response Questions*

Code	Motivation	Satisfaction	Dissatisfaction
Factual Knowledge	--	Stating an objective fact about PFAS, the study, the letter, etc. Mentioning the letter, meeting, results, numbers, levels. Not making definitive links between exposure and health effects.	*Lack of* objective knowledge about PFAS, the study, the letter, etc. (ex: they gave me results). Something that we can objectively say was or wasn't covered in the report back.
Subjective Knowledge	*Feeling* like they wanted to learn (words like: find out, see, educate, to know, curious, etc.) something about PFAS, research, etc.	Mentions of *perceived* knowledge or learning, things that cannot be objectively evaluated, are *not* explicitly outlined in the letter, or are value laden, subjective, or opinionated.	Mentions of *perceived* knowledge or learning (or lack of), things that cannot be objectively evaluated, are *not* explicitly outlined in the letter, or are value laden, subjective, or opinionated.
Self Efficacy	Believe/feel they can do (words like: find, understand, etc.) something.	*Feel that they are able to* do something (words like: find, look for, can, able to)	*Feel they are unable to* do something (words like: can't, aren't able to)
Response Efficacy	--	--	--
Risk Perception	Motivated by concern or worry about PFAS exposure, health effects, etc. for oneself, family, or community. Have previous knowledge of local PFAS contamination and worried about subsequent effects.	--	Ongoing, continued worry about exposure, long-term health risks, etc.
Private Behaviors	--	Taking actions that protect oneself or one's family.	Being unable to take actions that protect oneself or one's family.
Public Behaviors	Taking actions that contribute to collective understanding, addressing, and/or mitigating PFAS risks.	Taking actions that contribute to the collective understanding, addressing, or mitigating PFAS risks.	Lack of actions that contribute to the collective understanding, addressing, or mitigating of PFAS risks.

Results

Variable Summaries

Descriptive statistics for all variables used in the regression analyses are presented below. Most of the sociodemographic control variables were categorical, and frequencies are presented below. The last set of control variables, other independent variables, and the dependent variables were all either continuous (age) or Likert scale (political ideology and religiosity) and have central tendencies presented below.

Sociodemographic Variables

Just over half of participants (57.4%) live in the Lower Cape Fear area, with 20% living in the upper basin, and 22.3% in the middle of the basin near the chemical manufacturer. Most participants were White (93.9%), and two thirds of participants were female (67%). Participants' reported income was normally distributed, with about half of participants reporting between $50,000 and $129,000 in annual household income in 2022. Most participants (68.7%) had at least a Bachelor's degree.

Table 9. *Descriptive Statistics for Categorical Sociodemographic Variables*

	Frequency	Percent	Valid Percent	Cumulative Percent
Location				
Fayetteville	77	22.3%	22.3%	22.3%
Pittsboro	70	20.3%	20.3%	42.6%
Wilmington	198	57.4%	57.4%	100%
Total	345	100.00%		
Missing	0	0		
Sex				
Male	113	32.8%	32.8%	32.8%
Female	231	67.0%	67.2%	100%
Total	344	99.7%		
Missing	1	0.3%		

Table 9 (continued).

Race				
American Indian or Alaska Native	5	1.4%	1.5%	1.5%
Black	10	2.9%	2.9%	4.4%
White	322	93.3%	93.9%	98.3%
More than one race or one not specified	6	1.7%	1.7%	100%
Total	343	99.4%	100%	
Missing	2	0.6%		
Income				
$19,999 or less	10	2.9%	2.9%	8.4%
$20,000 to $49,999	54	15.7%	15.7%	24.1%
$50,0009 to $89,999	90	26.1%	26.1%	50.1%
$90,000 to $129,999	87	25.2%	25.2%	75.4%
$130,000 to $149,000	27	7.8%	7.8%	83.2%
$150,000 or more	58	16.8%	16.8%	100%
Total	326	94.5%	100.0%	
Missing	19	5.5%		
Education				
Completed High school or GED	15	4.3%	4.4%	4.4%
Some college, technical, or trade school	77	22.3%	22.5%	26.9%
Bachelor's degree	125	36.2%	36.5%	63.5%
Graduate or professional degree	125	36.2%	36.5%	100%
Total	342	99.1%	100%	
Missing	3	9%		

Participants skewed older ($\bar{x}$ = 63.07 years). When asked about their political ideologies, where 1 was "very liberal" and 5 was "very conservative," the average participant reported being fiscally ($\bar{x}$ = 2.78) and socially ($\bar{x}$ = 2.29) moderate, but the standard deviation values show the variation among participants (1.284 and 1.349, respectively). Similarly, where 1 was not religious and 5 was very religious, participants skewed slightly religious ($\bar{x}$ = 2.83), but a standard deviation of 1.504 shows the spread in religiosity.

Table 10. *Descriptive Statistics for Numerical (Age) and Ordinal Sociodemographic Variables*

	Min	Max	Mean	*SD*	Skew	std. error
Age	21	93	63.07	13.784	-0.578	0.133
Fiscally Conservative	1	5	2.78	1.284	0.17	0.133
Socially Conservative	1	5	2.29	1.349	0.736	0.133
Religiosity	1	5	2.83	1.504	0.145	0.131

Independent variables.

Knowledge. Participants were asked about their objective and subjective PFAS knowledge. To measure objective, conceptual knowledge about PFAS, participants were given five true/false questions (e.g., *PFAS are substances that do not exist naturally and are only man-made*) that could be scored correctly (1) or incorrectly (0). Scores for all five questions were averaged to create an objective knowledge score from 0 to 1. The average score was 0.57, indicating participants answered about half of the questions correctly. Subjective knowledge was measured from three, five-point Likert scale responses (*I understand the risks and benefits of contributing to the GenX Exposure Study*). Scores ranged from 1 to 5, with the average response ($\bar{x}$ = 4.1822) being "Somewhat Agree."

Efficacy. Participants were asked about their perceived self-efficacy by responding to questions using five-point Likert scales (*How much are you able to find answers to the questions you have about PFAS and their health effects?).* Most participants were between ($\bar{x}$ = 3.78) "Some" and "Quite a bit." For response efficacy, participants were asked how much they agreed or disagreed with statements about various PFAS-related behaviors (*How effective do you think Contacting elected officials to reduce PFAS inputs to the environment is at reducing PFAS?).* Participants ranged from 1 to 5, with the average ($\bar{x}$ = 3.4) participant response between "Somewhat Effective" and "Quite a bit effective."

Knowledge Sufficiency. Participants were asked to self-evaluate their level of knowledge about PFAS compared to the knowledge they feel they need about PFAS to respond to it (*On a scale of 0-100, how much do you currently know about the risks of PFAS? On that same scale, how much do you feel you need to know about the risks of PFAS in order to make a decision about your health?)* The "knowledge sufficiency" variable is the difference between what participants feel they need to know and how much knowledge they feel they already have, ranging from -100 (feeling they know 0 and needing to know 100 to act) and 80 (feeling they have more than enough knowledge to act). A mean value of -20.174 indicates that most participants felt they needed to know more about PFAS than they currently do to be able to make informed decisions.

Risk Perception. Participants were asked about the perceived risk to their own health and the health of their community using a five-point Likert scale, with responses ranging from "None at all" to "A lot." Average responses were combined to create one variable for risk perception. Most participants had elevated levels of perceived risk ($\bar{x}$ = 4.267, "Quite a bit") with very little spread among the responses (σ = 0.446).

Perceptions of Research. Finally, participants were asked to respond to statements about how participation in research benefits themselves (*Participating in this study benefits me personally)* and scientists (*Participating in this study benefits researchers at NC State)* using a five-point Likert scale options from "Strongly Disagree" to "Strongly Agree." In general, participants felt that research participation was beneficial, with the average participant responding "Somewhat Agree" about personal benefit and between "Somewhat Agree" and "Strongly Agree" for researcher benefit.

Table 11. *Descriptive Statistics for Independent Knowledge and Belief Variables*

	Min	Max	Mean	*SD*	Skew	*SE*
Knowledge						
Factual Knowledge	0	1	0.57	0.22498	-0.362	0.131
Subjective Knowledge	1.25	5	4.1822	0.72704	-1.336	0.131
Efficacy						
Self-Efficacy	1	5	3.7762	0.85415	-0.884	0.131
Response Efficacy	1	5	3.3954	0.74072	-0.212	0.131
Knowledge Sufficiency	-100	80	-20.174	32.675	0.228	0.132
Attitudes and Beliefs						
Average Total Risk Perception	1	5	4.267	.0446	-1.216	.132
Research is personally beneficial	1	5	4.27	.931	-1.541	.131
Research is beneficial to scientists	1	5	4.51	.872	-2.254	.132

Dependent Variables

Participants were asked to respond to questions about their PFAS-related behaviors using five-point Likert scales. Responses for the three private behaviors, two past public, and two future public behaviors were averaged to create composite variables for each type of behavior. Private behaviors—actions participants reported taking that only impact their own PFAS exposure (*How often have you avoided eating locally grown foods?)*— had the highest average ($\overline{x}$=3.539), indicating that most participants have done some private risk reduction behaviors "Some" and "Quite often." Public advocacy behaviors—behaviors that use advocacy and civic engagement to effect change (*How often have you contacted elected officials about reducing PFAS?)*—were also asked about in the past tense. Participants reported doing these types of actions less often ($\overline{x}$ = 2.378), between "A little" and "Some." Finally, participants were asked about their willingness to engage in future public non-advocacy behaviors—actions that use non-advocacy methods to generate collective impacts (*How willing would you be to sign up for another health study?).* In general, participants reported being between "Quite a bit willing" and "Completely willing" ($\overline{x}$ = 4.523) to participate in future research similar to the GenX Study.

RQ1. After receiving results from a PFAS exposure study, what factors—demographics, knowledge, capacity, risk perception, perceived benefits—relate to exposure reduction behaviors?

To answer RQ1, regression models were utilized to examine relationships between the dependent variable—past or future risk reduction behaviors—and independent variables—knowledge, efficacy, risk perception, attitudes, and demographics. Regressions were conducted step-wise, adding one group of constructs at a time in order to see how they related to behaviors. Each model used the same step-wise progression: Step 1. demographic control variables, Step 2. narrow EHL constructs, Step 3. additional attitude variables, and the model for RQ1c included a fourth step to include additional belief variables. Table 12 shows an overview of descriptive statistics for all constructs used in the three models.

Table 12. *Descriptive Statistics for Dependent Behavior Variables*

	Min	Max	Mean	*SD*	Skew	*SE*
Past Private Behaviors	1	5	3.539	1.074	-.652	.131
Past Public Behaviors	1	5	2.378	1.203	.459	.131
Future Public Behaviors	1	5	4.523	.852	-2.195	.131

RQ1a. What factors relate to past private behaviors? The first OLS regression model looked at factors related to participants' prior private exposure reduction behaviors—things they report having done in the past to directly reduce their or their family's exposure to PFAS. Past behaviors included activities such as filtering drinking water, avoiding locally grown foods, and changing purchasing habits.

Step 1. Sociodemographic variables explained less than 4% of the variance in behavior ($r^2 = .039$, $F = 2.397$, $p < .001$). Income and religiosity were significantly related to behavior ($\beta = -.126$, $p < .05$; $\beta = -.135$, $p < 05$).

Step 2. The constructs of EHL as outlined in the EHS literature—objective knowledge, self-efficacy, and response efficacy—were added to the regression. This explained 12.8% of the variance in past private behaviors (r^2 = .128, F = 12.257, p < .001), and high income (β = - .128, p < .05) and response efficacy (β = .289, p < .001) were significant predictors.

Step 3. After adding variables for subjective knowledge, knowledge sufficiency, and risk perception, the model explained just over 20% of the variance (r^2 = .202, F = 11.074, p < .001). The only significant predictors were response efficacy (β = .266, p < .001) and risk perception (β = .284, p < .001).

Table 13. *Results of Model 1: Stepwise Linear Regression Predicting Past Private Behaviors*

	Step 1		Step 2		Step 3	
	B	*SE*	*B*	*SE*	*B*	*SE*
Male	-0.097	0.127	-0.074	0.122	-0.059	0.117
White	0.028	0.233	0.047	0.225	0.072	0.217
High Income	-0.126*	0.121	-0.128*	0.119	-0.1	0.115
Education	0.046	0.136	0.042	0.132	0.072	0.127
Fiscally Liberal	0.05	0.153	0.018	0.147	-0.002	0.141
Socially Liberal	-0.1	0.168	-0.104	0.161	-0.076	0.154
Not Religious	-0.135*	0.133	-0.101	0.128	-0.085	0.123
Older Age	-0.015	0.122	-0.043	0.117	-0.015	0.113
Pittsboro	-0.063	0.15	-0.049	0.143	-0.032	0.139
Fayetteville	-0.004	0.151	0.022	0.145	0.027	0.138
Factual Knowledge			0.007	0.293	0.001	0.281
Response Efficacy			0.289***	0.077	0.266***	0.074
Self-Efficacy			0.096	0.074	0.079	0.084
Subjective Knowledge					-0.02	0.093
Knowledge Sufficiency					0.034	0.116
Risk Perception					0.284***	0.066
Constant	3.831***	0.275	1.827***	0.43	0.251	0.536
Average *VIF*	1.3018		1.313		1.346	
F-value	2.397**		12.267***		11.074***	
*R*2	0.039		0.128		0.202	
N	342		342		342	

Note. *p < .05, **p < .01, ***p < .001

RQ1b. What factors relate to past public behaviors? The second step-wise regression model used past public advocacy behaviors as the dependent variable—actions that have less impact on personal exposure reduction but may contribute to larger structural changes and collective benefits. Examples of past public behaviors included contacting elected officials and working with local advocacy and nonprofit organizations to address PFAS issues. As with the model above, the same groups of constructs were added in the same step-wise progression.

Step 1. Sociodemographic variables explained none of the variance in behaviors (r^2 = -.001, F = .0962).

Step 2. The three EHL constructs along with past private behaviors accounted for 11.5% of the variance (r^2 = .115, F = 11.898, p < .001). Factual Knowledge (β = .176, p < .01) and previous private behaviors (β = .308, p < .001) were significant predictors of behavior.

Step 3. Additional attitude variables accounted for 12.8% of the variance in past behaviors (r^2 = .128, F = 2.57, not significant). Factual knowledge (β = .175, p <.01) and previous private behaviors (β = .265, p < .001), and risk perception (β = .144, p < .01) were significantly related to behavior.

Table 14. *Results of Model 2: Past Public Advocacy Behaviors*

	Step 1		Step 2		Step 3	
	B	*SE*	*B*	*SE*	*B*	*SE*
Male	-0.03	0.145	0.018	0.137	0.022	0.137
White	0.015	0.266	-0.009	0.253	-0.001	0.254
High Income	-0.046	0.138	-0.048	0.135	-0.041	0.135
Education	0.086	0.156	0.047	0.148	0.062	0.148
Fiscally Liberal	-0.089	0.175	-0.116	0.165	-0.126	0.164
Socially Liberal	0.099	0.191	0.115	0.181	0.124	0.181
Not Religious	-0.116	0.151	-0.088	0.145	-0.088	0.144
Older Age	-0.009	0.14	-0.008	0.132	0	0.132
Pittsboro	0.032	0.171	0.055	0.161	0.052	0.162
Fayetteville	0.007	0.172	0.019	0.163	0.023	0.162
Factual Knowledge			0.176**	0.33	0.175**	0.328

Table 14 (continued).

Response Efficacy			0.025	0.09	0.022	0.09
Self-Efficacy			-0.003	0.083	-0.036	0.099
Previous Personal Behaviors			0.308***	0.062	0.265***	0.065
Subjective Knowledge					0.034	0.108
Knowledge Gap					-0.039	0.136
Risk Perception					0.144**	0.626
Constant	2.274	0.314	0.483	0.498	-0.3	
F-value	0.962		11.898***		2.57	
Average *VIF*	1.3018		1.3167		1.36	
*R*2	-0.001		0.115		0.128	
N	342		342		342	

Note. *$p < .05$, **$p < .01$, ***$p < .001$

RQ1c. What factors relate to future public behaviors? The third model looked at the relationship between independent variables and participants' willingness to participate in future research studies, considered a public non-advocacy action for its limited impact on personal exposure reduction but potential to generate information that may contribute to systemic, collective changes. Examples of this type of behavior include willingness to participate in future environmental health research studies.

Step 1. Sociodemographic variables explained little variance ($r^2 = .027$, $F = 1.943$, $p < .05$), though race was significantly related to future behaviors ($\beta = .124$, $p < .05$).

Step 2. EHL variables explained 15.3% of the variance ($F = 10.824$, $p < .001$), and factual knowledge ($\beta = -.123$, $p < .05$) and self-efficacy ($\beta = .382$, $p < .001$) were statistically significant.

Step 3. Additional attitude variables explained 17.2% of variance in future behaviors ($r^2 = .172$, $F = 3.385$, $p < .05$). Race ($\beta = .115$, $p < .05$), factual knowledge ($\beta = -.119$, $p < .05$), and subjective knowledge ($\beta = .19$, $p < .01$) were all significant predictors.

Step 4. An extra step was added in this regression model to account for constructs specifically related to the question of future research participation. Variables for perceptions of

personal or scientist benefit were added. In this fourth step, the model itself was no longer significant (r^2 = .171, F = .814, p > .05), but factual knowledge (β = -.125, p < .05), self-efficacy (β = .28, p < .001), and subjective knowledge (β = .177, p < .01) were all significant predictors of future behavior.

Table 15. *Results of Model 3: Future Public Behaviors*

	Step 1		Step 2		Step 3		Step 4	
	B	*SE*	*B*	*SE*	*B*	*SE*	*B*	*SE*
Male	-0.093	0.102	-0.089	0.096	-0.075	0.095	-0.082	0.096
White	0.124*	0.187	0.109*	0.177	0.115*	0.176	0.113*	0.177
High Income	-0.003	0.098	-0.004	0.095	-0.012	0.094	-0.017	0.095
Education	-0.035	0.109	-0.054	0.103	-0.039	0.103	-0.044	0.104
Fiscally Liberal	-0.108	0.124	-0.128	0.116	-0.13	0.115	-0.132*	0.115
Socially Liberal	0.116	0.135	0.091	0.127	0.083	0.126	0.076	0.127
Not Religious	0.007	0.107	0.019	0.102	0.033	0.101	0.033	0.101
Older Age	-0.058	0.098	-0.097	0.092	-0.098	0.092	-0.093	0.092
Pittsboro	0.059	0.121	0.075	0.113	0.057	0.113	0.059	0.114
Fayetteville	-0.077	0.121	-0.047	0.114	-0.043	0.112	-0.053	0.114
Factual Knowledge			-0.123*	0.233	-0.119*	0.231	-0.125*	0.232
Response Efficacy			0.059	0.063	0.043	0.063	0.043	0.063
Self-Efficacy			0.382***	0.058	0.271***	0.069	0.28***	0.069
Past Personal Behaviors			0.055	0.045	0.046	0.046	0.042	0.047
Past Public Behaviors			0.041	0.039	0.031	0.039	0.033	0.039
Subjective Knowledge					0.19**	0.075	0.177**	0.081
Knowledge Gap					0.036	0.095	0.036	0.096
Risk Perception					0.032	0.056	0.034	0.057
Personally Benefit							0.003	0.139
Researcher Benefit							0.066	0.147
Constant	4.237***	0.22	2.691***	0.347	2.04***	0.435	1.944***	0.444
F-value	1.943*		10.824***		3.386*		0.814	
Average *VIF*	1.3061		1.3236		1.365		1.372	
*R*2	0.027		0.153		0.172		0.171	
N	340		340		340		340	

Note. *p < .05, **p < .01, ***p < .001

Summary of RQ1 Findings

RQ1a. What factors relate to past private behaviors? Using a narrow definition of EHL, only response efficacy predicted behaviors. Income and religiosity were significant in the first two steps but no longer predictive after Step 3 where response efficacy ($\beta = .266$, $p < .001$) and risk perception ($\beta = .284$, $p < .001$) were significantly related to past private behaviors.

RQ1b. What factors relate to past public behaviors? Increased factual knowledge and previous private behaviors were consistent predictors of past public behaviors. As with past private behaviors above, increased risk perception was associated with increased behaviors. No sociodemographic variables were significant predictors.

RQ1c. What factors relate to future public behaviors? Factual knowledge, self-efficacy, and subjective knowledge were consistently significant predictors of future public behaviors. However, as opposed to RQ1b, *lower* factual knowledge was related to increased future research behaviors. Additionally, unlike in RQ1a and b, risk perception was not a predictor of future public behaviors. The addition of people's perceptions of the benefits of their future involvement in research in Step 4 had no predictive value for the model. This was the only model where political ideology and race were related to behaviors. While race was consistently significant across all four steps of the model, political ideology was only significant in Step 4.

RQ2: How do participants describe their motivations and experience participating in a PFAS exposure study?

The three open-ended questions provided qualitative responses that were coded using the independent and dependent variables as a priori codes and analyzed for trends through frequency counts. There are more responses to Q4-6 ($n = 374$) because some participants provided written responses to these questions but left a portion of the other items blank, and they were unable to

be included in the quantitative analysis (n = 343). The unit of analysis is one person's full response. In some cases, participants' responses did not align with the codes of interest for this study. In other cases, responses contained multiple ideas that yielded multiple codes for the same response. For example, someone could describe learning something and fear of risk in one response and was therefore coded as knowledge and risk perception. Tables 16–18 summarizes themes, frequencies, and representations of responses created to capture the overarching sentiment of responses in that theme. Frequencies presented in the table are the number of responses coded with that theme, not necessarily the number of participants.

Motivation. In the first of the open-ended questions, participants were asked about their motivation to participate in the GenX Study. In total, 368 participants gave substantive responses to the question. Most participants (176) had a response related to subjective knowledge and to feel like they learned about their own exposures (48%, n = 176). Risk perception was mentioned by 134 participants (37%) and public behaviors and the desire to contribute to collective knowledge about PFAS was mentioned by 105 participants (29%). Table 16 shows the themes within each overarching code, and the number of times each theme appeared in the data.

Table 16. *Codebook and Frequencies for Open-Ended Response Questions to Survey Q4*

Why did you sign up to participate in the GenX Study?		
Theme	Frequency	Representation of Responses
Factual Knowledge: Stating an objective fact about PFAS or the study. Not a feeling or an opinion about PFAS. Something that can be deemed accurate or inaccurate.		
--	0	--
	Total: 0	
Subjective Knowledge: ***Feeling*** like they wanted to learn something about PFAS, research, etc. (use words like: find out, see, educate, to know, curious, etc.)		
To understand or confirm personal (or family) *exposure* levels, measurements.	103	*"I wanted to know how much I was exposed"*
To feel like they learned more, generally.	59	*"I was curious about it"*

Table 16 (continued).

To understand or confirm *health effects*	26	*"I wanted to see how it impacts my health."*
	Total: 188	
Self-Efficacy: Believe/feel they can do something (use words like: find, understand, etc.)		
Capacity for personal exposure reduction	3	*"I want to see if using a filter works"*
Capacity for lifestyle changes, broadly	3	*"I want to be able to stay healthy."*
Context for talking with one's doctor.	1	*"I wanted to know how to talk to my doctor."*
	Total: 7	
Response Efficacy: Believe/feel that something *they do* will work (use words like: help, fix, solve a problem).		
--	0	--
	Total: 0	
Risk Perception: Being concerned or worried about PFAS exposure, health effects, etc. for oneself, family, or community. Knowing about sources of PFAS contamination and worried about subsequent effects.		
Worried *specifically* about *contaminated water*; making a conceptual link between PFAS in water and GenX Study.	63	*"I'm worried because I drink unfiltered water"*
Location- names one of the three communities as source of PFAS worry.	33	*"I live in Wilmington and am worried"*
Time- worried about length of exposure, years drinking water, years in community	29	*"I have lived here for 20 years"*
Specifically worried about links to/causes of *health* conditions (which this study is not able to prove)	27	*"I want to know if PFAS caused my illness"*
Worried about health broadly.	22	*"I was worried about my health"*
Worried about risk to family, loved ones, community.	9	*"My children were born here and drank the water"*
	Total: 183	
Private Behaviors: Talking about actions to protect oneself or family.		
--	0	--
	Total: 0	
Public Behaviors: Actions that contribute to collective understanding, addressing, and/or mitigating PFAS risks.		

Table 16 (continued).

Contribute to learning, understanding, knowledge base of PFAS.	60	--
To help the community generally, civic duty.	19	--
Solving the problem, contributing to policy change	16	--
To help document *specific* impacts on their community.	12	--
Solving the problem, specifically via legal action or polluter accountability.	6	--
To help general environmental and public health wellness.	4	--
	Total: 117	

Satisfaction. The second open-ended question asked participants, "*What have you felt the most satisfied with from the GenX Exposure Study?"* Out of the 374 returned questionnaires, 338 people (90%) gave a substantive response to this question, and another 36 people had a response that was left blank or not responsive (e.g., "nothing" or "n/a"). Of the 338 responses, 181 people (54%) described satisfaction related to gaining factual knowledge, with 112 people specifically mentioning satisfaction with having one's own PFAS measurements. Subjective knowledge was mentioned by 71 participants but generated 89 units of coded text because of responses containing multiple ideas. People described people what they felt they had learned (e.g., "now I have an answer"), and the perceived quality of the information (e.g., "the results were good").

Table 17. *Codebook and Frequencies for Open-Ended Response Questions to Survey Q5*

What have you felt the most satisfied with from the GenX Exposure Study?		
Theme	Frequency	Representation of Responses
Factual Knowledge: Stating an objective fact about PFAS, the study, the letter, etc. (ex: they gave me results). Something that we could deem accurate or inaccurate. Mentioning the letter, meeting, results, numbers, levels. Not making definitive links between exposure and health effects.		

Table 17 (continued).

Specifically mentioning personal blood results, levels, measurements, relativity to other participants or national average.	112	*"I could see my levels of different individual PFAS."*
Being satisfied with the study's production of knowledge, generally	36	*"The communication and clarity"*
Learning facts, broadly	12	*"They gave me information"*
Learning facts about PFAS	8	*"I know that certain PFAS don't stay in the body forever."*
Learning facts specifically about PFAS and health effects	5	*"PFAS can affect the immune system."*
Learning things specifically from the report back materials	5	*"The stripcharts showed me my levels relative to other people in my town."*
Learning specific facts that are not related to PFAS	3	*"I learned my cholesterol levels."*
	Total: 181	
Subjective Knowledge: Perceptions of learning or knowledge that are value-laden, subjective, or opinionated. Feeling they learned something *beyond what was explicitly outlined* in the letter.		
Affective descriptions or value judgements about the study or data that cannot be objectively judged as in/accurate.	40	*"The results were detailed and valid"*
Descriptions of what they *felt* they learned, perceiving a gap in knowledge as being filled that cannot be objectively judged as in/accurate.	26	*"This confirmed what I thought"*
Subjective assessment of their own data.	13	*"My levels were so much lower than I thought."*
Feeling the data confirmed or proved a definitive, causal link between PFAS and health effects.	10	*"Now I know what caused my kidney issues"*
	Total: 89	
Self-Efficacy: Believe or feel that they are able to do something (words like: find out, look for, can, able to)		
The ability to interact with healthcare providers	7	*"I am able to take this information to my doctors"*
Describing the ability make informed decisions.	5	*"I know my numbers and what to do about them"*
Describing the ability to answer questions, find answers, identify trends.	2	*"Now I'm able to find out my levels"*

Table 17 (continued).

	Total: 14	
Response Efficacy: Believe or feel that something they did worked, helped, fixed a problem.		
--	0	--
	Total: 0	
Risk Perception: Ongoing, continued worry about exposure, long-term health risks, etc.		
--	0	--
	Total: 0	
Private Behaviors: Take actions to protect oneself or family.		
Taking actions related to healthcare	6	*"I took this information to my doctors"*
Private actions taken, broadly.	3	*"I am taking actions to protect my family"*
Actions taken specifically related to drinking water	2	*"I saw my levels and bought a water filter for my sink."*
	Total: 11	
Public Behaviors: Taking actions that contribute to the collective understanding, addressing, or mitigating of PFAS risks.		
Collective understanding of PFAS exposures and risks is a good in and of itself.	18	*"I participated in this study and helped researchers better understand PFAS."*
The Study's contribution to PFAS knowledge may lead to other collective benefits.	9	*"This put a spotlight on our problem and now maybe it will get better."*
The Study's contribution to PFAS knowledge prompts structural or policy changes.	6	*"This Study helps hold polluters accountable."*
Improvements to municipal/public water supplies, which could be connected to results from the GenX Study.	6	*"This may have been the reason my drinking water got cleaned up."*
	Total: 39	

Dissatisfaction. The final open-ended question asked, "*And what have you felt <u>least satisfied with</u>?"* There were 250 substantive responses about dissatisfaction and 124 responses that were either blank or described a lack of dissatisfaction (e.g., "nothing!"). Responses were more evenly distributed among factual knowledge (16%, $n = 40$), subjective knowledge (12%, $n = 30$), private behaviors (10.1%, $n = 27$), and public behaviors (8.4%, $n = 21$). Of the 40 responses related to factual knowledge, 16 people (40%) expressed wishing they had gotten more

information in their letters (detail, length, numbers). Of the units of text related to subjective knowledge, almost half (N = 13) described not understanding what the results specifically meant for their health. Of the 48 responses related to behaviors, 11 people (23%) described dissatisfaction with the private behavior of being unable to lower PFAS body burden, and 20 people (42%) described anger that public behaviors have not "held polluters accountable" and led to mitigation or remediation.

Table 18. *Codebook and Frequencies for Open-Ended Response Questions to Survey Q6*

And what were you least satisfied with?		
Theme	Frequency	Representation of Responses
Factual Knowledge: Stating an objective fact about PFAS, the study, the letter, etc. (ex: they gave me results). Something that we could deem accurate or inaccurate. Mentioning the letter, meeting, results, numbers, levels. Not making definitive links between exposure and health effects.		
Lack of, wishing they had *more information provided* by the Study (that objectively was not covered by the study's report back)	16	*"I wanted more information on each health impact."*
Wishing they had *more opportunities* to provide information *to* the study.	11	*"I want to provide more blood samples more often."*
Logistical issues and the time it took to receive results	9	*"It took too long to get them."*
Mentioning their own results as a source of dissatisfaction.	5	*"I'm not happy with my results."*
	Total: 41	
Subjective Knowledge: Mentions of knowledge or learning that are *not* explicitly outlined in the letter that are value laden, subjective, or opinionated. Feeling they learned something beyond what was *objectively* in the letter.		
Not understanding what the results mean for *health.*	13	***"****What do the high levels in me mean?"*
Lack of understanding when *reading the letter* (and information therein).	11	*"I didn't fully understand the charts."*
Feeling that there is not enough information about a certain topic, either specifically assigning blame to the study, or speaking more broadly.	7	*"Which PFAS are the problem? Not GenX?"*
Lack of understanding more broadly.	7	*"How could this happen, I just moved here!"*

Table 18 (continued).

Not understanding what the results mean for *water*	2	*"So can I drink my water?"*
	Total: 40	
Self-Efficacy: Feeling they *can't* do something (words like: find out, look for, can't, aren't able to)		
Lack of *usefulness* of information provided to *do something.*	7	*"I'm not sure what I can do with this information now."*
Difficulty with information seeking.	1	*"It's hard trying to find answers"*
	Total: 8	
Response Efficacy: Believe or feel that something *won't work,* won't help, won't fix a problem.		
--	0	--
	Total: 0	
Risk Perception: Ongoing, continued worry about exposure, long-term health risks, etc.		
Feeling new, continued, or unresolved worry.	6	*"I don't know the full scope of this, but my high levels are scary."*
Anger about ongoing risks.	3	*"This shouldn't have happened in the first place!"*
	Total: 9	
Private Behaviors: Taking actions (or being unable to) that protect oneself or one's family.		
Wanting to be able to reduce body burden	11	*"How can I get PFAS out of my body?"*
Wanting to reduce exposure, broadly	9	*"I need to do something to fix my exposure"*
Wanting to do something healthcare related	7	*"I don't know what medical actions to take."*
Wanting actions to do at home	3	*"Is filtering water really all I can do?"*
	Total: 30	
Public Behaviors: Actions that contribute to collective understanding, addressing, or mitigating of PFAS risks.		
Lack of action from polluters to reduce collective exposure.	15	*"I want this information to hold the companies accountable"*
Collective access to clean water.	5	*"We should be able to drink clean water"*
The amount of time between contamination and remediation	3	*"It's going to take a long time to help us."*

Table 18 (continued).

Uncertain future impacts	3	*"What happens next? I don't want people to forget about us."*
	Total: 26	

Summary of RQ2 Findings

When asked three open-ended questions about motivation, satisfaction, and dissatisfaction, most participants (368) had responses about motivation, and many (338) had responses relating to satisfaction. Notably, far fewer participants (250, 67%) chose to write a response about their dissatisfaction. Risk perception was listed as a motivation for participation in more than a third of participants. The desire to receive personal PFAS measurements drove participation and satisfaction among participants. A feeling of uncertainty around next steps and long-term solutions was the predominant source of dissatisfaction, mentioned by 86 people (34% of responses).

Discussion

Fundamental to EHS research is the notion that environmental exposures may negatively impact human health. One way to study this is through exposure science and biomonitoring studies, which rely on the voluntary participation of the public to provide environmental and biological samples. Sharing individual measurements and study results with participants is seen as one strategy for demonstrating reciprocity to participants and encouraging their continued participation. Furthermore, report backs are believed to (or hoped to) improve participant's environmental health literacy. As EHL remains a popular framework among EHS researchers, and reporting back results becomes increasingly commonplace among exposure studies, it is important to understand how participants make sense of and use the information they receive, and what role it plays in reducing exposures through private and public behaviors. The goal of

this study was to better understand the experience of participating in and receiving research results from one such study involving PFAS exposure, while using EHL as a theoretical lens through which to view participants' knowledge, attitudes, and behaviors.

In answering the first research question, *after receiving results from a PFAS exposure study, what factors—demographics, knowledge, capacity, risk perception, perceived benefits—relate to exposure reduction behaviors,* this study found that among all the dependent variables included in the models, none were consistently related to private or public exposure reduction behaviors, though risk perception was a significant predictor of both types of past behaviors. While increased factual knowledge predicted past public behaviors, *decreased* factual knowledge predicted future public behaviors. No sociodemographic or geographic characteristics were consistently related to behaviors, and only model 3 had sociodemographic variables that were significant predictors in the final model, identifying as White and being less fiscally liberal.

To answer the second research question, results indicated that participants were motivated by concern about their own PFAS body burden and desire to have personal PFAS measurements. Overall, people were satisfied and had positive experiences participating in the GenX Study, as evidenced by their open-ended responses, and by more than 90% of participants providing a response about their motivation and satisfaction, and only two thirds wrote a response about their dissatisfaction. Moreover, many of the responses about dissatisfaction were not with the GenX Study itself, but the uncertainty about what to do next now that they had the information.

From these findings, six recommendations for the field are proposed. First, a broader conceptualization of EHL may help better describe exposure reduction behaviors. Second,

inconsistencies in measurement need to be addressed among EHS practitioners. Third, high quality report back should be used as an incentive to promote broad participation in EHS research. Relatedly, exposure studies must continue working to recruit participants that are demographically representative of their communities. Fifth, when sharing results with study participants, researchers should design materials that support participants in continued and long-term exposure reduction. Lastly, EHS researchers should share information as "honest brokers" of scientific findings, allowing participants to truly make informed decisions (Pielke, 2007). Each of these recommendations is expanded upon below.

Broaden the Conceptualization of EHL to Describe Behaviors, not Predict Them.

The fields of education and behavior change have shown the limited role that knowledge plays in predicting behavior (Brewer et al., 2004; Goebel & Wardropper, 2023; Wong-Parodi & Berlin Rubin, 2022). In this study, more factual knowledge only predicted public advocacy behaviors (e.g., calling policymakers, working with advocacy groups), and *lower* levels of factual knowledge predicted future public behaviors (e.g., participating in future EHS research). The two measures of efficacy in this study were also not consistent predictors of behavior, relating to previous research on the complex, interconnected links between efficacy, behaviors, and other affective measures (Bandura, 2006b). Self-efficacy was only related to future public behaviors, and response efficacy was only predictive of past private behaviors. In EHS literature, EHL is depicted as a combination of knowledge, efficacy, and behaviors (Finn & O'Fallon, 2017; K. Gray, 2018). Yet in this study, factual knowledge and efficacy were not predictive antecedents for private or public behaviors related to PFAS exposure, but the addition of other types of knowledge and attitudes increased the predictive strength of each model.

Measures of subjective knowledge were used because they have an important role in how people make sense of and respond to environmental hazards, and are distinct from measures of factual, conceptual EHS knowledge (J. P. Carlson et al., 2009; Goebel & Wardropper, 2023). Indeed, in this study, participants' beliefs about their own (subjective) knowledge was related to more willingness to participate in future public behaviors when having more objective PFAS knowledge was not. Other research has shown a relationship between increased subjective knowledge and increased positive feelings towards research participation (Drummond & Fischhoff, 2020). Given the contextual nature of environmental hazards (K. Gray, 2018; K. M. Gray & Lindsey, 2019; Lindsey et al., 2021b), and because the lived experiences of contaminated community members are often different than those of the exposure scientists (Edelstein, 2018), the knowledge that participants believe they have about an environmental issue may be different from what researchers consider important or factually accurate about it. For instance, in open-ended responses, some participants expressed feeling that GenX Study results had confirmed or proven their knowledge that PFAS exposure had caused specific health effects—a sentiment that is not yet supported by objective data but still feels subjectively true to those participants.

In addition to subjective knowledge, additional variables related to attitude and beliefs were added to try and increase the predictive potential of each model and better explain participants' behaviors. Behavior change theories have long emphasized the complexity of human decision making (Bandura, 2001), highlighting the importance of affective constructs like risk perception, outcome expectancy, attitudes, and social norms when investigating human behaviors (Ajzen, 1991; Bandura, 2001; Fishbein & Azjen, 2011; Hochbaum, 1958). In turn, this study added risk perception, beliefs about their knowledge sufficiency, and beliefs about research

participation. These affective considerations are particularly important in the context of research participants from contaminated communities, where residents' sensemaking and evaluation of a hazard is inherently through the lens of their lived experiences, which may generate different conclusions than how scientists would characterize a hazard (Edelstein, 2018; Vyner, 1988). That is, residents often weigh their *perceptions* of an exposure differently than a researcher's quantitative measurements of a chemical or documented rates of illnesses (Edelstein, 2018; K. M. Gray et al., 2021; Slovic, 2012). In this study's open-ended responses, participants consistently described their motivation to participate in the current research study as a function of their perceived risk from previous PFAS exposures. In the regression models, however, higher risk perception was not related to more willingness to participate in future research, though it was related to past protective behaviors.

Clearly, there is a complex relationship between people's knowledge, attitudes, beliefs, and behaviors. Although this study had an imperfect operationalization of EHL, the findings may imply that operationalizing EHL more broadly, to understand and account for other variables may help us better understand what drives exposure reduction in the face of environmental hazards. In addition to risk perception and subjective knowledge, trust, information seeking, social norms, and other attitudes and beliefs may also be important. Future work may benefit from including more variables to better describe EHL and behaviors in the face of environmental exposures.

Address Issues in Measurement and Assessment of EHL

There have been efforts among EHS researchers to reach consensus on what constitutes "having" EHL (Valdez et al., 2014), but at present, there is a limited foundational research base for consistently, reliably measuring EHL because there is such variation across the field in how it

is operationalized and assessed (Lindsey et al., 2021b). Some EHL interventions focus on quantitative assessments of knowledge as indicators of EHL (K. Gray, 2018; K. M. Gray & Lindsey, 2019; Lindsey et al., 2021b). Many use surveys to assess EHL related to a specific exposure (e.g., Binder et al., 2022; Irvin et al., 2019; Kim et al., 2024; Madrigal et al., 2016; Raufman et al., 2020), to measure EHL as a singular broad concept (Lichtveld et al., 2019; Ratnapradipa et al., 2015), or to allow for assessing a baseline level or changes in EHL over time (e.g., K. M. Gray et al., 2021). But the context-specific nature of EHL is such that a validated instrument designed to measure EHL for air pollution in one community will likely not be fully adequate for measuring air pollution in a different place, let alone a different contaminant (K. M. Gray & Lindsey, 2019). Moreover, some findings suggest that surveys inadvertently resemble assessments used in schools and thus may privilege people who had more years of or more recent formal schooling, creating an inherent bias when trying to measure EHL. For instance, in (K. M. Gray et al., 2021), college students scored quantitatively higher on the scales used to measure EHL, but the community members were able to describe more sources of water contamination and strategies for information seeking. Finally, survey instruments almost inherently measure what is considered conceptually relevant by academic researchers for a given exposure, and not necessarily what people living with the exposure feel is important knowledge, attitudes, beliefs, or behaviors (Gibson et al., 2024).

Above, this study highlighted the difficulty in relying only on conceptual knowledge and efficacy to statistically predict behavior and model EHL, arguing for a broader definition of EHL. And while some believe there is already an issue with limited reproducibility in academic research and there is a need for consistent constructs and measurement tools (Flier, 2017; Moher et al., 2018; Topol, 2016), increasing the conceptual scope of EHL may only exacerbate issues of

inconsistent measurement and assessment across the field. Still, if affective measures account for what participants consider as most salient for their environmental exposure, then incorporating subjective knowledge and other affective constructs may be necessary for more holistically describing EHL. These are inherently more difficult to measure consistently with survey instruments due to their subjective nature, and they may be more difficult to draw comparisons from (Bandura, 2006b). As an example, there are multiple ways to measure self-efficacy and there are multiple ways to operationalize risk perception (Bandura, 2006b, 2006a; N. T. Brewer et al., 2004, 2007). For instance, someone might report lower perception of risk because they have *already* taken a risk reduction action (e.g., installing a water filter), which is different than the risk they perceived from that same exposure before exposure reduction (N. T. Brewer et al., 2004). In this study, none of the models had r^2 values greater than 0.20, meaning that more than 80% of variance in behaviors was not explained by the constructs in this survey—objective knowledge, subjective knowledge, self-efficacy, response efficacy, risk perception, attitudes, or demographics—implying that important constructs were not included or operationalized effectively. These results highlight the need for more robust and consistent measurement of EHL in order to draw comparisons among studies and within the field.

Do not Rely on Fear or Altruism to Encourage Participation in EHS Research, Promote Report Back Instead

Participants' responses to open-ended questions showed both private and public motivations for participating in the GenX Study—a desire to receive personal information, and a desire to contribute to a good cause. Participants expressed perceived risks and fears about their personal exposures and wanted to support the larger scientific effort to document PFAS contamination and human exposure in their communities. Risk perception underlies many health

behavior theories (N. T. Brewer et al., 2007) and has been predictive of health protective behaviors in previous studies (N. T. Brewer et al., 2004). Interestingly, however, increased risk perception was not statistically related to increased willingness to participate in future research in this study's quantitative analyses. One explanation is that risk perception was already elevated overall among participants with little variation ($\bar{x} = 4.267$, $\sigma = 0.0446$), preventing it from being a useful predictor of behaviors in this study's regression models. Additionally, how participants appraised and perceived risk may have varied when the closed-ended question explicitly used the term "risk," and the open-ended question only asked about motivation. As such, participants may have appraised risk from different psychological distances in terms of visibility, probability, anticipation, or severity (N. T. Brewer et al., 2004, 2007; Edelstein, 2018), considering risk in the abstract versus explicitly describing their fears of known drinking water contamination as current motivators for getting concrete information about levels of PFAS in their bodies (Bandura, 2001).

In addition to risk perception, some participants cited a contribution to the collective good as motivation for participation in this study (e.g., helping the research team), aligning with other research on motivation in environmental health research (Carrera et al., 2018). What they reported feeling most satisfied with after the fact was having access to their personal data. Many PFAS are considered "emerging contaminants" (Kwiatkowski et al., 2020; Ryu et al., 2021), with limited toxicity data, little regulatory guidance, and limited medical recommendations (Fenton et al., 2021), yet participants were happy to have their results despite this inherent uncertainty. The promise that study data would be shared with participants was both a motivating factor, and the results themselves were seen as a direct benefit of participation. This aligns with many previous studies that show that participants' desire for personal information outweighs

hesitation or anxiety related to scientific uncertainty or limited regulator guidance (Altman et al., 2008; Brody et al., 2014a, 2018; Morello-Frosch et al., 2009, 2015; Ohayon et al., 2017). Much of exposure science research relies on the voluntary participation of the public, often including members of communities facing environmental contamination, to allow environmental or biological samples to be used for scientific analysis (Creager, 2018; Ladeira & Viegas, 2016; National Resource Council, 2006). Thus, making research participation seem appealing to the public may be critical to ensuring ongoing engagement and robust data. Instead of relying on risk perception or collective altruism alone to initially motivate research participation, emphasizing the unique access to personal measurements and study data as a direct, unique benefit may increase participation and retention over time. Sharing this information, however, requires a commitment to doing report back well. There are documented best practices for effective report back that investigators can dedicate the financial resources and expertise to following, ensuring that high-quality report back will be an outcome of the research process, and advertising it as an incentive during study recruitment (Brody et al., 2018; Dunagan et al., 2013; Korfmacher & Brody, 2023).

Broaden and Diversify Participation in EHS Research

Much of the public engagement with science literature has documented an overrepresentation of White participants (Soleri et al., 2016; Sorensen et al., 2019) and lack of representation among people of color to join research studies, including/especially those related to health and medicine (Mahmoudi et al., 2022; Oh et al., 2015; Shavers et al., 2002). Infamous historical mistreatment of research participants (Brandt, 1978; Freimuth et al., 2001; Skloot, 2010) and ongoing lack of trust in research processes has contributed to increased apprehension and decreased rates of participation of Black and Hispanic people in health studies (Oh et al.,

2015; Payne-Sturges et al., 2021; Shavers et al., 2002; Soleri et al., 2016). In this study, future participation in research was the only dependent behavior variable where race was a significant predictor. Interestingly, however, being White was inversely related to future research participation, which contradicts much of the above research. Although only 6% of this study's participants were Black, American Indian, or multiracial, thereby limiting the conclusions to be drawn, these results highlight the opportunity for continued and intentional engagement with Black, Hispanic, and American Indian residents in the Cape Fear River basin in EHS research. Demographically diverse study populations generate better scientific data (L. F. Davis et al., 2020; Shirk et al., 2012; Sorensen et al., 2019). More importantly, given that access to personal data was reported to be such a motivation and seen as a unique benefit of the GenX Study, and that these types of data can be used to directly inform exposure and risk reduction decisions (Adams et al., 2011; Altman et al., 2008; Brody et al., 2018; Korfmacher & Brody, 2023; Ohayon et al., 2017; Ramirez-Andreotta et al., 2016b; Tomsho et al., 2019), ensuring equal access to the EHS research process and the subsequent data should be viewed as a matter of social equity and environmental justice. There are already documented best practices for building trust, increasing recruitment, and promoting retention among communities of color, including acknowledging previous harm from research, clearly articulating how participants will be protected, emphasizing the importance of diverse representation in datasets to reduce health inequities, partnering with trusted community members, and committing to building long-term relationships in those communities (L. F. Davis et al., 2020; Fouad et al., 2014; Otado et al., 2015; Shavers et al., 2002; Yancey et al., 2006). Thus, as is the case with ensuring high-quality report back, committing the financial and personnel resources towards these strategies may help

increase the diversity and equity in their studies in a way that authentically benefits the researcher and the participants.

Intentionally Design Report Back to Support Participants' Exposure Reduction

Often the initial impetus for EHS research is a known environmental pollutant and suspected links to human health (Lioy, 2010; Olden & Klein, 1995; Wilson & Schwartz, 2006). EHL is depicted as a framework for reducing exposure to these pollutants and ultimately protecting human health (Finn & O'Fallon, 2017; K. Gray, 2018) and report back materials can be a tool for supporting this (L. Davis et al., 2018; Garzón-Galvis et al., 2019; Lindsey et al., 2022; Madrigal et al., 2016; Perovich et al., 2018; Ramirez-Andreotta et al., 2016a; Sandhaus et al., 2018). In this study, quantitative measures of subjective knowledge and self-efficacy showed that participants felt they were able to identify and utilize information from the personal letters they received from the GenX Study. In open-ended responses, participants reported feeling satisfied that they were able to learn about their own PFAS levels, but, notably, they reported being unsatisfied that there were not clear next steps for them to take to address PFAS at personal or structural community scales. Participants expressed sentiments like, "I don't know what to do now," feeling uncertain about how to use the information they received from the GenX Study. Some participants felt they did not know how to fully interpret the quantitative values in the letter (e.g., "is this number un/safe?"). Others wanted to know how to reduce their PFAS body burden (e.g., "how can I get PFAS out of my body?"). These results indicate that sharing results with participants, while important and appreciated, requires attending to how the report back materials can support participants' decision making and behaviors. For instance, because healthcare providers receive limited training in the connections between environmental exposures and human disease (Gordon et al., 2023; Rha et al., 2024), intentionally designing

report back materials that participants can share with their healthcare teams to provide important context about PFAS may help patients and providers be more proactive with medical monitoring. Given the recent publication by the National Academies of Science, Engineering and Math (NASEM) of the first medical guidance for PFAS, more people will want to engage with their healthcare providers about PFAS exposure and their health, so providing research participants with extra information they can take to appointments may be helpful in these conversations (National Academies of Sciences, 2022). Indeed, some participants in this study reported having taken results to their doctors and their providers being unaware of PFAS or not having enough understanding about PFAS exposure and health effects to provide the participant with any recommendations.

As mentioned, how the public perceives and characterizes an environmental exposure will inform how they behave in response to it. Like lead, PFAS is a widespread contaminant that causes ongoing human exposures that are often at low levels or not readily visible, which can make risk reduction behaviors unclear or difficult (Goebel & Wardropper, 2023). Still, these types of contaminants require individual behaviors to reduce exposure in the short term, and larger structural changes to reduce, remediate, and prevent contamination in the long term (L. F. Davis & Ramírez-Andreotta, 2021; Goebel & Wardropper, 2023). Previous literature has shown that participants in EHS research can use report back materials to inform how people take actions to reduce their exposures and risk. For instance, participants in Arizona used exposure study results about pollutants in their soil to change how their gardening practices and reduce exposure to toxic metals (L. Davis et al., 2018; Ramirez-Andreotta et al., 2016a, 2016b; Sandhaus et al., 2018). Others showed that participants used their personal study results to reduce their household exposure to radon and cigarette smoke (Huntington-Moskos et al., 2021). Similarly, participants

in the Northern California Household Exposure Study used results they received to change their household cleaning and consumer products to reduce exposure to endocrine disruptors (Brody et al., 2009; Brown et al., 2012). Given continued evidence showing factual knowledge as an insufficient predictor of behaviors, researchers can use report back to do more than simply share results in an effort to build conceptual knowledge among participants. EHS investigators who plan to conduct report back can encourage ongoing communication with participants and use messaging that supports participants' decision making for exposure reduction behaviors.

Act as Honest Brokers of Scientific Findings to Support Larger Structural Changes

Importantly, most environmental issues cannot be solved by the private actions of individuals (Ardoin et al., 2023; L. F. Davis & Ramírez-Andreotta, 2021; Gibson et al., 2024; K. Gray, 2018). And while individual private behaviors are necessary for reducing immediate personal exposures (Stern, 2000), individuals' public actions are needed to create the structural changes that ultimately reduce widespread exposure to environmental hazards through mitigation and remediation. Thus, EHS research, namely through the report back process, may begin to consider what structural changes are necessary for preventing exposure to the environmental pollutant that prompted their research in the first place.

In open-ended responses, participants expressed frustration over a lack of large-scale progress to address PFAS contamination in their communities (e.g., "why is it still in the water," "why aren't polluters being held accountable?"). This raises a potential moral quandary about EHS research that relies on the participation of people living with environmental contamination. If researchers assume an exposure may be harmful, prompting them to conduct the research in the first place, then what is the role of the research process in supporting the mitigation and

remediation of that exposure, or to improving the lived condition of their participants? Environmental issues require concerted public behaviors to affect change, and although university scientists cannot be seen as advocating for certain policies or political positions, there is space for researchers to share information in a way that supports public behaviors while maintaining their credibility as scientists. Pielke outlines a typology for characterizing scientists' relationship with the public based on the information they share (Pielke, 2007). As opposed to acting as a "pure scientist" who is only focused on sharing facts and not on the public's decision-making, or an "issue advocate" that argues for a specific policy, the "honest broker" presents factual information *and* the range of policy alternatives needed for informed decision-making (Pielke, 2007). This critical distinction encourages scientists, in the same unbiased ways in which they share their research findings, to share information that addresses participants' concerns about "what to do next."

EHS researchers get publications, research grants, and professional accolades from studying human exposure to pollution. Many of their studies, however, would not be possible without the participation of residents from communities impacted by those pollutants (Creager, 2018; Dunagan et al., 2013; Ladeira & Viegas, 2016; National Resource Council, 2006), and in many ways, residents are dependent upon scientists for information about their exposures (Edelstein, 2018). For these reasons, researchers can work to be honest brokers of science throughout the research and report back process. This may mean openly outlining "possible courses of action" (Pielke, 2007) that might contribute to structurally addressing the contamination. In the case of PFAS, this might include outlining the policy or regulatory processes that relate to PFAS in drinking water, naming the institutions in charge of drinking water regulations, or reviewing existing strategies for PFAS remediation. Importantly, this does

not suggest that researchers be political or advocate for certain policies or entities, but rather to more comprehensively share information that supports participants' short and long-term exposure reduction. This strategy demonstrates greater respect for participants' situation and acknowledges that individual exposure measurements alone will not solve a community's environmental contamination.

Limitations and Future Research

This study was designed to investigate how participants in a PFAS health study understand and behave in response to PFAS exposure through the lens of EHL. The intent was to generate data and conclusions that have specific implications for the GenX Study's ongoing engagement with its participants, and to contribute to a larger conversation about EHL in the context of report back. This work had inherent limitations largely due to methodological constraints. First, the GenX Study was a convenience sample of volunteer participants, and among them a self-selecting group completed the questionnaire to participate in this study. Thus, neither study has participants that demographically represent all communities along the Cape Fear River (See Table 1). The NC State IRB and GenX Study research team only allowed access to participant mailing addresses, and this study did not have access to contact information for each individual participant. This limitation, in addition to resource constraints, drove the decision to use each household with one adult currently enrolled in the GenX Study as the sampling frame (n=643). Using random selection of all adult GenX Study participants to generate a list of participants to receive questionnaires may have increased the representativeness of the sample. Still, this study did not set out to make generalizations about all report back or all PFAS impacted communities, but to explore in more depth the relationship between report back and EHL among one study's participants.

The questionnaire used in this study was originally designed to provide general feedback to the GenX Study investigators and was not designed to measure EHL or predict behavior from the outset. As such, the operationalization of some constructs was less precise than if it the survey had been initially designed from an EHL framework. For instance, questions from the GenX Study team intended to understand the clarity of their report back materials (e.g., Q1, 2, 3A-E) became proxies for self-efficacy and subjective knowledge in this study. Additionally, the GenX Study's report back materials were not initially designed from an EHL framework, and were not intending to "build" knowledge, capacity, or behaviors. Moreover, this study's questionnaire was administered after all participants had already received at least one round of report back. A pre/post design would have allowed more conclusive claims about the relationship between report back and variables related to EHL, attitudes, and beliefs. As some studies assert that report back "builds" EHL, this study cannot make causative claims.

Moving forward, data from this study can be used to compare participants' responses to closed and open-ended questions to see if there are patterns between concepts like factual knowledge, self-efficacy, risk perception, or reported behaviors, and open-ended responses about motivations, satisfaction, and dissatisfaction. Similarly, the use of structural equation modeling may help determine which factors are related to each other, such as knowledge measures potentially predicting risk perception per the Health Belief Model (Rosenstock, 1966; Rosenstock et al., 1988). Still, this study reduced EHL to a finite set of constructs when there are many more facets of living with PFAS exposure that may be relevant. Future research might use qualitative methods to understand the broader experience of PFAS contamination in the Cape Fear River basin. The impacted "community" is geographically large, demographically diverse, and faces widespread PFAS exposure from a variety of sources (Cahoon, 2019, 2020; Ehsan et

al., 2023; Kotlarz et al., 2020; McCord & Strynar, 2019; Sun et al., 2016; Vandermeyden & Hagerty, 2020; Weed et al., 2023). Findings from this study imply that people felt value in participating in the GenX Study, but they remain unsatisfied with the unresolved PFAS exposure and contamination in their communities. This study contributes to what is hopefully an ongoing conversation about demonstrating reciprocity to EHS research participants, who are invaluable to the data collection process, but who live with the environmental contamination long after data collection is over.

Conclusion

EHL literature and established behavior theories establish that knowledge is necessary but insufficient on its own for predicting behavior. Indeed, psychosocial variables (e.g., attitudes) and structural and contextual factors (e.g., income) are often larger drivers of behavior. While this study still relied on predominantly quantitative measures, it intentionally incorporated additional constructs with the conceptual knowledge and efficacy measures of EHL to more comprehensively understand their relationship to receiving individual PFAS results and exposure reduction behaviors. This study makes an argument for using a broader scope of EHL as a lens for understanding how people make sense of and respond to PFAS exposure.

Past behavioral research as well as results from this study highlight that measuring knowledge is not enough to explain changes in the behaviors needed to privately or publicly reduce environmental exposures. Relying on a narrow definition of EHL that only uses factual knowledge and efficacy as behavioral antecedents did not produce a useful model for predicting behavior. Instead, a broader conceptualization that includes risk perception, subjective knowledge, and other affective measures accounts for what participants find salient, and may help create a more comprehensive framework for understanding and responding to

environmental exposures. Moreover, if community change and improved health is the goal of EHL, then the knowledge, efficacy and other affective attributes of EHL should directly relate to the range of private and public behaviors needed to create that change. This study reiterated participants' desire to receive their data and the value of report back efforts. An early, intentional commitment by researchers to doing effective report back can be advertised as a way of encouraging research participation and retention. The lack of diversity in this study and the larger GenX Study, coupled with the inverse relationship between Whiteness and willingness to participate in future research, highlights the importance of community engagement in communities of color. Not only does this help ensure more robust, representative data in EHS research, but—more importantly—it helps build equity in access to data and resources that build self-efficacy and inform decision making for exposure reduction. Finally, this study contributes to a larger question about the role of EHS in responding to contaminated communities. It is good to see participants expressing their satisfaction in having access to individual measurements and data, and it supports the ongoing paradigm shift of report back becoming the norm in EHS research (Brody et al., 2014a; Dunagan et al., 2013; Korfmacher & Brody, 2023; Lebow-Skelley et al., 2020). However, the overarching "what do I do now" sentiment from participants in this study highlights that report back alone is not sufficient in making participants better off than before the research. The ways in which those results contribute to behaviors that ultimately reduce private and public exposures determines if participants tangibly benefit from the research process. This study builds on a growing body of literature exploring the relationship between EHL, report back, and structural improvements in environmental health.

CHAPTER 3:

AN EXPLORATORY STUDY OF THE PFAS EXPOSURE EXPERIENCE: HOW COMMUNITIES UNDERSTAND AND ADDRESS PFAS CONTAMINATION

Abstract

Environmental health science (EHS) research studies the ways in which these environmental exposures impact human health from the molecular level to the scale of the human population. Environmental health literacy (EHL) was created as a multidimensional framework for the knowledge, skills, and actions needed to address environmental contamination. This conceptualization of EHL, along with the quantitative measures that EHS researchers use to characterize environmental contamination and its impacts, may not fully capture the lived reality of people in communities with chronic contamination. This study used an exposure experience framework to understand how residents of North Carolina's Cape Fear River basin Carolina characterize their exposure to per- and polyfluoroalkyl substances (PFAS). Interviews were conducted with 33 people who live in the river basin and are current participants in an ongoing PFAS health study. Results describe participants' lived experiences with PFAS, including their involvement in EHS research, and the knowledge, skills, and actions they identify as relevant for addressing PFAS contamination. This study showed the contextual nature of environmental contamination, the burdens placed on impacted residents, opportunities for structural and institutional changes in policy, and the potential for EHS research to support contaminated communities. This study has implications for how EHS researchers, decision makers, and institutions engage with residents impacted by PFAS contamination, providing a more nuanced understanding of what information, resources, and actions they need to address their exposure to PFAS.

Introduction

Environmental Health Science and Literacy

Environmental health literacy (EHL) was proposed as a framework for how findings from environmental health science (EHS) researcher are used to build the knowledge and capacity needed to reduce exposure to environmental hazards and ultimately improve human health (Finn & O'Fallon, 2017). Initially, EHL was modeled after Bloom's Taxonomy of learning (Bloom & Krathwohl, 1956), a series of learning benchmarks that vary for different EHS issues. Then, Gray (2018) depicted EHL, seen in Figure 3.1, as three overarching dimensions of knowledge, skills, and behaviors people need to understand an environmental exposure and take actions that reduce individual and collective exposure (K. Gray, 2018; Hoover, 2019).

Figure 3.1. *Conceptual Model of EHL*

Note. Gray (2018).

Sharing data from EHS studies is thought to be a means of cultivating EHL (Brody et al., 2014a, 2018, 2021; L. Davis et al., 2018; Garzón-Galvis et al., 2019; Lindsey et al., 2022; Perovich et al., 2018; Ramírez et al., 2019; Ramirez-Andreotta et al., 2016a; Sandhaus et al., 2018) and today, the public has more access than ever to data from EHS studies (Altman et al., 2008; Brody et al., 2007). These data, through quantitative measurements and reference levels,

contribute to traditional, positivist ways of scientific knowing (Adams et al., 2011; Altman et al., 2008) and are purported to be key contributors to EHL by supporting informed decision making and the likelihood of taking exposure reduction behaviors (Lindsey et al., 2022; Samon et al., 2023; Tomsho et al., 2022). Previous studies that have investigated the impact of sharing results with participants have shown increases in scientific knowledge, self-efficacy related to certain exposure reduction behaviors, and self-reported risk reduction behaviors (Lebow-Skelley et al., 2020; Oksas et al., 2022; Ramirez-Andreotta et al., 2016b; Tomsho et al., 2019). However, many EHS researchers and practitioners who apply EHL in their work acknowledge that the type and experience of environmental exposures can vary from community to community (Hoover, 2019; Lebow-Skelley et al., 2022; Ramirez-Andreotta et al., 2016a). People who face acute and chronic exposure to environmental hazards have a lived reality that inherently cannot be fully captured by data from EHS studies alone (Edelstein, 2018; Vyner, 1988). It is quite possible that biomonitoring data and our current conception of EHL do not fully account for how contaminated communities would define their environmental exposure or how they would characterize the knowledge, skills, or actions needed to address it.

The Environmental Exposure Experience

The idea that this experience—the "exposure experience"—is nuanced and complex originated from the field of medical sociology and emphasizes the social construction of knowledge and the differences between academic and laypeople's ways of defining environmental exposures and health effects (Bird et al., 2010; Brown, 1992; Lawton, 2003; Rier, 2010). It acknowledges the embodied experience of exposure and the potential contradictions between how scientists and residents define and characterize exposure. For example, the nature of research studies—with their bounded research questions, finite resources, and reliance on

statistical significance—may fail to capture the ways in which residents physically and emotionally experience o r make sense of environmental contamination (Barker, 2010; Brown, 1995a). Moreover, scientific uncertainty, lack of medical diagnoses, or the slow pace of regulatory policy may feel in opposition to the severity or certainty with which residents experience their exposure (Adams et al., 2011; Barker, 2010; Brown, 1995a). Ultimately, using the idea of the exposure experience helps to broaden how EHS researchers think about describing exposure to environmental hazards, beyond what may be characterized by laboratory or biomonitoring data.

Over the last ten years, there has been an increase in social science research investigating aspects of the exposure experience in relation to EHS and environmental exposures. To date, much of the literature on exposure experience focuses discretely on the experience of participating in EHS research studies, rather than the broader experience of chronic contamination (Ramirez-Andreotta et al., 2016a, 2016b). In 2008, Altman and colleagues (2008) first used it to frame how they interviewed 25 women participating in a larger biomonitoring study, comparing the quantitative biomonitoring measurements of exposure to the personal and emotional experience of learning about the exposure. The study highlighted participants' pragmatic relationship with uncertainty and the desire for definitive health data (Altman et al., 2008). Adams (2011) documented how the experience of being in a biomonitoring study generated a shared sense of collective harm among individual, unrelated participants. Judge interviewed 16 participants as part of a larger study on the ethics of reporting back research results (Judge et al., 2016), using exposure experience to understand how people made sense of receiving personal biomonitoring results, revealing the importance of participants' social, economic, and historical contexts as mediators of their experience with environmental hazards.

Another study interviewed nine community leaders and public health officials from across the country about exposure to PFAS, uncovering the role that institutional mistrust and financial hardship plays in shaping people's exposure experience (Calloway et al., 2020). In many cases, EHS research studies originate from the need to understand the impacts of environmental hazards to which people already have known or suspected exposures, so while understanding the experience of research participation and receiving results is a critical piece, an exposure experience lens helps to look more broadly at the daily lived reality of exposure.

PFAS Exposure Experience

Given the relatively small literature base on exposure experience—particularly as it relates to specific types of contamination or specific communities—there is a unique opportunity to explore the experience of chronic exposure to an understudied, under-regulated class of contaminants known as per- and polyfluoroalkyl substances (PFAS). PFAS are a class of over 14,0000 synthetic chemicals designed to resist water, stains, grease, and fire (Agency for Toxic Substances and Disease Registry, 2023; Fenton et al., 2021; Obeng-Gyasi, 2022; Richter et al., 2018). Although PFAS have been in production since the 1930's (Sunderland et al., 2019), the United States only started regulating six PFAS in drinking water in 2024, and existing toxicity and human health data are very sparse relative to the thousands of PFAS in use (Cadore et al., 2009; Rosen et al., 2022; Wallis et al., 2023). Thus, while the pace of EHS research documenting PFAS exposure is increasing, the limited human health data and regulatory guidance can make it difficult to contextualize quantitative PFAS measurements (Ohayon et al., 2017), and may feel invalidating and unsupportive to those experiencing the chronic, daily PFAS exposure. Indeed, many residents of communities impacted by PFAS have shared stories of their exposure experience and the ways in which what they see and feel is contested by academic experts or

institutional policies (McLaughlin, 2023; Perkins, 2022; Severance & McLaughlin, 2023). There is a contradiction between their daily hardships, the symptoms, illnesses, and deaths seen in their communities, and the lack of data, medical diagnoses, or regulatory actions needed to formally prove or validate their experiences (McLaughlin, 2023; Perkins, 2022; Severance & McLaughlin, 2023), which created an important opportunity to use exposure experience as a tool for exploring individuals' and communities' responses to PFAS (Banwell et al., 2021; Calloway et al., 2020; Judge et al., 2016; Menegatto et al., 2022).

Many EHS studies have reported quantitative measures of PFAS in communities' air, water, and soil (Sun et al., 2016), and biomonitoring studies have shown levels of PFAS present in residents' blood (Hall et al., 2023; Kotlarz et al., 2020; Wallis et al., 2023). But people experience PFAS exposure in ways that extend beyond these quantitative measurements or current policies and regulations. This presents a unique context in which to explore EHL and exposure experience. Describing the embodied experience of long-term exposure to these understudied and under-regulated chemicals gives voice to how individuals impacted by PFAS understand, define, and respond to their exposure in a way that biomonitoring studies alone cannot capture.

Theoretical Framework

This study used EHL as an overarching theoretical framework to guide the research, complemented by exposure experience and toxicity continuum. As seen in Figure 3.1, EHL outlines a concentric process for understanding and addressing an environmental hazard and improving one's health (Finn & O'Fallon, 2017; K. Gray, 2018). As biomonitoring studies increase in number and scope, most data are shared with participants and in public repositories, giving the public more access than ever to EHS data, and theoretically EHS knowledge (Altman

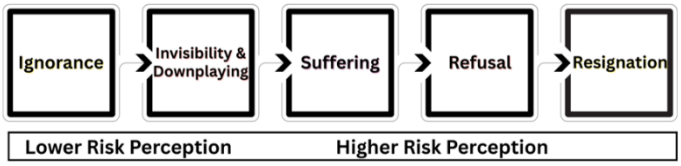
et al., 2008). At its core, EHL is conceptualized as more than just knowledge, with an emphasis on action—the culmination of knowledge, skills, and behaviors that reduce exposure to ultimately protect health (Finn & O'Fallon, 2017, 2018; K. Gray, 2018; Hoover, 2019; Valdez et al., 2014). Reducing exposures occurs at individual and collective scales—actions that directly reduce personal exposure, such as installing a water filter, and actions that create structural changes that reduce collective exposures, such as voting, advocacy, legal action (L. F. Davis & Ramírez-Andreotta, 2021). These structural changes may come from a range of local "small p" policies to larger, national-level statutes and regulations, all of which have the potential to materially impact people's exposure to environmental hazards (L. F. Davis & Ramírez-Andreotta, 2021).

Environmental exposures are inherently context specific. For instance, PFAS exposure and the means to reduce exposure will vary greatly depending on geographic location, source of drinking water, filtration options, and types of PFAS present (Kotlarz et al., 2020; Wallis et al., 2023). Additionally, the way people experience, understand, and make meaning of environmental exposures—what ultimately constitutes their EHL—can vary by individual and community (Clapp et al., 2016). Moreover, many communities currently face a "mitigatory gap" where contamination has been documented but remediation has not taken place, creating a myriad emotions, judgments, and subsequent behaviors among residents (Renfrew & Pearson, 2021).

The environmental exposure experience framework, with its roots in medical sociology, and tenets of social constructivism acknowledges that the embodied experience of living with environmental contamination varies among individuals and communities, and that there may be inherent differences between how academics and residents define exposure (Brown, 1992,

1995b), impacts to health and wellbeing, and what is necessary for exposure reduction (Clapp et al., 2016). In the case of EHS research, residents may see their biological or environmental measurements in direct support or contradiction of their exposure experience. One piece of this exposure experience is how residents perceive and feel about the exposure. Renfrew and Pearson (Renfrew & Pearson, 2021) used the "toxicity continuum" to describe the range of emotions and beliefs people embody in the face of environmental contamination (See Figure 3.2). These include knowing nothing very little about the issue (ignorance) or ignoring it (invisibility), extreme stress and worry (suffering), collective action (refusal), or emotional exhaustion (resignation). This continuum is useful for framing the many ways in which individuals may emotionally approach PFAS contamination, and people may remain static or move dynamically along the continuum throughout their experience with exposure.

Figure 3.2. *Toxicity Continuum*

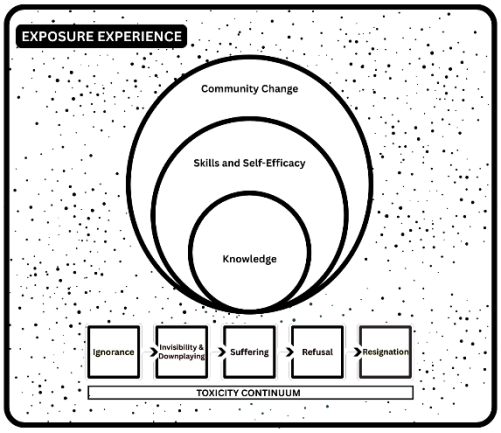


Note. Adapted from Renfrew and Pearson (2021).

EHL has three overarching constructs for how individuals and communities make sense of environmental health science information and respond to environmental contamination. These constructs—knowledge, skills, and actions—may not fully capture the contextual and emotional nature of living with chronic environmental contamination. For this study, EHL was conceptualized as existing within a broader exposure experience, a part of which is the toxicity continuum. Adding the emotions and risk perception of the toxicity continuum to the multiple ways of knowing from the exposure experience created a more complete framework for describing residents' exposure to PFAS (See Figure 3.3). Biomonitoring studies provide

information on types and levels of exposure, EHL outlines constructs that may relate to reducing that exposure, and the exposure experience and toxicity continuum complement EHL by providing a broader context in which to characterize the impact of environmental exposures on human health and wellbeing (Adams et al., 2011; Altman et al., 2008). It is through this theoretical framing that this study intended to more holistically understand what it means to be exposed to PFAS.

Figure 3.3. *More Complete Conceptual Framework for Exposure Experience*



Research Questions

Advances in biomonitoring studies have outpaced complementary social science studies that investigate the experience of living with the environmental hazards that biomonitoring studies measure (Altman et al., 2008; Renfrew & Pearson, 2021). Additionally, as many EHS biomonitoring studies now report data back to participants (Brody et al., 2007, 2014a; Ohayon et al., 2017), there is a need to understand the role that receiving those measurements plays in their development of EHL, their overall exposure experience (Adams et al., 2011; Altman et al., 2008), and what it means for ongoing engagement with research participants. To date, there is a small but growing body of research looking at the exposure experience of PFAS

contamination (Adams et al., 2011; Calloway et al., 2020; Judge et al., 2016). These studies have made important contributions in understanding the lived experience of environmental contamination, receiving one's biomonitoring results, learning about chemicals—including PFAS—found in household products (Adams et al., 2011), the experience of serving in government or leading environmental advocacy groups (Calloway et al., 2020), the experiences of people employed by PFAS manufacturers (Judge et al., 2016), embodied PFAS exposure in Australia (Banwell et al., 2021) and in Italy (Menegatto et al., 2022), and how the exposure experience varies temporally (Judge et al., 2016), and the role of collective action (Oksas et al., 2022). Additionally, previous studies have used a range of methods and sampling frames from which to draw participants. For example, Giannini (2018) used mail surveys to quantitatively measure report back comprehension; Ohayon et al. (2025) conducted interviews across five years with highly engaged PFAS activists from 14 communities across the country; Judge et al. (2016) conducted interviews in the Ohio River Valley with a range of researchers, IRB members, and participants from two EHS studies ten years earlier; Oksas et al. (2022) used online focus groups to inform the development of report back related to PFAS and other chemicals; Perovich et al. (2018) used observations of community meetings and interviews with research participants to evaluate report back related to non-PFAS chemicals.

As such, to add to this literature, this study uniquely focused on a discrete geographic region of the United States, and used in-depth interviews to collect data from adult participants currently enrolled in an ongoing PFAS biomonitoring study. It aimed to contribute to the literature by answering the overarching research questions:

1. How do people in North Carolina's Cape Fear River Basin experience living with PFAS contamination?

2. How does environmental health literacy manifest in those experiencing PFAS contamination?

3. What do residents of North Carolina's Cape Fear River Basin perceive as necessary to address their individual exposure and their community's exposure?

This work has practical implications for how biomonitoring researchers communicate results with their participants—including those currently studying PFAS exposure in North Carolina (NC)—and opportunities for broader outreach and education related to PFAS exposure. More broadly, this study generated data with theoretical implications for how the field of EHS understands chronic exposure to emerging environmental contaminants, and how EHS research may support residents' efforts to address contamination.

Methods

Research Design

This was a basic exploratory qualitative study that used in-depth interviews and collected qualitative data about individuals' PFAS exposure experiences (Ardoin et al., 2022; Merriam & Tisdell E J, 2015). While this was not a case study design as outlined by Creswell (J. Creswell, 2013), it followed Merriam and Tisdell's (2015) "analysis of a bounded system" definition of case study to frame participant selection. As such, with GenX study participants as the system, each community served as a case in which to investigate the experience of PFAS exposure (Merriam & Tisdell E J, 2015). Each community has distinct exposure profiles and community demographics that made for important variation among the cases shown in Table 19 (Merriam & Tisdell E J, 2015; Miles, Huberman, & Saldan, 2014) and better captured both the complexity and shared experience of living in a PFAS contaminated community (J. W. Creswell & Creswell,

2007). This allowed for comparisons within and among the three communities and within the GenX Study participants more broadly (Merriam & Tisdell E J, 2015). The qualitative research generated by this study complements the quantitative environmental and biological measurements from residents of these communities, by documenting people's experience living with ongoing PFAS contamination, and how they have constructed, defined, and responded to these exposures (Merriam & Tisdell E J, 2015). This study was not intended to predict behavior or make generalizable statements about PFAS exposure, but rather, as is common in education-centered research, to conduct an in-depth, inductive exploration of this topic among a small group of participants with elements of a shared exposure profile (J. Creswell, 2013; Merriam & Tisdell E J, 2015).

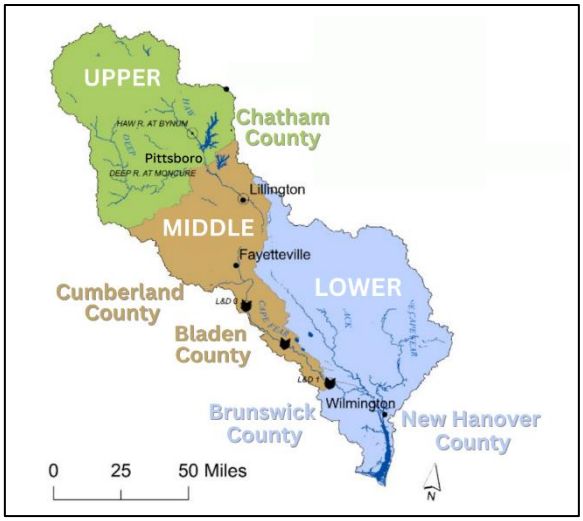
Research Context

This study explored the PFAS contamination experience of people living in North Carolina's (NC) Cape Fear River basin. Widespread PFAS contamination has been documented throughout the river basin since 2016 residents face elevated exposure to PFAS through their drinking water sources (Sun et al., 2016). In 2017, the GenX Exposure Study (GenX Study) began. It is an ongoing prospective cohort study that uses biomonitoring data to understand long-term health effects of exposure to a suite of legacy and understudied PFAS (Hoppin, 2023). To date, there are 1,019 participants in the GenX Study, and 994 aged six or older who have provided blood, urine, and questionnaire data. Each participant has received at least one report to date with their individual PFAS measurements, and some have received multiple letters depending on how long they have been enrolled (Hoppin, 2023).

GenX Study participants were recruited from three areas (henceforth communities) along the upper, middle, and lower parts of the basin, as seen in Figure 3.4, using the following sampling frame:

- **Upper:** residents of the town of Pittsboro served by two municipal drinking water facilities who volunteered for the GenX Study;
- **Middle:** residents of Bladen and Cumberland County who have private wells that were previously tested by the North Carolina Department of Environmental Quality for PFAS and specifically were invited by the GenX Study team; and
- **Lower:** residents in Brunswick or New Hanover Counties served by two municipal drinking water facilities who volunteered for the GenX Study.

Figure 3.4. *Map of Cape Fear River Basin and Counties*



Note. Adapted from DeMeester et al. (2019)

Despite the ubiquity of PFAS in today's society (Kwiatkowski et al., 2020; Sunderland et al., 2019), the communities along the Cape Fear face uniquely elevated exposure to PFAS through contaminated air, water, and soil from historical and ongoing PFAS manufacturing, textile manufacturing, and agricultural processes (Hall et al., 2023; Kotlarz et al., 2020). For

instance, there is a PFAS manufacturer currently operating in Bladen County, near Fayetteville, NC (Sun et al., 2016); there are some PFAS that are uniquely produced only by this company and have only been measured in drinking water and human serum samples collected *downstream* from the company (Kotlarz et al., 2020). Yet upstream from the manufacturer, elevated levels of other types of PFAS are measured in the environment and humans, indicating multiple sources of PFAS contamination throughout the river basin (Cahoon, 2019). Additionally, sources of drinking water vary throughout the basin; some residents get drinking water from their local municipality, which is surface (river) water treated by a municipal drinking water system, some of which have been updated since 2017 to remove some PFAS (Kotlarz et al., 2020; Sun et al., 2016). Other residents rely on private wells for drinking water, which draw from groundwater, are not subject to testing or treatment by any municipality, and rely on personal testing and maintenance to identify and remove potential contaminants (North Carolina Department of Health and Human Services, 2021).

Although the three communities broadly share a common geography and environmental exposure, Table 19 shows the variation in specific PFAS exposure profiles. The widespread presence of PFAS in our environment, coupled with the severity of exposure for communities like those in the Cape Fear has warranted ongoing attention and notable policy developments. As such, there is a unique opportunity in which to explore the PFAS exposure experience, using GenX Study participants as a bounded system with each community serving as a unique case of PFAS exposure.

Table 19. *Drinking Water Characteristics and Sources of PFAS in Study Participants' Three Communities Along the Cape Fear River Basin*

Upper: Pittsboro	Middle: Bladen and Cumberland Counties	Lower: New Hanover and Brunswick Counties
Drinking water source? Type of water and party responsible for treating and testing drinking water.		
Surface (river) water treated by municipality: Town of Pittsboro; Aqua, North Carolina	Ground water sourced from private wells: Individually owned and monitored by residents	Surface (river) water treated by Municipality: Cape Fear Public Utility Authority; Northwest Brunswick County Treatment Plant
Legacy PFAS present? PFAS are no longer in production or use and have more toxicity data available.		
Yes	Yes	Yes
New PFAS present? PFAS are currently in production and commercial use and have less toxicity data available		
No	Yes	Yes
Known sources of PFAS? Direct discharges to the environment or leaching and runoff from other sources.		
Indirect Sources: Historical manufacturing processes, and current agricultural application of biosolids containing PFAS impacts surface and groundwater	Direct Source: Historical and current discharges from PFAS manufacturer impacts air, surface, and groundwater Indirect Sources: Runoff from upstream discharges	Direct Source: Historical and current discharges from PFAS manufacturer impact surface water Indirect Sources: Runoff from upstream discharges

Participants and Recruitment

Similar to the methodology of Ramirez-Andreotta et al. (2016), all participants for this study were selected from the existing cohort of adult GenX Study participants (N = 994), who live in one of the three communities described above. Because GenX Study participants are from a self-selecting convenience sample (Vaske, 2019), and participants from this study were drawn using purposeful, random, and convenience sampling, this study's participants are inherently not a representative sample of all Cape Fear River basin residents (Merriam & Tisdell E J, 2015).

In general, GenX Study participants skew older and whiter than the average resident of the three GenX Study communities (See Figure 3.2). By using the higher end of the ranges across the three locations for each demographic group, this study was designed to recruit participants to more closely match the demographics of Pittsboro and Chatham County (upper), Fayetteville and Bladen and Cumberland Counties (middle), and Wilmington and New Hanover and Brunswick Counties (lower). From the pool of GenX Study participants, this study prioritized recruiting a group of racially and ethnically diverse participants, followed by diversity among the three geographic locations, and finally diversity in age. To ensure a variety of viewpoints and saturation of ideas, this study was intended to have 30 participants and recruited the following participants (see Table 20).

Figure 3.5. *Recruitment and Sampling Protocol*

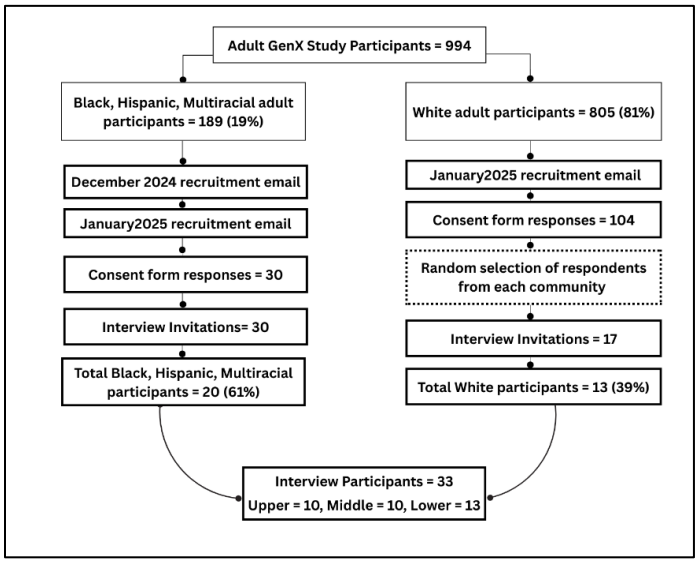


Table 20. *Target Recruitment Demographics for this Study Compared to Actual Demographics of the Relevant County or Counties*

	Target Demographics for this Study	Actual Participant Demographics		
	N = 30	Upper: Chatham County	Middle: Bladen, Cumberland Counties	Lower: Brunswick, New Hanover Counties
Black	40% (12)	12%	33-40%	9-13%
Hispanic	13% (4)	12%	9-13%	5-6%
White	40% (12)	72%	40-55%	77-83%
Median Age	44y	48y	31-45y	40-56y

Note. A range is shown for the middle and lower parts of the river basin because participants live in multiple counties, as opposed to the upper basin where participants are only from Pittsboro.

In compliance with NC State's Institutional Review Board (IRB) and the GenX Study principal investigator, recruitment materials were sent by the GenX Study to its participants via email so as not to share any personally identifying information about people who did not wish to participate in this study. Participants received a short note about this study, describing it as standalone research separate from the GenX Study (See Appendix F), with a link to the online consent form, which collected participants' names, demographic, and contact information (See Appendix G). Only individuals who completed the online consent form were contacted via phone or email to schedule a time for the online interview. Participants received an email and calendar invitation with their secure Zoom link to participate.

Because the demographics of GenX Study participants do not match local demographics, a blanket recruitment strategy to all GenX Study participants may have resulted in an overrepresentation of White or older participants. As such, recruitment emails were sent in two waves. In December 2024 and again in January 2025, an email invitation was sent to all adult GenX Study participants who identified themselves as Black, Hispanic, or "more than one race"

(*n* = 189). At the end of January 2025, the same email invitation and consent information was sent to all GenX Study participants who identified themselves as White (*n* = 805) so that by the end of recruitment, all adult GenX Study participants had been invited to participate. All 30 consented individuals from the first wave of recruitment were invited to participate, and 21 (70%) followed up and participated in interviews. During the second wave of recruitment, which focused on White GenX Study participants (*n* = 805), significantly more people consented (*n* = 104) than were able to be selected for participation. The list of consented individuals was split up based on their location, and a random sample of participants from each of the three communities was selected, ensuring that each community had at least 10 participants. This generated 17 names, and 12 of them (70.1%) followed up and participated in interviews. The final participant demographics can be seen in Table 21. Some demographic categories are combined so that no characteristics that belonged to two or fewer participants were reported.

Table 21. *Study Participant Demographic Characteristics*

	Study participants *N* = 33	Upper *n* = 10	Middle *n* = 10	Lower *n* = 13
Black	8			5
Hispanic	9	5*	3*	5
More than one race	3			3*
White	13	5	7	
Median Age	61	46	62	63
Men	14	5	4	5
Women	19	5	6	8

Note. No characteristics were reported that belonged to two or fewer individuals. *Denotes demographic categories that are presented in aggregate to protect participant anonymity.

Data Collection

At the beginning of each interview, participants were reminded of the informed consent information, including the voluntary nature of participation and this study's defined separation from the GenX Study. Interviews followed a semi-structured protocol based on this study's theoretical framework, where all participants were asked about similar thematic areas related to their community (e.g., "Tell me about your community and how long you've lived there."), their knowledge, feelings, and beliefs about PFAS (e.g., "Tell me about how you first learned about PFAS contamination;" "How would you describe the risk that PFAS poses to you and your family?"), their participation in research (e.g., "How has your participation in the GenX Study impacted how you think about PFAS?"), and their vision for addressing their community's contamination (e.g., "What do you see as most important for broadly reducing PFAS exposure and protecting the health of your community?"). All interviews allowed for natural follow-up questions or discussion of related topics (Meriam & Tisdell, 2015). All interviews were conducted remotely by the same researcher, and were audio recorded using NC State's institutional Zoom license. Interviews ranged in length from 17 to 77 minutes ($\bar{x}$ = 37 minutes). See Appendix I for full interview protocol.

Data Analysis

Each audio recording was automatically transcribed by Zoom and manually edited for accuracy and consistent formatting. Conversations were transcribed verbatim within 24 hours of each interview, with a memo and observational notes created for each participant (Braun & Clarke, 2006; Meriam & Tisdell, 2015). Recordings were deleted after transcription. Transcripts ranged in length from 4.5 to 13 pages ($\bar{x}$ = 7.9 pages). Each transcript was uploaded into ATLAS.ti for thematic analysis. The data analysis was an iterative, ongoing process that began

during data collection, where each transcript was read multiple times before formal coding began (Merriam & Tisdell E J, 2015). Analysis followed a basic, comparative and inductive approach, allowing codes and patterns to emerge were developed from the data (Braun & Clarke, 2006; Merriam & Tisdell E J, 2015). Using three transcripts from each of the three communities, the researcher created an initial codebook from this first-cycle coding; simultaneous coding allowed some segments of data to belong to multiple codes (Miles, Huberman, & Saldana, 2014). Memos were used to document the process of refining and prioritizing codes, and created an audit trail of decisions as the codebook was finalized with the remaining transcripts (Guba, 1981; Meriam & Tisdell, 2015). Then, the full codebook was applied to each transcript following a more deductive approach (Meriam & Tisdell, 2015). Because participants were from three distinct communities, codes and themes represented both recurring patterns and similarities as well as notable differences among the three cases. At the end of this coding process, there were 2,363 units of coded text across the 33 transcripts ($\bar{x}$ = 72 segments per transcript).

Interrater reliability was used to triangulate among multiple coders and establish face validity of the codebook and the systematic nature in which it was applied (Denzin & Yvonna, 2011). Four colleagues were each given 64-66 segments of coded data, totaling 261 (15% of all coded data) segments (O'Connor & Joffe, 2020). Each person was given the codebook and a spreadsheet with a unique selection of the data, representing each type of code and multiple examples of each overarching theme. Percent agreement was calculated by dividing the number of agreeing units of text by the total number of coded units (Huberman & Saldana, 2014b). Percent agreement ranged from 80%-86% ($\bar{x}$=84%); literature suggests a minimum of 65% for establishing validity, with upwards of 80% a ideal (Cheung & Tai, 2023; Huberman & Saldana, 2014b; Shenton, 2004).

To support the study's credibility and demonstrate participant reciprocity, each participant was sent an individual email with a link to a secure, view-only Google document that included a summary of the study's results with quotes intended for publication and the opportunity to provide any feedback (Birt et al., 2016; J. A. Carlson, 2010; J. Creswell & Miller, 2000; Meriam & Tisdell, 2015). Six participants (18%), collectively from three communities, ultimately responded and provided feedback. All four expressed gratitude at receiving the summary and one asked to read the final research paper. As will be discussed more below, three of the respondents had specific comments related to surprise, resignation, and the need for more outreach with PFAS information. None of the respondents expressed disagreement or contradictions with study findings and themes as they were presented.

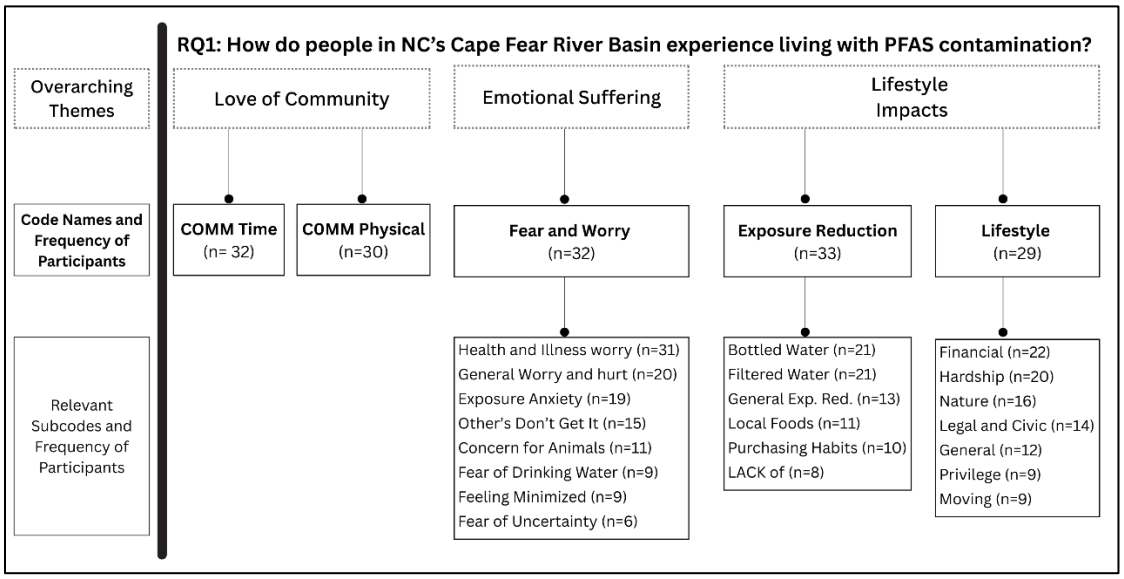
Results

This study conducted in-depth interviews with 33 residents of NC's Cape Fear River basin who are impacted by PFAS contamination and are participants in an ongoing PFAS health study. Participants' responses were coded thematically, and Figure 3.6–3.8 present overarching themes, codes and subcodes in response to each research question. Appendix K shows the full codebook with themes, individual codes, subcodes, and exemplary quotes that emerged from the data. Below, detailed descriptions of these codes and themes are presented using cross-case synthesis and comparison to highlight nuance and agreement among the three communities (Creswell & Creswell, 2007).

RQ1: How do people in North Carolina's Cape Fear River Basin experience living with PFAS contamination?

In response to the first research question, codes that related to the emotional and physical aspects of participants' exposure to PFAS were synthesized to create a description of their overall lived experience. In general, participants talked about three main ideas: an underlying love for their community, the ways PFAS has caused them emotional distress, and the ways they have had to adapt their lives in response.

Figure 3.6. *Conceptual Map of Codes Related to Research Question 1*



Love of community. Across the three communities, participants ranged from more recent transplants who had arrived within the last ten years, to people whose family had lived in the area—sometimes even on the same land—for generations. In general, participants in the middle and lower Cape Fear regions had lived in the area for much longer on average than participants from Pittsboro. For instance, four of the ten participants from Fayetteville have lived there their entire lives, and the remaining six participants have lived there for the last 7–39 years ($\bar{x}$ = 22 years). Of the 13 participants from the lower Cape Fear, five were born there and the

other eight have lived there between 8 and 35 years ($\bar{x}$ = 27 years). In contrast, none of the 10 participants from Pittsboro are originally from there, one has lived there for 36 years, and the rest have moved there within the last 15 years ($\bar{x}$ = 13 years). Regardless of how long they had been there, almost all participants (n = 30) all described a range of characteristics of their communities that attracted them to move there or compelled them to remain. People from all three communities talked about the location, access to the outdoors, and people in their neighborhoods make their home special; they described loving and building a life in a place that PFAS has since contaminated.

In Pittsboro, participants described a quaint, friendly, "suburban family community." Participants talked about it in contrast to the "hustle and bustle" of larger cities they had previously lived in, describing its "small town feel" and mentioning their appreciation of safe, nicely kept neighborhoods, being able to walk to stores and restaurants, while still being close to the nearby rivers, lakes, and walking trails. There was a distinct sense of community and connection shared among Pittsboro residents, in which "everybody knows each other here, our kids play together, they're over at each other's houses, they're riding bikes outside." Participants used words like "warm," "accepting," "awesome," and "tight knit" to describe the people in their town. One person said, "some people have likened it a little bit to Mayberry." Across the interviews, there was a consistent description of a community with walkable neighborhoods, friendly people, and proximity to central North Carolina's larger cities, businesses, and universities. And while descriptions may sound idealistic, participants conveyed an authentic sense of appreciation for their town and the people who live in it.

People in the lower Cape Fear talked about the friendliness of people in their communities and an ongoing trend of increased development. One participant quipped,

“Wilmington is a beautiful place, though the secret is kind of out on that, because it's a kind of ballooning population.” Most participants’ stories, however, were about a connection to the river and nearby beaches, such as “what people love about Wilmington is the water.” Participants fondly recalled memories of catching and eating fish with family members, noting that “a lot of our culture has a lot to do with the water.” People talked about how they “couldn’t think of anything better to put in [their] life” than the “beauty” of the beach, the ability to go surfing and swimming, or being able to walk and sit along the river. The aesthetic appeal of a “beautiful and ecologically fragile” community by the water, the area’s “unique coastal ecosystem,” the ability to use and enjoy the area’s rivers and beaches was a common thread among participants from this community.

While people in Pittsboro described physical and social closeness, participants from Fayetteville commented on the appeal of space and privacy. Participants talked about the “freedom” of living away from bigger cities, intentionally “being out in the country” with access to the woods, wildlife, and “wide open spaces.” Participants from the upper and lower Cape Fear regions mentioned proximity to nature trails or beaches, but participants from Fayetteville talked about the access to nature they can have on their own properties, with many participants living on multiple acres of land. They described having room to farm and raise livestock, to have their “own little chunk of woods,” and ample room for children and grandchildren to enjoy the outdoors. Participants specifically describe seeking out this lifestyle, with multiple people lamenting, “we thought this was heaven,” and “I love it out here, this is where I thought I was going to permanently retire,” and “except for the fact that my well is contaminated, otherwise it would be perfect.” Indeed, multiple participants spoke to the contradiction between what they thought would be a clean, peaceful life in the country—"we thought we were coming this way

and that it would be a lot better environment for us"—and the impact of industrial pollution— "I moved out here for a nice, quiet, healthy country life, and I'm not getting that. I'm getting the country life, but it's not healthy."

Suffering. Renfrew and Pearson (2021) put forth the "Toxicity Continuum" as a representation of the dynamic ways in which people may make sense of and describe their experience with environmental exposure (See Figure 3.1). Suffering, in the middle of the continuum, can be characterized with higher perceived risks, embodied negative emotions (e.g., fear, worry, stress), and the physical impacts of exposure (Renfrew & Pearson, 2021). While participants spent the beginning of their interviews recounting all that they love about their communities, they spent most of each conversation illustrating a range of emotions and experiences that would be categorized as suffering along the continuum, they spent much of each conversation recounting a range of emotions and experiences that would be categorized as suffering along the continuum. Of the 32 participants who described these ideas, they spent between 16% and 37% ($\tilde{x}$ = 16%) of their respective transcripts on the topic, representing 24% of all coded segments of data.

Emotional impacts. After describing an array of positive aspects of their communities and the people who live there, many participants (n = 20) reflected on the "jaw dropping" surprise, disappointment, and "complete betrayal" that existing people and institutions seemed to quietly allow chemical pollution to impact their communities, "no one said anything…just nobody really was honest about it." As people learned about PFAS and the extent of contamination in their communities, they expressed feeling "contamination anxiety" and ongoing worry about exposing themselves and their families to PFAS (n = 19). They described filtering their drinking water but still worrying each time they bathe or use water for cooking, feeling fear

that they "are still ingesting poisons" and stress that they will never be able to "get to a zero-level exposure." Some female participants revealed the fear they felt while pregnant knowing that their community had PFAS contamination. One woman recounted having complications with her first pregnancy and needing her husband to bring water to the hospital,

> I was in the hospital for a month because of pregnancy complications, and I remember, asking the nurses how the water was filtered…and they just didn't seem to either know or be concerned. So, my husband was filling up a three-gallon jug of water and bringing it in and that was the water I was using. I couldn't even ask the nurses to fill up the cup they gave me because I didn't trust the water and they didn't know how the water was being filtered. I was like, 'well, I don't really need to make things worse right now, I don't need to be drinking this water while I'm in the hospital for a pregnancy-related condition.

In fact, some people (n = 9) expressed worry that filtration systems are not truly working, noting stains on plates after washing dishes, being told that only cold water is safe from PFAS, wishing they could test their water more often so they do not have to "live by faith" that their filters are effective, and some believe that "the water may be even worse now."

Ultimately, these anxieties and fears from learning about and trying to reduce exposure to PFAS seemed to drive an overarching worry that PFAS may cause harmful health effects among almost everyone (n = 31). In fact, when people were expressing emotions related to PFAS, more than 50% of the time ($\bar{x}$ = 53%) they were specifically describing fear and worry about the impact that PFAS has or might have on their own, their families', their pets', or their neighbors' health. When asked if they felt they saw certain health conditions within their communities, most participants believe they see trends that seem more prevalent compared to other communities. In the lower Cape Fear region, those participants who felt this way described trends in immune

("I've noticed a lot of autoimmune diseases"), thyroid ("I know a tremendous number of people who have thyroid issues"), and kidney ("I do notice that I have run into friends with kidney issues") health effects. In Pittsboro, half of residents (n = 5) felt they had not lived there long enough to see trends or did not believe they saw any more prevalent health conditions, and half (n = 5) described elevated rates of cancers, including in younger residents. Though it was in the middle Cape Fear Region where cancers were brought up most frequently, and with assertive links to PFAS contamination. Eight of the 10 participants (80%) from this region described high rates of cancer, talking about how "rampant" the disease is, with people seeing "cancer after cancer," "my friends in the neighborhood," and "the young people dying" from a variety of cancers. Participants recounted their own battles with cancer, losing family members to cancer, and a larger trend of watching members of their community suffer.

> Cancer is rampant. I know more people who have died from cancer, and not just older people, I'm talking multiple people my age. I lost my own sister…I know three or four people in her grade alone who have had crazy types of cancer…utter sadness and devastation…I just look at all the other young people and breast cancer has been something that seems like everybody I know has had.

Participants described worrying about certain people within their communities. For instance, some participants (n = 5) in the middle and lower regions described fear in how PFAS may impact women's health, citing pregnancy complications ("my daughter will not have any more children simply because of the hypertension she experienced during childbirth"), hormonal disorders ("a lot of people I know have been diagnosed with PCOS"), issues with infertility ("you'll never prove it [was caused by PFAS], but I'm infertile"), and pregnancy loss ("between my three daughters, I've lost seven grandchildren to miscarriage"). Most participants (n = 18)

across the communities (upper = 6, middle = 8, lower = 4) described worry about the impacts to children's health. Given that all participants were adults, there was a sense that it is their "job to protect [children]," which caused feelings of "constant worry" about currently preventing children's exposure to PFAS, and "guilt" at exposures children may have faced before parents knew about PFAS ("you're making baby formula…you're making them food with this"). Interestingly, five participants in both the upper and middle regions (n = 5) brought up, without being prompted, their concerns that schools in the area are not providing filtered water for children. One participant had heard that the teacher's lounge was the only area in their child's school that had access to filtered water. Another described giving her young daughter "large bottles of water" to take to school and teaching her to "never drink the water, only wash your hands" while at school. Two participants from the Fayetteville area described what they believed to be unsuccessful efforts to get bottled water to the multiple schools in the area, talking about the logistical improbability that all students were getting clean water during the day. One doubted that it was possible to get water given the scope of need, "we have one, two, three, four, five schools in our community…I mean thousands and thousands of kids." Another described related mistrust,

> I don't think there's any possible way that you could manage that all those kids at those schools are getting bottled water, or that they're cooking in the cafeteria with bottled water. I don't buy it, not for a second.

Even people whose children are adults or who do not have children described a fear of how children's PFAS exposure today may result in harmful health outcomes in the future, wondering "how is this going to affect them later on in life" and saying, "I just don't want them to get sick."

When talking about health conditions, some participants in each community did caveat their statements, admitting they are not sure that PFAS definitively caused a certain health condition or that they have not lived there long enough to be sure. More than half of participants (n = 18) across all three communities, however, described a connection between PFAS exposure and negative health outcomes. A participant from Pittsboro recalled getting "severe stomach aches" when he drank unfiltered water that contained PFAS. This was echoed by a participant whose wife was diagnosed with breast cancer within one year of moving to the Cape Fear River basin and beginning to drink water "without any kind of filtration." Another participant from the middle Cape Fear reflected on their sibling's battle with cancer after having spent her whole life in the area, "nobody will ever connect the two, but you can't tell me they're not connected." People remembered starting to investigate connections between PFAS and health effects, "I read a little bit about my autoimmune disease, and it said it could be caused by the PFAS" and their ongoing belief that "it has to do a lot with our water" and they "can't help but think it's because of the PFAS because it's in the water, it's in the ground, it's in the air, it's everywhere." Ultimately, the suffering related to mistrust of institutions, fear of ongoing exposure, and the perception of increased health conditions caused by PFAS contributed to this ongoing sense of illness anxiety. Half of participants (n = 16) explicitly expressed a sense of wondering "what's next" regarding illness and harmful impacts of PFAS, feeling they are just "sitting here on a bullseye" until then.

Lifestyle impacts. Given the range of fears and anxiety participants are feeling, people recounted a variety of actions they have taken in response to PFAS exposure to attempt to minimize their emotional and physical suffering. All participants (n = 33) discussed directly

reducing their exposure to PFAS by changing the way they get drinking water, either by filtering the water in their home or purchasing bottled water, which varied by community.

In Pittsboro, the city is in the process of transitioning to a municipal drinking water system that removes for PFAS. All participants from this community are on municipal water and their tap water will be provided by this system. Still, many participants (*n* = 21) reported installing their own filtration systems "to take matters into our own hands" while they waited for assurance that the city's tap water was sufficiently treated. Participants used a range of strategies installing reverse osmosis systems, whole-house systems, filters for their kitchen sinks and their refrigerators, and strictly using only filtered water ("I see both my boys nagging my husband whenever he reaches for the unfiltered water") for drinking, cooking, and even giving to their pets. Multiple participants remarked on their appreciation for the Town of Pittsboro creating multiple locations where residents could go and fill containers with filtered water to take home for free. Three of the ten participants from this region will still only drink bottled water, "we drink bottled water, and we have since we got poisoned the first time." Pittsboro is upstream from the industrial PFAS manufacturer in the middle Cape Fear region, and its residents do not receive any of the state-mandated testing or filtration for which many communities in the middle and lower portions of the river basin are eligible, meaning that reducing exposure by using filtered or bottled water is up to each individual based on their desire and ability to do so.

Similar to Pittsboro, all participants in this study from the lower part of the river basin (*n* = 13) are served by municipal drinking water systems and are not eligible for state-provided testing or filters. As the community that learned about their PFAS contamination first, they have had the most time to respond to the issue, and the treatment systems in this area have received significant technological overhauls to drastically reduce PFAS levels and improve drinking water

quality over the last eight years (Cape Fear Public Utility Authority, 2023; Solon & WECT Staff, 2022). And yet, eight of the 13 participants (62%) from this region only drink bottled water, and five installed in-home filtration systems after first learning about PFAS contamination. The fact that many residents from this community still use alternative drinking water sources despite assurances that the municipal water is safe may speak to that sense of betrayal and mistrust from having had their water contaminated in the first place described above, “I don’t think it's as bad as it was, so that’s good, but I still prefer my [reverse osmosis] treated water.”

Participants from the middle of the river basin described distinctly different experiences with exposure reduction. Each of them (n = 10) relies on a private well for drinking water, and they are all within the radius defined by the state of North Carolina that requires the PFAS manufacturer to test homeowners’ wells for PFAS and provide alternative drinking water if the water exceeds 10 parts per trillion of certain PFAS (“they put in the reverse osmosis because we fell up under the 10 parts per trillion when they were checking just for GenX”). All participants from this region had had their well sampled, but not all of them exceeded the threshold necessary to qualify for alternative drinking water, so they recalled a combination of strategies that included company-provided water, personal filtration systems, and purchasing bottled water (“we stopped drinking the water and bought bottled water immediately”). It is worth noting, however, that even though many residents qualified for free drinking water, they described a range of difficulties accessing and using it. Some residents chose to have the company provide them with jugs of water instead of in-home filtration, which was not without issue. According to one participant, the company initially expected residents to drive to the factory each week to pick up drinking water—a resource they used to simply turn on their sink and have access to—“you had to go show your ID where you lived to pick up water at the security shack at the Chemours

plant, and that was for several months." Once the company began delivering water, participants recalled, "sometimes they would just stop delivery for months and you'd have to call them up and say, 'hey where's my water?'" and given the large plots of land residents live (and love living) on, many have very long driveways that the company would drop water at the end of, "they could have been two miles from the house and they're just dropping the water at the mailbox to sit in the elements." Participants highlighted the "unrealistic" allotments of water they were given, "because you have to cook with it…you're bathing in it, you're washing your clothes in it, your dishwasher your plates and all of that…everything other than what you're just drinking or cooking with." Another participant highlighted inconsistencies in water quantity, "I have a two-car garage and at one point, it was pretty much full of these bottles of water because I was just one person," while other people in the community were not receiving enough, "there were families that weren't getting enough—or any—so I would share with them." One participant revealed that after the company installed their home's filtration system, only one faucet in the house will work at a time, so they keep a bowl of "recycled shower or bath water" in the bathrooms in case someone is using a faucet elsewhere in the house when they need to wash their hands. He recalled how his wife loves to garden, and if she wants to go water the plants with the hose, "the whole house has to shut down," and after having lived this way for close to seven years, he said, "we're kind of used to it but it's pathetic." Interestingly, even though this is the one community of the three that was eligible for free drinking water, its participants seemed to experience the most difficulty related to acquiring clean drinking water, 80% (n = 8) of the participants discussed it as compared to 60% (n = 6) in the upper and 46% (n = 6) in the lower basin. Moreover, of all coded segments of data related to burdens and hardships caused by PFAS, 75% (n = 66 segments) were from residents of the middle basin. Their stories highlighted

how individual exposure reduction actions are part of larger lifestyle changes that can range in inconvenience and burden.

In addition to the logistics of choosing and acquiring drinking water described above, participants recounted other, broader ways their lifestyles have been impacted due to PFAS contamination. These ranged from inconvenience to outright hardship for things many people take for granted being able to do, like turn on their sink for clean (or any) water, plant a garden, or pay their water bill. For instance, residents (*n*= 11) from the middle and lower parts of the basin reflected on how they have had to start avoiding local foods—no longer growing gardens and avoiding fish and seafood—"I eat fish and seafood that comes from other states, I listen to the advisories. I won't eat anything that comes from the Cape Fear River." More broadly, they described changing their relationship to nature, which for so many is what attracted them to their homes in the first place. One participant from the lower Cape Fear reflected,

> The water that's so important to so many people…also there's so many people here that this is their livelihood—they're commercial fishermen, or they lead sailing charters, or for so many people surfing or swimming or sailing, canoeing, kayaking is how they like to spend their leisure time. And PFAS really dimmed the charm of that for so many people. It took that joy away. It tainted something that was beautiful and healthy and made it unhealthy.

In Pittsboro, participants regretted not being able to fully enjoy the nearby rivers and lakes, some refusing so swim or even touch the water; they can no longer "take advantage of what nature has to offer." One participant said in a member checking email, "one nasty lifestyle change is that I have been cut off from visiting and swimming with my dog in Jordan Lake." In the Fayetteville area, six of the ten participants reflected on making the choice to stop growing fruits and

vegetables, stop producing honey, and stop raising chickens for eggs. As one participant said, "we have the [natural] resources" but feel they are unable to use them now because of PFAS.

These changes in how participants acquired drinking water and being unable to rely on local—free—sources of food were part of a larger theme of financial burdens that PFAS had created in participants' lives. Participants (*n* = 22) described the "huge expense" that comes from buying bottled water, choosing a water filter ("trying to find the best filter is expensive. If it's a good filter, I think it's at $2,000!"), or upgrades to municipal drinking water systems that increase their water bills. A participant from Pittsboro emphasized that their water bill had already quadrupled in price, and another said that they were now paying "a lot more" for water to "compensate for that filtration system" their municipality had installed. Moreover, some worried that despite the increases in cost, they do not know that they can trust the finished water, "there's no guarantee that this water bill that I'm paying every month that the PFAS is completely gone." While acknowledging the unintended financial costs they were each facing, some participants (*n = 9)* also remarked on the privilege that is needed to make these protective lifestyle changes. They noted that upon learning that their water is contaminated, most people "can't just move" but "not everyone has $7,000 to $8,000 to spare to put a water filtration system in their home." Despite having just told me in detailed about their worries about PFAS exposure and health effects, and the difficulty and burden of getting safe drinking water, eight of the participants still recognized talked about how "privileged," "fortunate," and "blessed" they felt that they were able to do those things, because they knew many people in their communities could not.

Participants across all three communities had so many positive things to note about their communities and the people who reside there. They specifically chose to move to or chose *not* to move away from these places because of the friendly people and tight-knit social networks, the

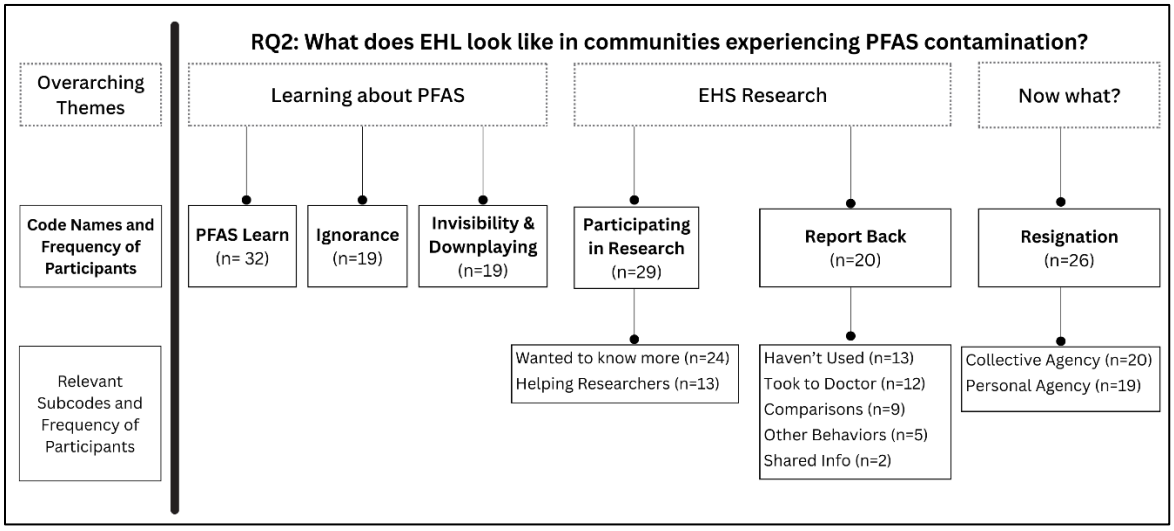
"small town feel" of the towns, and the access to the outdoors they saw as a source of healthy recreation and joy. Learning of PFAS contamination has caused a range of suffering-based affective and somatic experiences for participants and they continue to worry about ongoing PFAS exposure, possible health effects, ensuring they have safe drinking water, and generally adapting their lifestyles in the face of environmental contamination. This type of suffering may seem like a logical or predictable impact of environmental contamination. Yet there was a sentiment underlying the conversations that participants' lived experience with PFAS contamination was more complex and all-encompassing than what could be conveyed in environmental measurements, or even in hour-long interviews, stressing that "they need to walk a mile in our shoes." Close to half of participants (n = 15) described this feeling of being misunderstood—that people who have not experienced "a lot of little things" that they have cannot understand the scope of the emotional impact of contamination, "how it truly affects us physically and mentally." One participant from the Fayetteville area admitted, "It's bigger than you think. You don't realize it until you're in the middle of it like us."

RQ2: What does environmental health literacy look like in these communities experiencing PFAS contamination?

Because EHL is outlined in the literature as combination of knowledge, efficacy, and behaviors (Finn & Fallon, 2017; Gray, 2018), codes related to what people know and how they learn about PFAS, the role of EHS research and report back, and people's perceived efficacy and agency were synthesized to answer the second research question about EHL in the Cape Fear River basin. Participants described a reliance on social and traditional media outlets for finding and synthesizing information about PFAS. It was clear from the interviews that not all participants, and presumably not all residents of these communities, make sense of PFAS the

same way, representing other portions of the Toxicity Continuum. Finally, participants talked about their thoughts on EHS research and participating in the GenX Study, if and how they used information from the study's report back, and how they perceived their ability to enact personal or collective change in response to PFAS.

Figure 3.7. *Conceptual Map of Codes Related to Research Questions 2*



Learning about PFAS

In general, each community had a different experience gaining knowledge about PFAS, and participants varied in how distinctly they recalled learning about PFAS, with participants from Wilmington and the surrounding areas seeming to have the most detailed recollections. Of the three communities in this study, residents of the lower Cape Fear region were the first to learn about PFAS contamination after local news outlets first reported on it 2017 (Hagerty, 2017; Vandermeyden & Hagerty, 2020). Of the 13 participants from this community, half (n=6) described first learning about PFAS from the local news and half (n = 7) said they learned from friends, neighbors, and their community social networks. All of them were able to distinctly recall how and from whom they first learned about PFAS. One woman recounted "just little bits

of information, and then all of the sudden it became this big boom of information," highlighting the high-profile nature of the issue in that community. They also outlined how they continue to learn about PFAS, naming community leaders, local nonprofit organizations (e.g., Cape Fear River Watch), and academic researchers (e.g., NC State and the GenX Study) as sources they find reliable.

In contrast to the lower part of the river basin that had a concerted effort from local media and outreach from local organizations, only two participants from the middle region recalled learning about PFAS from the news or social media outreach. Instead, participants recounted the much more inadvertent ways they first learned about PFAS. One participant remembered learning about PFAS in 2017 when a reporter knocked on her front door, told her they were "just here reporting about the contamination in the wells," and asked to interview her. That was the first time she was given any inclination that her well might be contaminated. Half of the participants from this community learned about PFAS because they either received a letter in the mail from Chemours—the local PFAS manufacturer—or someone affiliated with the company, showed up at their home insisting on testing their well, "they were having people go around and testing various places, and they just happened to come by our house." Some participants recalled learning about PFAS before 2017 when the public outcry in Wilmington was generating more widespread attention. For instance, one woman recollected first finding out when her granddaughter was in elementary school, more than twelve years ago, "I remember my daughter saying that [students] couldn't drink the water out of the fountains because it was bad… And that was the first time I had heard anything about PFAS." Stories like hers paint a picture of PFAS knowledge spreading more slowly and quietly in this community, perhaps due to the geographic

distance between residents or their proximity to Chemours and local corporate communication strategies.

Finally, participants from Pittsboro generally revealed a more anticlimactic or subtle introduction to PFAS, as opposed to the distinct media coverage or personal anecdotes of the lower and middle parts of the river basin. Instead, half (n = 5) the participants from Pittsboro struggled to recall how they learned first learned about PFAS, saying things like, "I probably saw something in the newspaper… or maybe online," and "I can't remember how we found out." The other half (n= 5) talked about family members happening to encounter information about PFAS "kind of by accident," which prompted them to begin looking into PFAS on their own. One participant remarked on the relative *lack* of information sharing by the town, "there was one little post that came out and said, 'Don't drink the water, it's poisoned.' And that was it. Nothing else after that, no door to door… no announcements, no papers pinned up at any bulletin boards, nothing." Still, just as some participants in the lower Cape Fear highlighted sources they trust to continue learning about PFAS, multiple participants from Pittsboro specifically named two local women-led organizations, Clean Haw River and the Haw River Assembly, as trusted sources for PFAS information and civic engagement opportunities.

Given that one of the key components pieces of environmental health literacy is knowledge, how participants gain information helped describe aspects of their PFAS knowledge. In the lower part of the basin, participants were able to describe when and how they learned about PFAS and where they continue to go for information about it. In the middle part of the basin, residents remember learning about PFAS, but not during one distinct period of time, and not from the same sources. Finally, participants from Pittsboro described learning about PFAS with the least specificity, with most unable to recall where, when, or how they first learned about

it. Pittsboro is upstream from the Chemours manufacturing plant; they have more individual, yet subtle sources contributing to their PFAS contamination, which creates a more complex narrative of where to assign blame and may explain the relatively less publicity and the slower, inadvertent spread of PFAS information.

Making sense of PFAS

Regardless of when or how participants first learned about PFAS, they each individually made sense of the contamination and its perceived severity, which subsequently informs how they make decisions and enact behaviors related to PFAS. In Renfrew and Pearson's Toxicity Continuum described above, there is a range of ways people can perceive risk and situate the contamination relative to their daily lives (Renfrew & Pearson, 2021). Indeed, participants remarked on the "huge range" of awareness, knowledge, and engagement on PFAS among people in their community. Along the continuum, Ignorance and Invisibility are to the left of Suffering, indicating relatively lower risk perception and daily visibility. Two participants described ignorance as related to traditional intelligence, citing a lack of formal education among residents as an explanation for why people in their community may lack awareness or engagement related to PFAS, "we have a lot of people out that direction that just never graduated high school, so [understanding PFAS] is way above their head. They just don't process it." But on the Toxicity Continuum, ignorance is not meant to describe educational attainment or the choice to remain unaware of an environmental issue, but to describe how it is the inevitable result of our regulatory systems that allow many environmental issues to remain "structurally hidden" (Renfrew & Pearson, 2021). It is this connotation of ignorance that participants (n = 19) illustrated most frequently, describing how systemic issues produce ignorance, telling me, "there's also people that just still don't know, which you know is kind of crazy," "it's not

publicized at all," and that this absence of outreach leads many to assume there are no issues, "some people are just a little too trusting." For instance, a system that does not require disclosure about water quality to people buying homes in the area means that "people that move here that are new to the area don't realize there's water issues." Participants also seemed to distinguish between two groups of people who fall along the Ignorance portion of the continuum, the first being those described above that lack the initial awareness of the PFAS issue. The second group being people in their communities who know about PFAS but who, in their opinion, do not understand the scope of the issue, feeling that "the misconception is like, 'oh, we're all good.' But I don't think we are" and "Yes, we have our water being filtered, but there's still other potential contamination sources… And I think that people think it's fixed, that it's cleaned up. And it's not." One participant's response during member checking served as an example of this, as they expressed surprise at the scope of the issue after having read a summary of the analysis, "I had no idea that people as far as Fayetteville were also contaminated." Related to potential connections between PFAS and health effects, one participant said, "I think that people, my community as a whole are so unaware what could happen to them, or they're just so unaware of what might be lurking in their body."

Similar to Ignorance, Invisibility entails having awareness and understanding of PFAS but "unseeing" it in their daily lives because of how they have situated and made sense of the risk relative to other things in their lives (Renfrew & Pearson, 2021). For instance, one participant from the Fayetteville area emphasized that other aspects of her life take priority over PFAS, "I don't know if I should be alarmed…I got all this other stuff going on that kind of takes precedence." Another shared a similar sentiment, "I mean, do I worry about it every day? No, because I've got too much other stuff to do." Indeed, many participants (n = 19) expressed

having PFAS “on their radar” and “in the back of their mind,” but not a source of immediate worry or prioritized action. Interestingly, 18 of the 33 participants described PFAS in a way that downplayed or minimized the severity of PFAS when specifically comparing their situation to that of other geographic areas or demographic groups. For instance, three participants from the middle and lower regions made comparisons to the crisis in Flint, Michigan, with one saying, “there is a spectrum, like in Michigan it was worse there,” and another remarked, “we don’t want to be in a situation like we would see on the news in Flint.” Some participants minimized their PFAS experience relative to others within the Cape Fear Rive basin (“I’m a little further upstream than Fayetteville…. they get it doubly as bad.”) or other GenX Study participants,

> I mean [my PFAS levels] are still in the medium risk level area. But I guess it’s not as bad as other people that I've talked with that have participated in the study that are much, much higher. So, I guess, in a sense I feel grateful.

Participants described how they make meaning of PFAS and its risk relative to their age. One woman from Pittsboro summed up her Invisibility experience saying of her PFAS levels, “I was hoping they would be better. I wasn't horrified at where they were, though again, if I was in my twenties I'd have been very upset.” A male participant from the lower Cape Fear summarized this notion of Invisibility, saying, “I'm older. I'm in my seventies. If I was younger and had children at home, I would be more worried, which a lot of people in this community do. And I think that impacts how I think about what's going on.”

This study used the Toxicity Continuum to help frame how people understand and make sense of PFAS information and risks they perceive from it, and how that ultimately relates to their overall experience with PFAS exposure. This framing allows for the description of the dynamic ways in which people think about exposures, moving back and forth along the

continuum. As described above, all participants expressed aspects of Suffering, but many also noted the ways in which they or people in their communities ignore, unsee, minimize, and downplay their experience with PFAS exposure. Participants' responses highlight the heterogeneity with which people create knowledge and beliefs about an environmental hazard.

Environmental Health Science Research

Because many EHS studies that rely on public participation now share data back with their participants (e.g. Brody et al., 2007; Dunagan et al., 2013; Korfmacher & Brody, 2023; Lebow-Skelley et al., 2020), and this process of report back is purported to build and support EHL (Brody et al., 2018; Cleary et al., 2017; Perovich et al., 2018; Sandhaus et al., 2018), this study sought to understand the ways in research participation and receiving personal results related to participants' PFAS knowledge, efficacy, and behaviors. When participants recalled what initially motivated them to participate in the GenX Study, those from the lower Cape Fear talked about a desire to "help researchers" and specifically wanting to learn about their *own* PFAS levels and health. People wanted to "get a measurement," so they could "see how I'm doing with my health," have access to "another source of information to help me understand why my health was not optimal," or "know more about what to be on the lookout for" so they can be proactive about their healthcare. In contrast, participants from the upper part of the river basin expressed general curiosity and a desire to learn, rather than the desire for specific personal measurements. A male participant said, "I just wanted to learn more about PFAS" and a female told me, "I'm a very curious person. I get involved in a lot of different things." More than half (n = 6) of participants from this area also reported "wanting to help the science" as a reason for joining the study. Finally, in the middle of the basin, participants also recounted a desire to "help with the study," but also explicitly framed it as a way of contributing to their community and the

collective good, with one participant remarking, “I’ll do what I can to help everybody out.” One female participant said that they joined the GenX Study because they saw it as a way to help their community’s larger fight to address PFAS contamination, saying, “a tube of blood and pee in a cup, what can it hurt? All it can do is help the communities, I think.” One participant emphasized the importance of participating in research as a Black woman even though she perceived her own risk from PFAS to be relatively low, saying, “it felt important for us…people of color to participate…anything we can do—even if we’re not directly affected—may potentially help somebody else.”

Report Back

At the time of their interview, each participant in this study had received at least one round of report back from the GenX Study. Depending on when they first enrolled in the GenX Study, each participant has received at least one letter with cholesterol and other clinical measurements, their individual PFAS measurements, and recommendations for medical monitoring with their healthcare providers (See Appendix J for example GenX Study report back letter). For participants who have been in the study longer, they may have received comparisons of their PFAS levels over time, comparisons relative to other participants’ levels, or comparisons to national averages and any applicable regulatory thresholds. About half of participants (n = 18) did describe negative emotions that came from seeing what they perceived to be “very high levels” of PFAS in their bodies. One woman from Fayetteville admitted that seeing her numbers scared her “more than that reporter showing up [at my door] in 2017.” Another woman said, “sometimes I think I brought it on myself because I gained weight,” when describing elevated levels of PFAS in her body that are the result of industrial contamination. Still, when generally describing the report back process, participants felt appreciative that they had access to this kind

of information, finding it “comforting in ways, because I liked being able to know,” and being “given an extra level of awareness” about their PFAS exposure.

When asked how they have been able to use their report back letter or any other information provided by the study, participants reported sharing the information with their doctors, comparing their levels over time, using it to inform risk reduction behaviors, and using it to share information about PFAS with people in their community. Almost half (n=12) of participants had shared their report back letters with their healthcare providers, including bringing them to in-person appointments and uploading them to their online medical charts. Some participants recalled very positive interactions with their providers, describing ones who were interested in their results, willing to look more into PFAS on their own, and used the information to inform decisions about the participants’ care. Most participants who reported having taken their information to their doctors, however, recounted unproductive experiences. Of the 12 participants who took the information to their doctors, nine participants (75%) from all three communities felt that their doctors generally “don’t know what to do with it,” saying, they don’t “seem to be very versed on what’s going on,” they “don’t understand the scope of the problem,” and one participant was even told to “go see a lawyer” by their doctor. Nine participants—though none from Fayetteville—described being able to compare their measurements to those of their family members, and for those who have been enrolled longer, they explained being able to see how their own PFAS levels change over time, “we've done it twice now, so we did a second screen and our results are starting to drop and come down.” Five participants specifically cited the report back letter as the impetus for taking risk reduction behaviors, like changing their drinking water, eating less seafood, and more proactive medical monitoring. Two participants, both from the lower Cape Fear, said that they use the report back

letters to share information about PFAS with their family, friends, and neighbors. In many ways, it seems that the report back process and individual letters did support aspects of participants' efficacy in responding to PFAS, as at least 12 of them recounted behaviors they took as a direct result or when supported by the report back information.

It is important to note, however, that 13 of the 33 participants in this study either made comments about the lack of utility of their report back letters, or specifically described having not used their letter or the information therein *at all* since receiving it. For example, one participant reported having "took it to the [doctor]" but dismissively said they have "not done a whole lot" with it, and one participant admitted being "super excited" to initially see their measurements but "they've just been filed away in my filing cabinet, and I haven't really used them." Additionally, some described an *intent* to share the information with their doctors that they never followed through on, "every time I go, I forget to bring it, you know it's just one more thing." Another participant reiterated a similar idea that they have focused on other more visible issues in their lives that take precedence, "it's mainly because I've had a few other things going on since I've gotten that letter." Two participants from Pittsboro expressed something akin to guilt as they confessed that they have not shared their letter with anyone but "know they should." When participants recounted having misplaced or not used their letters, or having not done what they perceived to be enough with information from the GenX Study, there was an underlying theme of feeling like they do not know *what* to do or the impact it will have. One participant said,

> I have my test results from participating in the GenX Exposure Study, but I don't know what I do with that … I can bring it to my doctor, but I haven't. I haven't yet but, if I do, I'm not sure that that would even result in very much.

Whereas Ignorance and Invisibility are to the left of Suffering on the Toxicity Continuum, Refusal and Resignation are to its right (Renfrew & Pearson, 2021). Resignation is described as "helplessness" and "doubting the possibilities of redress and change" (Renfrew & Pearson, 2021). By this definition, many participants across all three communities expressed their report back letters and their broader set of knowledge and skills through a lens of resignation. More than half (n = 19) of the study's participants, and more than half from each community, conveyed a lack of personal agency related to their exposure to PFAS. Some participants talked specifically about not knowing how to translate information they gained from the GenX Study into next steps for action. One participant from Pittsboro felt appreciation for receiving data through the GenX Study's report back but felt stuck, "we have the information, but we don't know what to do with the information." Another from the lower Cape Fear said, "we have our test results from participating…but I don't know what to do with that," and another from Fayetteville reiterated that receiving her results were "scary but what can I do about it?" More often, participants expressed a broader sense of resignation, describing themselves as "feeling powerless," feeling that they "don't have a lot of choice" in their exposure experience, "there's not much I do about it," and generally feeling "stuck" with regards to their own PFAS exposure. A majority of participants (n = 20), and at least half the participants from each community, depicted similar feelings of resignation at the collective scale. Given the extent of PFAS contamination in the Cape Fear River basin and the fact that, like most environmental issues, the contamination requires collective actions to structurally address and the remediate the problem (L. F. Davis & Ramírez-Andreotta, 2021). Yet all 20 of these participants made declarative statements about their lack of confidence in actors and institutions addressing the problem on a larger scale. Four participants ranging in age from 48–72 years old used the exact

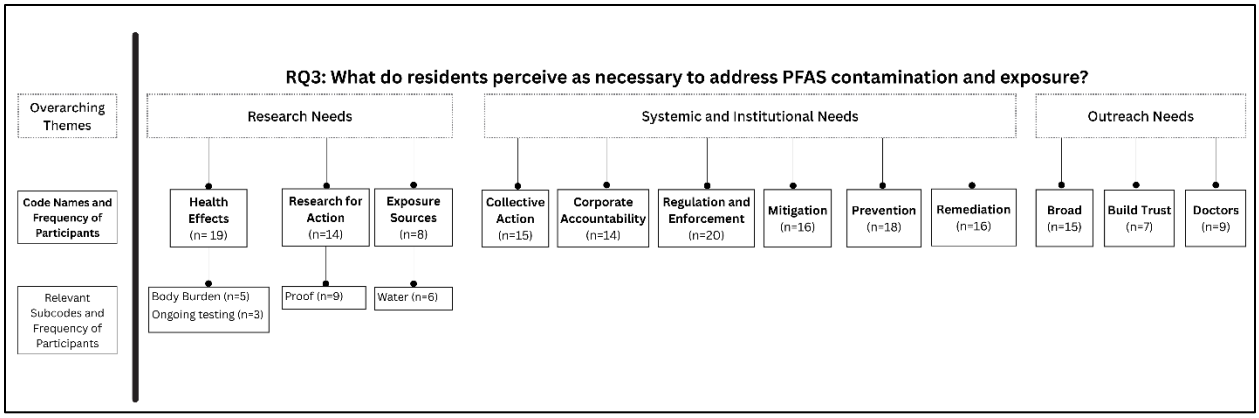
phrase “probably not in my lifetime” to estimate when they thought their community’s PFAS contamination might be addressed. Younger participants expressed similar sentiments, saying things like, “I don’t think it’s going to get better.” Participants expressed a “lack of confidence” in corporations, lawmakers, and regulators to address the issue, citing financial greed and political pressures. Even this study’s youngest participant felt they “have just kind of accepted” that ongoing, widespread environmental contamination is their community’s status quo.

To answer this study’s second research question, participants’ responses about acquiring PFAS knowledge, making sense of and forming beliefs related to PFAS, and participating in and receiving EHS research information were synthesized across the three communities. Participants’ sentiments reflected the heterogeneity of the broader exposure experience, as they described beliefs and behaviors that ranged across the Toxicity Continuum. Moreover, they highlighted the nuance with which people perceive external risks, self-efficacy, and options for individual and collective behaviors.

RQ3: What do residents perceive as necessary to address PFAS contamination and exposure?

During each interview, participants were asked what they think is needed to address PFAS in their communities beyond what their own individual exposure reduction behaviors can achieve. These responses were synthesized to answer the final research question. Participants across the three communities talked about three overarching types of initiatives that they believe need to happen in order to make larger-scale impacts on their community’s collective PFAS problem. In general, participants’ responses related to research efforts, institutional and governmental oversight, and education and outreach.

Figure 3.8. *Conceptual Map of Codes Related to Research Question 3*



Research Needs

It is important to note that many participants (*n* = 13) went out of their way to express their appreciation for the GenX Study. Of the science itself, they described "concrete" and "high-quality" data, "neutral and unbiased information," and feeling "lucky" and "privileged" to be able to contribute to it. More broadly, they expressed a sentiment that by conducting the GenX Study, its researchers were authentically supporting their communities. Some participants conveyed the idea of getting a type of recognition they were waiting for, saying of the study, "I'm glad that [the GenX Study is] doing this. I'm glad that people are finally looking into this matter and trying to find answers." Two participants from the lower Cape Fear said, "I appreciate anybody taking an interest," and "it's nice to know that someone cares about this community." Others articulated their gratitude for the study for "trying to get data that hopefully can be used to effect change." One male participant from Pittsboro affirmed how grateful he was that the GenX Study was "available to conduct this research and give this community the facts that we need." They used words like "incredible" and "wonderful" to describe the GenX Study and its researchers, telling me that "North Carolina State is working hard" and "I appreciate everything [they] do." Of note, some participants wanted to convey that the GenX Study and other scientists have roles to play in sharing information about PFAS contamination in their communities, saying

of researchers, “they are our voices.” A woman from Fayetteville urged me, "get the word out. Let people know that this [PFAS] is out there, and it's not just my community, it’s in all the surrounding communities, as well.” A participant from Pittsboro urged, “just try and keep fighting the fight for us.”

Just as participants expressed strong gratitude for the GenX Study, they also identified research gaps and most (*n* = 28) commented on the need for more research related to PFAS as one of the three paths forward for addressing contamination in their communities. Acknowledging the feelings of exposure and illness anxiety many people described earlier, participants report wanting to see more “definitive” research into the health effects of PFAS exposure. Unsurprisingly, many (*n* = 19) expressed the need to know “how it affects the body,” including long-term health outcomes, impacts to children, and potential links to cancer. Relatedly, participants (*n* = 5) talked about needing research on reducing body burden and “how to get it out of the body of the people that are already affected.” Some participants (*n* = 8) mentioned the need for more research on a range of topics, including other potential sources of PFAS exposure in their communities (e.g., air, local foods), impacts to wildlife, and ongoing access to blood and water testing for residents (*n* = 3). Perhaps more important than the individual research questions, however, was a connecting theme of wanting research to generate data that can be used for action. Participants felt that they need “definitive answers,” “actionable data,” and “hard facts” as to how PFAS impacts their health and their communities. Specifically, some (*n* = 9) felt that without perceived scientific certainty, it was harder to put pressure on institutions and systems to address PFAS, saying, “in order for us to even have a standing chance at some change, we have to have hard facts, we have to have numbers.” Almost half of participants (*n* = 14) expressed about the desire that research be conducted for a purpose and *for*

action, that research is needed "in order to take the steps forward, to be able to make a difference as a community." One participant asked of PFAS research in general, "are we just collecting this information or is it going to really make a difference?" A comment from a Fayetteville participant summed up many of the sentiments, saying that PFAS research has "got to be more than just a job, it's got to be a commitment to society to do the best thing to help your fellow man or woman."

Institutional and Systematic Needs

The second category of actions that participants identified as necessary to structurally address PFAS contamination was assigned to corporations and government actors. A third of participants (n = 14) described wanting to see companies "step up," take "accountability," and "be responsible" for preventing further PFAS discharges and addressing existing damages. Notably, many of these participants framed this accountability as something companies might willingly choose to do on their own accord. Suggestions included that companies pay for residents' filtration systems, support residents with the cost of medical care, and cover the cost of upgrades to municipal drinking water systems instead of the resident taxpayers. One participant even suggested that companies might help by dedicating some of their vast financial resources to "do some research themselves, get some scientists and some doctors, get somebody on this case like you do cancer." Some participants, however, felt that corporate greed and profit motives would disincentivize companies from making any changes, and that displays of corporate accountability would only come as a result of larger regulatory and enforcement efforts at the state and federal levels. Indeed, almost two thirds of participants (n = 20) called for regulatory actions to mitigate current issues and prevent future damage, including "massive fines" to force changes in companies' business practices. When asked who is or should be responsible for

enforcing fines and other accountability strategies, participants mentioned state and federal governments, though the US EPA was the only actor or entity mentioned by name (n = 4). Otherwise, participants used “the state” or “the federal government” generally. The participants that were adamant about governmental regulation were from all three communities, but there appeared to be some nuance in how they discussed the need for regulation. For instance, participants from one community seemed to express more reservations and couch their suggestions for regulation and enforcement in statements like, “I don’t think a government agency should have to do that,” “states should have more power and they should be more involved,” and “I would hate to say you have to have a state monitor there 24/7.”

Education and Outreach Needs

The final category of actions that participants described as being necessary to address PFAS in their communities related to increased education and outreach to various audiences. Slightly less than half of participants (n = 15, 11 female and only 4 male) described an ongoing need for broad education and outreach. They perceive a need to “publicize it,” increase “public awareness,” and help people “wake up” to the severity of the PFAS issue in their community. Interestingly, participants seemed to be illustrating these outreach efforts in the abstract, something more appropriate for other individuals or groups to address, not necessarily something they personally felt they could or should do. For instance, one participant from Pittsboro lamented that people in his neighborhood still have limited awareness of PFAS, but did not feel he was a capable messenger for this type of outreach, “It’s shameful that even the people in my neighborhood aren't being told, but I can't be the crier for the town. I'm not a town crier!” Two participants suggested that state and local health departments should be leading more comprehensive outreach efforts about PFAS. Still, overall, participants discussed the general

need for increased awareness among the public so that, as one participant from Pittsboro said, “it would get the attention that it deserves from people who can do something about it.”

Nine participants communicated a specific need for increased education and outreach to healthcare providers in the river basin. Each of them recounted trying to share their report back letters and personal PFAS measurements with their healthcare providers. And while some participants described their providers positively, “He's a very good doctor, but they don't know what to do,” others described being met with disinterest, a lack of understanding, or having the topic outright ignored. Participants felt that some doctors and nurses do not “seem to be very well versed” in PFAS and surmised that they do not receive training in environmental health during medical school, saying, “they’re just not generally knowledgeable about our exposure to all these [PFAS],” and “a lot of them may not even understand the chemicals very well.” To address this, multiple participants suggested outreach to providers that might address the “lack of education” they feel their doctors receive, which would help them talk to their patients about PFAS, order tests based on PFAS blood levels, “kind of keep an eye on things” when a patient has known or suspected PFAS exposures. One participant from Pittsboro felt that:

> It should be a standard thing where [providers] should, during any consultation, should say, ‘Hey! Listen! Would you be open to getting this test done? Because the levels here are blah blah blah,’ some kind of standard thing, like for lead… but I don't think physicians are promoting it or talking about it. They don't get trained in it, that's for sure. But still, I do think that [PFAS] should be something that should be more widely known.

Seven participants from the middle and lower river basin explicitly identified the need for outreach *to* them and their communities, particularly related to increasing “transparency” and rebuilding trust in their drinking water infrastructure. Participants from the lower Cape Fear

described wanting to see more frequent, consistent access to information from and about their municipal drinking water provider, suggesting things like newsletters and information on their monthly bills showing "how much of a percentage [of PFAS] has been removed" in order to know "if in fact that water is clean or am I still drinking the water I was drinking 25 years ago." Similarly, participants from the Fayetteville area reported wanting more information on how the filters they have been provided with work, their efficacy, and if the company is "testing it correctly." Perhaps more interestingly and importantly, many participants told stories or made comments that were not part of a specific conversation about educational and outreach needs for their community but were directly related to the idea that increased outreach is a way to address the PFAS issue in their community. For example, some people had questions or potential misconceptions about their own drinking water; one person, using a Chemours-provided filter, revealed that their water comes out of the faucet "grayish black," they "don't know what's going on there," but have been told "it's within the limits" when they tried to ask for help. Four participants described actions they take to make them feel more confident in drinking their filtered water. One remarked that they "leave our tap on a for a while and let it run" before using it to drink or cook," and three others mentioned heating the water to remove additional PFAS, despite a lack of scientific evidence for the efficacy of either method. Some participants discussed questions they had or things they wonder about related to PFAS in their communities, which have answers that could currently be addressed by researchers, public health educators, or healthcare providers. For instance, multiple people wondered, during interviews and member checking emails, "where the [PFAS] sources, especially locally, have been identified," and the ability to see areas with PFAS contamination on a map. Another from the lower Cape Fear wanted to know where their "drinking water is even coming from." It is possible that the

resources already exist that would address the questions and outreach needs participants described, but if people who are engaged with PFAS enough to simultaneously be participants in at least two PFAS research studies have not seen or do not know where to find the information, it should be instructive for the research and environmental health communities that more outreach may be needed.

Discussion

The goal of this study was to understand PFAS exposure in the Cape Fear River basin using a methodology that allowed for a richer description that complements data on quantitative levels of PFAS in participants' bodies and communities. All participants are currently enrolled in an ongoing PFAS health study, which allowed for the exploration of how research participation and report back contributes to EHL—knowledge, efficacy, and behaviors—and to their PFAS exposures experience in their own words. Given this study's pragmatic worldview, participants were asked about structural changes needed to address PFAS contamination in their communities to identify potential opportunities so that researchers, public health professionals, state institutions, and other actors working in the PFAS space may better support residents.

The PFAS Exposure Experience

It is important to ground the story of environmental contamination in the authentic, affective feelings of love and appreciation for their community expressed by all participants in this study. It serves as a reminder that PFAS contamination is not happening in a vacuum or on an individual by individual, measurement by measurement basis, but is situated within communities and ecosystems for whom participants care deeply. This inherently impacts how each participant came to learn about PFAS, made sense of the contamination, interpreted their

PFAS measurements, made risk reduction decisions, assigned blame, and determined what is needed to solve the issue more broadly (Carrera et al., 2018; Edelstein, 2018). Of note, some participants felt that conducting these interviews and allowing them to tell their story about PFAS exposure was "doing a service" for them. One expressed that his community's story may be "kind of atypical, unusual, niche interest" for research, but telling their stories "matters tremendously to the people who live here." One participant asked during member checking if they would be able to read the final research paper. Multiple participants ended their interviews saying things like, "now go get the word out," urging the researcher to "keep fighting the fight for us," expressing hopefulness that this study, as part of a larger research effort, might "do something great" for their community.

While the love of their community was consistent across participants, the way they perceived and situated risks from PFAS relative to their lives varied among and within communities, reiterating that the exposure experience is distinctly heterogeneous (Altman et al., 2008; Carrera et al., 2018). Moreover, participants in this study described feelings and behaviors that iteratively situated and moved them along the entirety of the toxicity continuum (Renfrew & Pearson, 2021). This was evidenced by the participants who described the Suffering-based fears and worries about future PFAS-induced illnesses, while also describing feelings of Resignation or downplaying their risks because of their age. One participant's response to their member checking email noted their surprise to "hear of similar experiences from other study participants" regarding the complexity of experiencing and responding to PFAS exposure. This aligns with previous research on other chronic, low-visibility environmental exposures, where people displayed multifaceted, sometimes seemingly contradictory feelings, risks, and behaviors related to exposure (Calloway et al., 2020; Goebel & Wardropper, 2023).

Within each community, participants described a range of perceived risks, an array of fears and worries, different decision-making processes, and various behaviors for reducing their risk from PFAS. For practical purposes, this implies that a river basin-wide engagement strategy, whether for research recruitment or general outreach, may not be effective. Additionally, it is a reminder of the community-specific nature of EHL (K. M. Gray & Lindsey, 2019); individuals and communities start from different places along the toxicity continuum, and dynamically move along it differently, which inherently shapes how they acquire knowledge, evaluate their self-efficacy, and decide to enact behaviors related to PFAS. In that sense, participants in this study highlighted the nuance of EHL, reiterating that EHL scholarship remains "in an early stage," and there is not yet a best way to consistently assess and understand how people move through the constructs of EHL in practice (K. M. Gray & Lindsey, 2019).

This idea that a person's experience with exposure is complex and nuanced was highlighted each time participants expressed the feeling that people who do not live in their communities "don't get it," and cannot understand the full scope of the lived experience of PFAS exposure until someone "walks a mile in their shoes." That is, participants seemed to describe that the sum of living in a contaminated community with ongoing exposure to PFAS is greater than the sum of its parts as quantified by measurements of PFAS in the water, air, or soil, and participants' bodies. As one participant said of the actions his family takes in response to PFAS, "I mean it's no big deal, each isolated incident, but you add all this stuff up." Moreover, participants highlighted how residents and researchers inherently have different ways of defining exposure. The exposure experience framework originated in response to this phenomenon that members of contaminated communities and researchers have inherently different ways of knowing exposure (Altman et al., 2008; Brown, 1992, 1995b; Lawton, 2003; Rier, 2010).

Sometimes, these complement each other, but oftentimes these differences can be in conflict, and residents may feel that the lack of scientific consensus or enforceable regulations is invalidating, minimizing, or dismissive of their lived experiences (Adams et al., 2011; Barker, 2010; Brown, 1995b; Calloway et al., 2020).

In this study, these conflicting experiences manifested most often as participants made sense of PFAS levels in their bodies and drinking water in relation to health effects that do not yet align with official consensus from researchers or health agencies. This is not to say that they are incorrect, but rather to highlight that contaminated communities might use "popular epidemiology," and evaluate and interpret evidence differently or earlier than those outside the community (Brown, 1992). For example, one participant said of seeing their PFAS measurements from participation in the GenX Study, "it is just a confirmation of what you already think, it's like, 'oh somehow I was right'." Other studies with participants impacted by PFAS documented similar findings, where they identified a "disconnect" between government officials and participants in their "perception of validity of PFAS risks" and health effects (Calloway et al., 2020). The fact that the ability to detect compounds like PFAS in the environment has far outpaced related medical and regulatory guidance (Boronow et al., 2017) likely contributes to these disconnects between "experts" within institutions and residents of contaminated communities—residents may be "sure" that PFAS levels in the environment are related to health impacts well before there is scientific or regulatory consensus for it.

Report back for Exposure Reduction and Structural Change

In many ways, results from this study highlighted the GenX Study's stated commitment to and success in sharing data with its participants and their communities (Hoppin, 2023). Participants described the ways in which they used their letters and information from the GenX

Study to increase their knowledge about PFAS, enhance their self-efficacy and inform decision making, and in some cases combine that knowledge and efficacy to enact risk reduction behaviors, like changing their drinking water and talking with their doctors. Other studies have similarly shown how report back helped participants increase their knowledge of environmental hazards and take personal risk reduction actions (Brody et al., 2019; Korfmacher & Brody, 2023; Ramirez-Andreotta et al., 2016a, 2016b). Some, though fewer, studies have documented examples of a connection between report back and the types of public behaviors (Stern, 2000) that contribute to reducing collective exposure and risk (Altman et al., 2008; Brody et al., 2019; Hernick et al., 2011; Korfmacher & Brody, 2023). Some participants have used their report back materials to work with advocacy organizations and become more engaged in local politics (Brown et al., 2012). Brody et al. (2009) documented participants' use of report back materials to advocate for changes to city planning permits that would reduce emissions from local oil refineries. Importantly, however, the authors note that their research, and subsequent report back, was framed by a larger policy goal from the outset (Brody et al., 2009), reflecting a larger push to situate EHS research within policy structures (L. F. Davis & Ramírez-Andreotta, 2021). Still, this study highlights an area of opportunity as report back continues to become more common (Korfmacher & Brody, 2023), and more EHS researchers situate their work relative to policy goals and environmental health actions (Brody et al., 2009; L. F. Davis & Ramírez-Andreotta, 2021; Korfmacher & Brody, 2023).

Participants in this study described appreciation and the "privilege" of having access to the information provided by the GenX Study and their report back letters, and they also expressed feelings of resignation, having limited agency, and being "stuck" now. That is, participants were able to enact some individual level risk reduction through private behaviors,

and none of them reported needing help choosing a water filter for their homes, for example. Still, they described not knowing what to do beyond that—how to get PFAS out of their bodies, how to ensure environmental remediation removes PFAS, or how to make sure progress to more broadly address the PFAS in their community will indeed "happen in our lifetimes." Moreover, when asked what was needed to solve the issue, participants did not describe private, individual-level behaviors; they described a need for increased collective effort from researchers and governmental organizations to generate actionable data, disseminate information, and enact and enforce protective policy measures. Oksas et al. (2022) had similar findings from a study looking at the perspectives on report back and collective actions among biomonitoring participants who reported wanting to be able to take more actions that had collective, community-level impacts. Importantly, the authors emphasize how this is "shifting the burden" of overall exposure reduction from individuals taking individual actions, to regulators and institutions via the collective pressure of individuals (Oksas et al., 2022). In a different study, Giannini et al. (2018) found that most participants reported having not taken any steps toward sharing their report back information for collective engagement. This, however, highlights the potential for report back to better support these behaviors.

If report back is indeed a tool for building and supporting EHL (L. Davis et al., 2018; Korfmacher & Brody, 2023; Oksas et al., 2022; Perovich et al., 2018; Ramirez-Andreotta et al., 2016a; Sandhaus et al., 2018), and if EHL is truly meant to facilitate behaviors that encompass Gray's (2018) outer circle of community change, then there is an opportunity to more intentionally design research and report back efforts to support both individual behaviors and collective behaviors (Brody et al., 2019; Oksas et al., 2022). Indeed, even in Finn & O'Fallon's (2017) first publication on the subject, they outlined EHL as a way for "individuals and

communities to exert control over the environmental exposures," and this requires situating EHS research, and subsequently report back, within larger societal systems and structures. For example, in this study, many participants mused "how did this happen in the first place," and "why haven't [PFAS manufacturers] been shut down?" Additionally, participants admitted to being unsure how local, state, and federal level PFAS policies relate to one another, and uncertainty as to who is responsible for drinking water regulation and enforcement in North Carolina, to whom they might apply pressure to enact policy change. During member checking, one participant asked, "is the Governor aware of the problem?" These feelings, which were expressed by participants across all three communities, when taken together speak to the "scientific ignorance of this chemical class" that facilitates the United States' reactionary approach to chemical regulation (Ohayon et al., 2025), and an unfamiliarity with the public policy discourse (Oksas et al., 2022) that is necessary for applying collective pressure and enacting community-level interventions for environmental hazards (Cardona Cordero et al., 2023). Thus, there is an opportunity for report back efforts to adopt a broader approach that, in addition to clearly presenting the study's data, would provide a deeper contextual understanding of an environmental issue, and build capacity to contribute to collective, structural changes (Boronow et al., 2017; Calloway et al., 2020; McNew-Birren & Gaul-Stout, 2022; Oksas et al., 2022).

Given that most exposures require systems changes through both individual and collective actions, an intentional approach to report back can provide information and acknowledge the distinction between exposure reduction through individual behaviors and the types of corrective actions that require collective effort (Brody et al., 2019; Korfmacher & Brody, 2023; National Science and Technology Council, 2024; Oksas et al., 2022). This draws

on two established concepts related to public engagement with science. The first being scientific civic engagement, which frames the ways in which people use their scientific knowledge to participate in solution-oriented political processes (Feinstein, 2011b; Levy & Zint, 2013; McNew-Birren & Gaul-Stout, 2022; Rudolph & Horibe, 2016). The second related concept is Pielke's (2007) "honest broker" approach to science communication, where scientists provide the public with broader contextual information about relevant actors, systems, and policy structures, and allow participants to choose how to interpret, engage, and act upon that information. Although some researchers may perceive this as approaching advocacy, Ohayon et al., (2025) note that scientific research is already "intimately entangled with politics and economics in ways that promote or constrain social change" (p. 5). Thus, a broader approach to report back simply acknowledges the reality that EHS research and report back are already situated within those systems and allows people to make more informed decisions within them. Goho (2016) reiterated that to truly abide by respect for personal autonomy of participants, report back should "enable informed activism about community- or society-wide" environmental hazards.

In practice, this more intentional approach to report back that acknowledges our collective relative ignorance about the systems and structures in which environmental contamination occurs, may adopt a variety of approaches. For example, one such opportunity might be to demystify regulatory and political processes related to the environmental hazard. Previous studies have shown the potential for residents impacted by PFAS to pressure lawmakers for increased PFAS testing, increased PFAS research funding, and the establishment of clinical guidance for PFAS (Ohayon et al., 2025). Oksas et al. (2022) made recommendations for how future report back efforts might support this, including prompts and "consistent messaging" if

people want to contact lawmakers, reminding people to register and vote for candidates who supports environmental health, and suggesting strategies for applying pressure on companies as a consumer. These and similar strategies may help address some questions like those of participants in this study who reported being unsure where their municipal drinking water is currently coming from and who oversees it, highlighting a potential opportunity to provide participants with specific information on relevant drinking water infrastructure and regulations.

Another strategy may be to provide complementary materials or resources for healthcare providers. Some participants in this study (n = 12) reported having shared their report back materials with their providers, while others specifically said they never thought to do so. It has been well documented that healthcare providers receive limited information on EHS concepts during their medical training (Gordon et al., 2023; Rha et al., 2024), and participants in this and other studies reported feeling that their healthcare providers lacked awareness and understanding of PFAS when they tried to discuss it (Calloway et al., 2020). One participant said in their member checking email,

> I would like to see better dissemination of [PFAS] risks to healthcare entities in this area. My doctors at UNC have never addresses these risks or monitored me for damage. Frequent rechecking of levels for emerging health problems would be useful.

Moreover, previous studies have shown participants choosing not to take report back materials to their doctors (Giannini et al., 2018). Thus, in acknowledgement of this current system, future report back efforts might contribute to “new scientific infrastructures” that helps patients and providers take a more proactive approach to monitoring for health effects related to PFAS (Korfmacher & Brody, 2023; Ohayon et al., 2025).

Limitations

This study explored the lived experience of PFAS contamination for communities in North Carolina's Cape Fear River basin, specifically those who chose to participate in a long-term PFAS health study. The goal was to give a voice to residents impacted by PFAS contamination, describe their experience with exposure, understand their environmental health literacy, and generate practical recommendations for how researchers engage with participants and members of contaminated communities. More broadly, this study highlights a gap between what EHS researchers and participants gain from exposure science—in the information they perceive as being generated, the implications of the findings, and the contributions to their wellbeing.

Given the pragmatic underpinnings of this study, it was inherently limited by scope and resources. First, this study's participants were already members of a self-selecting subsample of Cape Fear River residents who chose to participate in the GenX Study. As such, the perspectives and experiences expressed during interviews may not be shared by all residents of upper, middle, and lower parts of the river basin. Relatedly, having drawn from this relatively small sampling frame (N = 994), using only one method of recruitment (email), and requiring the use of Zoom to participate may have limited response and participation rates, especially for those with limited access to the internet. Moreover, the recruitment and consent materials were only available in English, as this study did not have the resources for Spanish language translation and interpretation services. Still, 136 people (13.7%) filled out the online consent form, and of the 47 people subsequently invited to participate, 33 people (70%) ultimately participated in an interview, and participants were racially diverse than is often expected in EHS research (Carrera et al., 2018; George et al., 2004; Oh et al., 2015).

Conclusion

At present, there is limited but growing social science literature on PFAS exposure and its relationship to report back. There is a continued need to study how to improve report back methods (Korfmacher & Brody, 2023), the relationship between report back and EHL (Boronow et al., 2017), and the specific context that PFAS exposure creates. Additionally, given the contextual nature of exposure to environmental hazards and EHL (K. M. Gray & Lindsey, 2019), each study is inherently unique to its own context and thus each additional study adds nuance to the overall picture of report back, EHL, and PFAS. Moreover, methodological choices generate different data and subsequent conclusions specific to that study. As such, this study had a unique opportunity to provide important insight on PFAS exposure and research participation in a geographically bounded part of North Carolina Other studies have explored the PFAS exposure experience using interviews but had distinctly different participant populations than this study. For example, one study's (Calloway et al., 2020) participants (n = 9) were government officials and leaders of PFAS advocacy organizations from seven different US states, an inherently different sampling frame from this study. Importantly, the strength of their study was its production of tangible recommendations to address the PFAS-related needs identified during interviews and became the impetus for this study's third research question. More broadly, other research (Adams et al., 2011; Judge et al., 2016; Ramirez-Andreotta, 2016) has investigated the exposure experience as it relates to participation in EHS studies similar to the GenX Study, but not with a focus on PFAS health research as this study did. Thus, this study generated findings and recommendations that—although they may have broader implications—are unique to and grounded in the lived experiences of communities impacted by PFAS in the Cape Fear River basin. Data generated from this study may make important contributions to the literature by

having focused on a specific geographic area with a common environmental exposure, and whose participants are actively enrolled in an ongoing PFAS health study. These findings give researchers new insights into what people living with PFAS contamination perceive as relevant knowledge, skills, and actions needed to address the issue, thereby informing report back and community engagement to better support participants' information needs, as well as their capacity to contribute to individual and collective level behaviors to address their exposures.

CHAPTER 4:

CONCLUSIONS

A branch of environmental health sciences research aims to characterize how and in what quantities people are exposed to environmental hazards (Lioy, 2010; Schulte & Hauser, 2012). Many of these studies rely on people outside academia to participate and provide a range of environmental, biological, or behavioral data (Creager, 2018; Ladeira & Viegas, 2016; National Resource Council, 2006). Increasingly, such studies share results with their participants, including measurements of individual chemicals, aggregate findings, and comparisons to relevant regulatory thresholds and guidance values (Korfmacher & Brody, 2023). This process of report back has been shown to support participants' knowledge and decision making related to environmental hazards (Boronow et al., 2019; Brody et al., 2018; Korfmacher & Brody, 2023; Morello-Frosch et al., 2009). Because report back can provide participants with increased access to personally relevant data, it is believed to be a tool for building EHL, by contributing to participants' knowledge, efficacy, and ultimately their behaviors to reduce exposure to an environmental hazard (Lindsey et al., 2022; Samon et al., 2023; Tomsho et al., 2022). Indeed, previous studies have shown connections between receiving information through report back and indicators of participants' EHL (Lebow-Skelley et al., 2020; Oksas et al., 2022; Ramirez-Andreotta et al., 2016a). The ways people encounter and experience environmental hazards, and subsequently the ways in which they respond to them, are inherently variable across and even within communities. Because this environmental exposure experience is complex and nuanced (Adams et al., 2011; Brown, 1992; Judge et al., 2016), research on report back and EHL will fundamentally be unique to the participants and communities in which it occurs.

As such, this dissertation research was designed to explore the relationships between research participation, report back, and EHL specifically within the context of a defined geographic area and known environmental contaminant. By only recruiting participants from the Cape Fear River basin who are also participants in the GenX Study, this research aimed to intentionally generate findings about the experience of PFAS exposure and its intersection with report back and EHL. Moreover, by using tenets of an explanatory sequential mixed methods design, this dissertation research was designed to produce both quantitative and qualitative data to tell a more comprehensive picture of the phenomena. Indeed, both studies highlighted the importance of report back, efficacy, and risk perception in relation to participants' private and public behaviors, and thus ultimately their EHL. Overarching themes that crosscut the two studies, along with limitations and overall significance are outlined below.

Report Back and Efficacy

As report back initially gained prominence in EHS research, some academics expressed apprehension that sharing results would cause undue worry or stress for participants (Brody et al., 2007; Brown et al., 2010; Korfmacher & Brody, 2023). Some felt that sharing for chemicals that lack clinical recommendations, regulatory guidance, or threshold values that can help contextualize participants' levels—like PFAS—might be particularly worrisome or confusing (Brown et al., 2010; Ohayon et al., 2017). Yet, results from this research aligned with previous studies that documented participants' desire and appreciation for report back, regardless of limited research context or scientific uncertainty (Altman et al., 2008; Brody et al., 2014a). Indeed, in responses to both the survey questionnaire and interview questions, participants reiterated that access to their personal PFAS levels and report back was a driving factor in their motivation to participate in and satisfaction with the GenX Study. In responses to open-ended

survey questions, 48% of responses about motivation and 75% of the responses about satisfaction, as well as responses from 73% of interview participants related to the ability to learn one's PFAS levels via report back, and 89.9% of survey respondents said they would be "quite a bit" or "completely willing" to participate in future PFAS research. Importantly, 55% of interview participants did express fear and worry related to the PFAS levels presented in their report back letters. Still, none of the survey responses about dissatisfaction and none of the 33 interview participants expressed regret at having received their measurements or having participated in the GenX Study.

Instead, survey and interview responses seemed to create a nuanced story between report back, efficacy, and actions. Looking only at regression analyses, efficacy measures were minimally predictive of behaviors, as self-efficacy was only related to public non-advocacy behaviors (e.g., participation in future research) and response efficacy was only predictive of private behaviors (e.g., filtering water). But there appear to be more complex interactions between participation in the GenX Study, the information participants received, and how they have chosen to respond to PFAS. In general, participants were grateful for report back and were able to enact some information seeking and risk reduction behaviors, but ultimately felt limited in the extent to which they could utilize report back information and address PFAS contamination. In survey responses, with 3 indicating "some" and 4 indicating "quite a bit," participants reported feeling at least some self-efficacy ($\bar{x}$ = 3.78) as result of having this information, and 20 interview participants (61%) mentioned the new information they were able to identify and access using the letter. For instance, the survey asked participants about their self-efficacy related to identifying PFAS blood levels and understanding health effects, and in the open-ended responses, 20 survey participants reported intention to or having already shared

report back information with their healthcare providers, as did 12 interview participants. In the open-ended survey responses to the question about dissatisfaction, however 71% of responses related to wanting more breadth of information (e.g., sources of PFAS, more clinical measurements), depth of information (e.g., what do these numbers *mean*), and more support for enacting behaviors (e.g., what do I do now). Of note, Likert scale survey questions measured self-efficacy specifically in relationship to the report back letter and study information, while response efficacy and reported behaviors were measured with a broader set of known PFAS risk reduction actions.

Among these actions, survey participants felt that changing personal consumer habits (private, $\bar{x} = 3.74$) and working with local advocacy organizations (public, $\bar{x} = 3.65$) were the most effective ways of preventing PFAS exposure. And while 64.5% of survey respondents reported changing their purchasing habits at least "quite often," only 18.9% of respondents reported working with local organizations with the same frequency. Although, statistically, the response efficacy values were significantly correlated with each respective behavior, it may highlight a contradiction between what types of behaviors—private vs. public—participants feel they are able to enact effectively. Interestingly, response efficacy was a significant predictor of private behaviors—like changing drinking water—in the regression models, and 77.9% of survey respondents reported using filtered water "quite often" or "all the time," yet 44.8% of respondents felt it was at most only "somewhat" effective at preventing PFAS exposure. Interview responses reinforced this nuance, as all 33 participants reported having changed their drinking water source to reduce PFAS exposure, even as some wondered if their filters were working effectively or if "the water may be even worse now."

In both the survey and interviews, there was an overarching sentiment of increased but limited efficacy and agency. In open-ended survey responses to a question about dissatisfaction, 84 participants (24.5%) discussed not knowing what steps to take next, and during interviews, 13 participants (39%) admitted to not using the information from the GenX Study at all, and 19 participants (58%) expressed a lack of self-efficacy or response efficacy, using words like "powerless" and "stuck" to describe taking next steps and enacting protective behaviors. Importantly, these efficacy-related sentiments spoke to both private and public behaviors. For example, survey and interview participants reported wanting strategies for reducing PFAS body burden (private), to mitigate the exposure they already have. In the survey, 29 respondents (8.5%) reported dissatisfaction with the lack of institutional accountability and oversight, and interview respondents reported wanting to see increased corporate responsibility (n = 14, 42%) and government regulation (n = 20, 61%) to address PFAS contamination. These are the types of structural changes, however, that tend to rely on public behaviors and collective pressure to generate progress. Yet in survey responses, participants reported doing these types of behaviors (e.g., working with advocacy organizations, calling elected officials) less often than private behaviors. For instance, 22.5% and 18.9% of participants reported contacting elected officials or working with local advocacy groups, respectively, "quite often" or more as compared to changing drinking water (78.9%), avoiding local foods (32.7%), or changing purchasing habits (64.4%) "quite often" or more.

Both studies in this dissertation highlighted a complex relationship between sharing information about an understudied class of chemicals, perceptions of efficacy, and risk reduction behaviors. It was clear that both survey and interview participants wanted access to the information provided by the GenX Study's report back, even when they acknowledged its

limitations, aligning with previous research that measured participants' feelings and experiences with report back (Altman et al., 2008; Brody et al., 2014a). Neither regression models nor in-depth interview responses told a linear story about efficacy and actions, as perceived efficacy did not always seem to drive participants' behaviors, and participants described different patterns for private and public behaviors. Public behaviors drive collective action (Stern, 2000) and thus put collective pressure on corporations and institutions to enact the types of accountability and oversight measures described as necessary by survey and interview participants (Korfmacher & Brody, 2023; Ohayon et al., 2025; Oksas et al., 2022). These measures are ultimately what are needed for the community change circle of EHL (K. Gray, 2018), and they rely on both the efficacy of individuals and a collective, community efficacy (L. M. Gibson et al., 2022). Results from this dissertation's two studies hopefully contribute to a larger conversation about how report back and engagement with study participants might support their broader efficacy through information, resources, and strategies needed for effective private and public risk reduction actions (Korfmacher & Brody, 2023).

Exposure Experience and Risk Perception

The field of medical sociology first framed the ideas of illness experience and subsequently environmental exposure experience, where it was acknowledged that the embodied reality of exposure (or illness) is complex and the way it is characterized and defined by those living with it may differ from how academics would (Bird et al., 2010; Brown, 1992; Lawton, 2003; Rier, 2010). That is, the quantitative measurements of a contaminant in the environment, its presence in biological samples, documented rates of certain health effects, or preventive regulatory policies can range from supporting, reinforcing, lagging, or even contradicting the ways in which members of contaminated communities feel, see, and characterize contamination

(Adams et al., 2011; Altman et al., 2008; Barker, 2010; Brown, 1995b; Calloway et al., 2020). One aspect of this might be the different ways in which residents and "experts" perceive risks from an environmental exposure.

In this study's survey, each respondent was inherently already a participant in at least two PFAS research studies, but risk perception was not a predictor of future research participation as a type of public behavior. In contrast, risk perception was a significant predictor of both private and public advocacy behaviors in the regression models. However, the regression used a composite variable for total average risk perception that accounted for perceived personal and communal risk because the two measures skewed high ($\bar{x}$ = 4.17 and $\bar{x}$ = 4.37, respectively) and were very highly correlated to each other (.848, p <.001). When looking at the individual measures of risk perception, there was a statistically significant difference (-.198, p <.001) between average personal risk perception and the average perceived risk to their community members. That is, even though survey respondents reported elevated risk perception in both categories, they felt the risks from PFAS were higher for people in their community than for themselves. Interview responses provided interesting context and potential explanation for this, as participants' described emotions that spanned along the Toxicity Continuum (Renfrew & Pearson, 2021), even during the same interview. For example, 25 interview participants (76%) expressed sentiments indicative of Invisibility (n=7) or downplaying (n = 6), and 12 expressed Invisibility *and* downplaying, all of which imply lower perceived risks from PFAS. Yet, each of those 25 participants *also* expressed fears and worries indicative of elevated perceived risks and all 25 reported taking exposure reduction actions and changes to their lifestyle in response to PFAS. Thus, even those who seemed to describe lower perceived risks from PFAS due to lower

importance, visibility, or severity also made statements and reported taking actions that are indicative of higher risk perception.

Given the way interview participants highlighted the nuance and complexity of their own risk perception, taken in addition to the predictive capability of risk perception in the linear regression models, it speaks to both the importance of accounting for risk perception and the difficulty of disentangling risk perception from other constructs when characterizing EHL. It also echoed prior research that documented the sometimes-confounding interplay of "experts'" assessments of risk, participants' assessments of risk, and participants' risk reduction behaviors, especially in relation to ongoing or low visibility contaminants (Calloway et al., 2020; Goebel & Wardropper, 2023; Vyner, 1988). Moreover, it highlights the complexity of the broader experience of PFAS exposure, as not everyone in the Cape Fear River basin, let alone in a given community or study cohort seemed to perceive or experience PFAS contamination the same way. For instance, the location control variables for each community were not significant predictors in any of the regression models, but interview responses demonstrated overarching differences in lived experiences among the communities (e.g., relationship to nature, learning about PFAS, types of exposure reduction, participation in research, and health effects). Results from this dissertation lend credence to the notion that exposure and health data generated by EHS research likely does not fully capture the embodied experience of exposure (Edelstein, 2018; Vyner, 1988), as well as the importance of mixed methods for generating complementary data to better understand and explain what exposure truly means according to those who live with it (J. W. Creswell, 2013; Edelstein, 2018; Feilzer, 2010; Vyner, 1988).

Limitations

This dissertation, as with all research, has fundamental limitations. First, the survey questionnaire used in the first study was not intentionally designed at the outset for this dissertation research or the explicit purpose of characterizing participants' EHL. As such, some constructs were inherently operationalized imperfectly, thereby limiting the models' predictive capabilities. For example, the discrepancy between self-efficacy measures and response efficacy measures described above. Only adults were recruited for both studies, and participation in the interviews required the use of email and Zoom. As such, both studies excluded responses from younger GenX Study participants, and certain people may have limited internet accessibility to participate in the second study. More broadly, the GenX Study used a specific sampling frame for each of the three communities in the Cape Fear River basin, and within each of those, GenX Study participants were ultimately a self-selecting sample. Thus, participants in this study are not representative of all residents of each community or the river basin overall. These factors limit the generalizability of findings from this research. After establishing the nuanced nature of environmental hazards and exposure (Adams et al., 2011; K. M. Gray & Lindsey, 2019; Hoover, 2019), however, related research findings will always be specific to the context in which they were generated. Relatedly, this research sought to make specific claims about research participants in the GenX Study and residents of North Carolina's Cape Fear River basin, not communities impacted by PFAS in general.

Significance

This research contributed to the growing body of literature related to report back and EHL, specifically related to chemicals like PFAS with limited toxicity data or regulatory guidance. Previous research on the environmental exposure experience, including those focused

on PFAS (e.g., Calloway et al., 2020; Judge et al., 2016), used different methodologies and sampling frames that created space for this study to generate complementary data. That is, other studies did not draw participants from one geographic region with known PFAS contamination and an ongoing PFAS health study. Prior research generated data about PFAS report back and household exposures (Adams et al., 2011), PFAS report back and factual knowledge comprehension (Giannini et al., 2018), PFAS exposure in other countries (Banwell et al., 2021; Menegatto et al., 2022), the experience of PFAS exposure among those in government and advocacy organizations (Calloway et al., 2020), and the formative assessment of PFAS report back materials (Oksas et al., 2022). Moreover, while other studies have used focus groups (Oksas et al., 2022), interviews (Judge et al., 2016; Ohayon et al., 2025), and surveys (Giannini et al., 2018), this research as a whole was unique in its mixed methods design, and each of the studies herein contributed to a distinct niche by focusing on PFAS health study participants from the same region. As such, findings from this study can directly inform the way the GenX Study engages with its participants moving forward, including through report back messaging and materials. Additionally, it adds another example of research framed by EHL and exposure experience in which to investigate and characterize the impact of PFAS exposure beyond what EHS studies can capture with biological or environmental measurements.

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APPENDICES

Appendix A

Survey Packet materials: Cover Letter and Four-Page Survey

November 12, 2022

Dear GenX Exposure Study Participant:

You are receiving this packet because you or someone in your household has participated in the GenX Exposure Study, led by Dr. Jane Hoppin, at North Carolina State University. Our names are Katy May and Andy Binder, and we are researchers with the Community Engagement Core at Center for Human Health and the Environment, also located at North Carolina State University.

We are conducting an independent evaluation of the community engagement efforts related to the GenX Exposure Study. The researchers conducting the GenX Exposure Study are not involved in this evaluation study. In our only discussion with those researchers about this study, we requested a list of mailing addresses – but not names or any other identifying information – of participants in the GenX Exposure Study like you.

You are being asked to complete a survey for research purposes. The survey is about your experiences as a participant in the GenX Exposure Study. Completing this survey is voluntary, and you can choose not to participate.

You must be 18 years of age or older, reside in the United States, **and be a participant in the GenX Exposure Stud**y to participate in this study. We would like to hear from all different types of people. If there is more than one member of your household who is 18 or older and has participated in the GenX Exposure Study, we invite the person who had the **most recent birthday** to complete the survey.

There are minimal risks associated with your participation in this survey. We will be reporting the results of this study to GenX Exposure Study researchers and in a research article to be published in an academic journal. In both cases, we will not be reporting individual responses; all research reports will only include aggregate data. You are receiving a new $2 bill–included with this package–in exchange for your participation.

You may notice an identification number printed on the back of the questionnaire we have included in this mailing. This identification number is included so that we can remove your address from the mailing list when your questionnaire is returned. At the end of our data collection period, the list of addresses and identification numbers will be destroyed so that addresses can never be connected to responses.

If you have any questions about the survey, how it is implemented, or the research study, please contact the researcher, Andrew R. Binder, at arbinder@ncsu.edu and (984) 664-1973. Please reference study number 25440 when contacting anyone about this project.

If you have questions about your rights as a participant or are concerned with your treatment throughout the research process, please contact the NC State University IRB Director at IRB-Director@ncsu.edu, 919-515-8754, or fill out a confidential form online at https://research.ncsu.edu/administration/participant-concern-and-complaint-form/

By completing and returning the enclosed paper questionnaire, you acknowledge your consent to participate in this research study.

Hearing from you and your experience as part of the GenX Exposure Study is very important to us. The results from this study will help improve future environmental health research and outreach. If you agree to participate, you will need to complete the enclosed questionnaire and return it to us using the enclosed stamped envelope. And even if you choose not to participate, we appreciate your time and attention.

Sincerely,
Katlyn May
Doctoral Student, Ph.D. program in Learning and Teaching in STEM
Co-Director, Community Engagement Core

Andrew R. Binder, Ph.D.
Associate Professor of Communication
Co-Director, Community Engagement Core

NC STATE UNIVERSITY

EVALUATION SURVEY FOR GENX EXPOSURE STUDY

Recently, you received a letter from Dr. Jane Hoppin, the lead researcher on the GenX Exposure Study, with results from an analysis of your blood sample. We'd first like to ask you some questions about your blood results and the letter you received.

1. **How much <u>new information</u> did the letter provide for you personally?**

   ☐ No new information at all ☐ A little ☐ Some ☐ Quite a bit ☐ A lot of new information

2. **Whether it was new or not, how <u>useful</u> was the information presented in the letter?**

   ☐ Not useful at all ☐ A little ☐ Somewhat ☐ Quite useful ☐ Extremely useful

3. **Based on the letter you received with your PFAS blood results, how much were you able to…**

	Not at all	A little	Some	Quite a bit	Completely
Identify the sum of PFAS from your blood sample?	☐	☐	☐	☐	☐
Learn about new medical recommendations for different levels of PFAS in blood?	☐	☐	☐	☐	☐
Understand the blood results provided in the stripcharts?	☐	☐	☐	☐	☐
Describe the objectives of the GenX Exposure Study?	☐	☐	☐	☐	☐
Find answers to the questions you have about PFAS and their health effects?	☐	☐	☐	☐	☐

We'd like you to think about the past few years and your experiences in the GenX Exposure Study since it started.

4. **Thinking back, why did you sign up to participate in the GenX Exposure Study?**

_____

_____

5. **What have you felt the <u>most satisfied</u> with from the GenX Exposure Study?** _____

_____

6. **And what have you felt the <u>least satisfied</u> with?** _____

_____

7. **In general, how would you describe your feelings as a participant in the GenX Exposure Study? How much have you felt…**

Informed	☐	☐	☐	☐	☐	Uninformed
Disrespected	☐	☐	☐	☐	☐	Respected
Valued	☐	☐	☐	☐	☐	Not valued
Dissatisfied	☐	☐	☐	☐	☐	Satisfied

8. **Here are some statements people might make about the GenX Exposure Study. Could you tell us how much you agree or disagree with these statements?**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
Participating in this study benefits me personally.	☐	☐	☐	☐	☐
Participating in this study benefits the researchers at NC State University.	☐	☐	☐	☐	☐

9. **Could you tell us how much you agree or disagree with these other statements?**

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I understand the risks and benefits of contributing to the GenX Exposure Study.	☐	☐	☐	☐	☐
I feel that the objectives of the study have been clearly communicated by the researchers.	☐	☐	☐	☐	☐
The study provides answers to the questions I have about PFAS contamination.	☐	☐	☐	☐	☐

10. **How much risk do you think PFAS presents to…**

	None at all	A little	Some	Quite a bit	A lot
… you and your health?	☐	☐	☐	☐	☐
… the health of residents in your community?	☐	☐	☐	☐	☐

11. **On a scale of 0 (nothing) to 100 (everything you could possibly know), how much do you think you currently know about the risks of PFAS?**

Write a number between 0 and 100: _____

12. **On the same scale of 0 (nothing) to 100 (everything you could possibly know), how much do you feel you need to know about the risks of PFAS to make a decision about your health?**

Write a number between 0 and 100: _____

13. With all the different issues these days, it's impossible to keep track of them all. But can you tell us if each of the following statements about PFAS is true or false, or if you don't know?

	True	False	Don't know
All PFAS chemicals (including PFOS, PFOA, GenX) act the same way in humans and the environment.	☐	☐	☐
PFAS are substances that do not exist naturally and are only man-made.	☐	☐	☐
The National Academies report made recommendations about seven (7) PFAS found in people's blood.	☐	☐	☐
If GenX was not detected in my blood sample, then GenX was never in my body.	☐	☐	☐
By participating in a study like this one, people can learn if certain health conditions are caused by PFAS.	☐	☐	☐

14. How <u>effective</u> do you think each of the following activities is at preventing PFAS exposure?

	Not effective at all	A little	Some	Quite a bit	Completely effective
Not using unfiltered tap water for drinking and cooking.	☐	☐	☐	☐	☐
Avoiding food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)	☐	☐	☐	☐	☐
Not buying waterproof or nonstick products manufactured with PFAS.	☐	☐	☐	☐	☐
Contacting elected officials to reduce PFAS inputs to the environment	☐	☐	☐	☐	☐
Working with local organizations to do something about PFAS in your community.	☐	☐	☐	☐	☐

15. Regardless of how effective you think they are, how often have you done <u>any of the following</u> to prevent exposure to PFAS?

	Not at all	A little	Some	Quite often	All the time
Stopped using unfiltered tap water for drinking and cooking.	☐	☐	☐	☐	☐
Avoided food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)	☐	☐	☐	☐	☐
Quit buying waterproof or nonstick products manufactured with PFAS.	☐	☐	☐	☐	☐
Contacted elected officials to reduce PFAS inputs to the environment	☐	☐	☐	☐	☐
Worked with local organizations to do something about PFAS in your community.	☐	☐	☐	☐	☐

16. Based on your experience as a participant in the GenX Exposure Study, how willing would you be to sign up for …

	Not willing at all	A little	Somewhat	Quite a bit	Completely willing
Another health study related to PFAS?	☐	☐	☐	☐	☐
Another health study conducted by researchers at NC State University?	☐	☐	☐	☐	☐

The last few questions are about your background.

17. What is the highest level of education you have completed?

- ☐ Some high school
- ☐ Completed high school or GED
- ☐ Some college, technical, or trade school
- ☐ Completed four-year college with a bachelor's degree
- ☐ Completed a graduate or professional degree

18. The terms "liberal" and "conservative" may mean different things to people, depending on the kind of issue one is considering.

	Very liberal	Somewhat liberal	Moderate	Somewhat conservative	Very conservative
In terms of economic issues, would you say you are:	☐	☐	☐	☐	☐
In terms of social issues, would you say you are:	☐	☐	☐	☐	☐

19. How much guidance does religion give you in your everyday life?

☐ No guidance at all ☐ A little ☐ Some ☐ Quite a bit ☐ A lot of guidance

20. What was your sex assigned at birth?

☐ Male ☐ Female

21. What year were you born? _____

22. What is your race? Check all that apply:

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black
- ☐ Hawaiian or Pacific Islander
- ☐ White
- ☐ Something else: _____

23. What is your ethnicity? ☐ Hispanic or Latino ☐ Not Hispanic or Latino

24. Finally, please estimate your total 2021 household income before taxes, combining income from all household members, from all sources. In 2021, was your before-tax household income:

- ☐ $19,999 or less
- ☐ $20,000 - $49,999
- ☐ $50,000 - $89,999
- ☐ $90,000 - $129,999
- ☐ $130,000 - $149,000
- ☐ $150,000 or more

Appendix B

Mapping EHL and Additional Affective Constructs onto Survey Items

Environmental Health Literacy		
Objective Knowledge		
13A	But can you tell us if each of the following statements about PFAS is true or false, or if you don't know? ... All PFAS chemicals (including PFOS, PFOA, GenX) act the same way in humans and the environment.	1= True, 0 = incorrect or blank
13B	PFAS are substances that do not exist naturally and are only man-made.	1= True, 0 = incorrect or blank
13C	The National Academies report made recommendations about seven (7) PFAS found in people's blood.	1= True, 0 = incorrect or blank
13D	If GenX was not detected in my blood sample, then GenX was never in my body.	1= True, 0 = incorrect or blank
13E	By participating in a study like this one, people can learn if certain health conditions are caused by PFAS.	1= True, 0 = incorrect or blank
Self-Efficacy		
2	Whether it was new or not, how useful was the information presented in the letter?	1= Not useful at all, 5= extremely useful
3A	Based on the letter you received with your PFAS blood results, how much were you able to... Identify the sum of PFAS from your blood sample?	1= Not at all, 5= completely
3B	Learn about new medical recommendations for different levels of PFAS in blood?	1= Not at all, 5= completely
3C	Understand the blood results provided in the stripcharts?	1= Not at all, 5= completely
3D	Describe the objectives of the GenX Exposure Study?	1= Not at all, 5= completely
3E	Find answers to the questions you have about PFAS and their health effects?	1= Not at all, 5= completely
Response Efficacy		
14A	How effective do you think each of the following activities is at preventing PFAS exposure? ... Not using unfiltered tap water for drinking and cooking.	1= Not effective at all, 5= completely effective

14B	Avoiding food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)	1= Not effective at all, 5= completely effective
14C	Not buying waterproof or nonstick products manufactured with PFAS.	1= Not effective at all, 5= completely effective
14D	Contacting elected officials to reduce PFAS inputs to the environment	1= Not effective at all, 5= completely effective
14E	Working with local organizations to do something about PFAS in your community.	1= Not effective at all, 5= completely effective
	Private Behaviors	
15A	Regardless of how effective you think they are, how often have you done any of the following to prevent exposure to PFAS? ... Stopped using unfiltered tap water for drinking and cooking.	1 = Not at all, = All the time
15B	Avoided food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)	1 = Not at all, = All the time
15C	Quit buying waterproof or nonstick products manufactured with PFAS.	1 = Not at all, = All the time
	Public Advocacy Behaviors	
15D	Contacted elected officials to reduce PFAS inputs to the environment	1 = Not at all, = All the time
15E	Worked with local organizations to do something about PFAS in your community.	1 = Not at all, = All the time
	Public Non-Advocacy Behaviors	
16A	Based on your experience as a participant in the GenX Exposure Study, how willing would you be to sign up for ... Another health study related to PFAS?	1 = Not willing at all, 5= Completely Willing
16B	Another health study conducted by researchers at NC State University?	1 = Not willing at all, 5= Completely Willing
	Additional Affective Constructs	
	Subjective Knowledge	
1	How much new information did the letter provide for you?	1= No new information at all, 5= A lot of new information

9A	Could you tell us how much you agree or disagree with these other statements? ... I understand the risks and benefits of contributing to the GenX Exposure Study.	1 = Strongly Disagree, 5= Strongly Agree
9B	I feel that the objectives of the study have been clearly communicated by the researchers.	1 = Strongly Disagree, 5= Strongly Agree
9C	The study provides answers to the questions I have about PFAS contamination.	1 = Strongly Disagree, 5= Strongly Agree
11	On a scale of 0 (nothing) to 100 (everything you could possibly know), how much do you think you currently know about the risks of PFAS?	0 – 100
12	On the same scale of 0 (nothing) to 100 (everything you could possibly know), how much do you feel you would need to know about the risks of PFAS to make a decision about your health?	0 - 100
Risk Perception		
10A	How much risk do you think PFAS presents to ... you and your health?	1 = None at all, 5 = A lot
10B	the health of residents in your community?	1 = None at all, 5 = A lot
Perceptions of Research		
8A	Participating in this study benefits me personally.	1 = Strongly Disagree, 5= Strongly Agree
8B	Participating in this study benefits the researchers at NC State University.	1 = Strongly Disagree, 5= Strongly Agree

Appendix C

Exploratory Factor Analysis for All Items

	Question	Factor Loadings							
		1	2	3	4	5	6	7	8
3C	Understand the blood results…	0.793							
3B	Learn about new medical recommendations…	0.75							
3A	Based on the letter you received with your PFAS blood results, how much were you able to...	0.714							
3E	Find answers to the questions…	0.652	0.451						
3D	Describe the objectives…	0.619	0.378						
13D	T/F: If GenX was not detected in my blood sample, then GenX was never in my body.	0.54						0.403	
13C	T/F: The National Academies report made recommendations about seven (7) PFAS …	0.537							
9B	I feel that the objectives of the study have been clearly communicated by the researchers.		0.794						
9C	The study provides answers to the questions I have about PFAS contamination.		0.749						
9A	Could you tell us how much you agree or disagree with these other statements? ... I understand the risks and benefits of contributing to the GenX Exposure Study.		0.738						
2	Whether it was new or not, how useful was the information presented in the letter?	0.342	0.425						
15B	Have you…Avoided food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)			0.764					
15C	Have you…Quit buying waterproof or nonstick products manufactured with PFAS.			0.679					
14C	How effective do you think... Not buying waterproof or nonstick products manufactured with PFAS.			0.678					
14B	How effective …Avoiding food products grown or raised near my home (for example: vegetables from a garden, fish from local lakes and rivers)			0.653					

Question	Factor Loadings							
	1	2	3	4	5	6	7	8
15A Have you…Stopped using unfiltered tap water for drinking and cooking.			0.612					
16A … how willing would you be to sign up for another health study related to PFAS?				0.869				
16B Another health study conducted by… NC State University?				0.858				
14D How effective …Contacting elected officials to reduce PFAS inputs to the environment					0.874			
14E How effective …Working with local organizations to do something about PFAS in your community.					0.843			
14A How effective …Not using unfiltered tap water for drinking and cooking.					0.381			
10A How much risk do you think PFAS presents to ... you and your health?						0.929		
10B the health of residents in your community?						0.903		
15D Have you…Contacted elected officials to reduce PFAS inputs to the environment							0.797	
15E Worked with local organizations …							0.778	
13A T/F: All PFAS chemicals … act the same way in humans and the environment.							0.466	
13E T/F: By participating in a study like this one, people can learn...								0.672
13B T/F: PFAS are substances that do not exist naturally…								0.522
1 How much new information did the letter provide for you?								0.427
Initial Eigen Value	5.914	3.429	2.051	1.712	1.606	1.426	1.356	1.096
% Variance	20.392	11.824	7.071	5.903	5.537	4.916	4.675	3.778
Cronbach’s Alpha	0.845	0.782	0.741	0.873	0.598	0.913	0.643	0.205

Appendix D

Control Variables Re-Coding

Recoded Control Variables

Age	Manual entry year of birth	Current age = 2024 minus the year entered. Study median age = 61 0 = < 61 years old 1= > 61 years old	Binary 1= Older age
Sex	Sex assigned at birth. 1 = Male 2 = Female	Dummy variable for male.	Binary 1 = Male
Race	1 = Am. Indian or Alaska Native 2 = Asian 3 = Black 4 = Hawaiian or Pacific Islander 5 = White 6 = Something else: _____	1 = Am. Indian or Alaska Native 3 = Black 5 = White 6 = More than one race or another race not listed.	Binary 1 = White
Politics-Economic	1= Very liberal 2= Somewhat liberal 3 = Moderate 4 = Somewhat Conservative 5 = Very Conservative	Dummy variable for fiscally liberal. 1 or 2 = "liberal" 3, 4, or 5 = "not liberal"	Binary 1 = Fiscally liberal
Politics-Social	1= Very liberal 2= Somewhat liberal 3 = Moderate 4 = Somewhat Conservative 5 = Very Conservative	Dummy variable for socially liberal. 1 or 2 = "liberal" 3, 4, or 5 = "not liberal"	Binary 1 = Socially liberal
Religiosity	1 = No guidance at all 2 = A little 3 = Some 4 = Quite a bit 5 =A lot of guidance	Dummy variable for lack of religiosity 1 or 2 = "not religious" 3, 4, 5 = "religious"	Binary 1 = Not religious
Income	1 = $19,999 or less 2 = $20,000 to $49,999 3 = $50,0009 to $89,999 4 = $90,000 to $129,999 5 = $130,000 to $149,000 6 = $150,000 or more	NC state median income = $92,000 1, 2, 3 = lower income 4, 5, 6 = higher income	Binary 1 = Higher than average income

Education	1 = Some high school 2 = High school or GED 3 = Some college, technical, or trade school 4 = Bachelor's degree 5 = Graduate or professional degree	Dummy variable for highly educated 1, 2, 3 = less education 4, 5 = more education	Binary 1 = Highly educated
Location	Participants did not enter this information. Researchers used address zip codes to manually code into the three study locations: Fayetteville, Pittsboro, Wilmington.	LOC variable: 1 = Fayetteville 2 = Pittsboro 3 = Wilmington	3 Dummy Variables 1 = Fayetteville 1 = Pittsboro 1 = Wilmington (Used as the control in the regression analyses)

Recoded Independent Variables

Knowledge Gap	Q11 manual entry of a value from 0 to 100. Q12 manual entry of a value from 0 to 100.	If Q11-Q12 < 0, then the person believes there is a gap and they have less knowledge than they need to make a decision.	Binary 1 = Knowledge gap
Risk Perception	1 = None 2 = A little 3 = Some 4 = Quite a bit 5 = A lot	Avg risk perception = 10A+10B/2 Q10A and Q10B had such a strong correlation (.848 significant at .001) that they were combined and used as one variable for the regressions.	Continuous 1-5
Personal Benefit	1 = Strongly Disagree 2 = Somewhat disagree 3 = Neither agree nor disagree 4 = Somewhat Agree 5 = Strongly agree	Dummy variable for someone feeling the GenX Study benefitted them personally. 1, 2, 3 = Does not benefit them 4, 5, = Benefits them	Binary 1 = Benefits me
Researcher Benefit	1 = Strongly Disagree 2 = Somewhat disagree 3 = Neither agree nor disagree 4 = Somewhat Agree 5 = Strongly agree	Dummy variable for someone feeling the GenX Study benefited the researcher. 1, 2, 3 = Does not benefit researchers 4, 5, = Benefits researchers	Binary 1 = Benefits researcher

Appendix E

Survey Questionnaire Open-Ended Question Coding Scheme.

Q4 – Motivation for participating in the GenX Study				
Code	Definition	Themes	Frequency	Example Quotes
Factual Knowledge	Stating an objective fact about PFAS or the study. Not a feeling or an opinion about PFAS. Something that can be deemed accurate or inaccurate.	--	0	--
Subjective Knowledge	*Feeling* like they wanted to learn (words like: find out, see, educate, to know, curious, etc.) something about PFAS, research, etc.	To feel like they learned more, generally.	26	"I wanted to know my exposure"
		To understand or confirm personal (or family) *exposure* levels, PFAS measurements.	**103**	**"I wanted to see how it impacts my health."**
		To understand or confirm *health effects.*	59	"I was curious"
			Total: 188	
Self Efficacy	Believe/feel they can do (words like: find, understand, etc.) something.	Capacity for personal exposure reduction	3	"I want to see if using a filter works"
		Context for talking with one's doctor.	1	"I wanted to know how to talk to my doctor."
		Capacity for lifestyle changes, broadly	3	"I want to be able to stay healthy."
			Total: 5	
Response Efficacy	Believe/feel that something *they do* will work (words like: help, fix, solve a problem).	--	0	--
Risk Perception	Being concerned or worried about PFAS exposure, health effects, etc. for oneself, family, or community. Knowing about sources of PFAS	Worried about health broadly.	22	"I was worried about my health"

Q4 – Motivation for participating in the GenX Study				
Code	Definition	Themes	Frequency	Example Quotes
	contamination and worried about subsequent effects.			
		Specifically worried about links to/causes of *health* conditions (which this study is not able to prove)	27	"I want to know if PFAS caused my illness"
		Worried *specifically* about *contaminated water*; making a conceptual link between PFAS in water and GenX Study.	**63**	**"I'm worried because I drink unfiltered water"**
		Time- worried about length of exposure, years drinking water, years in community	29	"I have lived here for 20 years"
		Worried about risk to family, loved ones, community.	9	"My children were born here and drank the water"
		Location- names one of the three communities as source of PFAS worry.	33	"I live in Wilmington and am worried"
			Total: 183	
Private Behaviors	Protecting oneself or family.	--	0	--
Public Behaviors	Taking actions that contribute to collective understanding, addressing, and/or mitigating PFAS risks.	**Contribute to learning, understanding, knowledge base of PFAS.**	**60**	**"I wanted to help researchers document the problem in my community."**
		Solving the problem, contributing to policy change	16	"I want to be part of the solution."
		Solving the problem, specifically via legal	6	"So Chemours can be held accountable."

Q4 – Motivation for participating in the GenX Study				
Code	Definition	Themes	Frequency	Example Quotes
		action or polluter accountability		
		To help document *specific* impacts on their community.	12	"To help figure out what happened to my community."
		To help the community generally, civic duty.	19	"I wanted to be a good member of my community."
		To help general environmental and public health wellness.	5	"I care about clean water"
			Total: 118	

Q5- Satisfaction				
Code	Definition	Themes	Frequency	Example Quotes
Factual Knowledge	Stating an objective fact about PFAS, the study, the letter, etc. (ex: they gave me results). Something that we could deem accurate or inaccurate. Mentioning the letter, meeting, results, numbers, levels. Not making definitive links between exposure and health effects.	Learning facts, broadly.	11	"They gave me information"
		Specifically mentioning personal blood results, levels, measurements, relativity to other participants or national average.	**112**	**"I could see my levels of different individual PFAS."**
		Specific, objective facts about PFAS health effects.	5	"PFAS can affect the immune system."
		Specifically mentioning the letter.	5	"The stripcharts showed me my levels relative to other people in my town."
		Specific factually correct statements about PFAS.	8	"I know that certain PFAS don't stay in the body forever."
			Total: 141	
Subjective Knowledge	Mentions of knowledge or learning that are *not* explicitly outlined in the letter. that are value laden, subjective, or opinionated. Feeling they learned something *beyond what was explicitly outlined* in the letter.	**Describing what they learned or a knowledge gap *they felt* they had being filled using relative or subjective terms that can't be deemed in/accurate.**	**26**	"**Now I know my risks"**
		Using adjectives or making value judgments about the Study or data.	**40**	"**The results were detailed"**
		Describing a subjective assessment of *their own levels.*	13	"My levels were so much lower than I thought."
		Believing they learned or got confirmation of a definitive link between	10	"I know I found the reason for my illness"

Q5- Satisfaction				
Code	Definition	Themes	Frequency	Example Quotes
		PFAS and health effects.		
			Total: 89	
Self Efficacy	Believe or feel that they are able to do something (words like: find out, look for, can, able to)	Describing the ability to answer questions, find answers, identify trends.	2	"Now I'm able to find out my levels"
		Describing the ability make informed decisions.		
		Describing the ability to interact with healthcare providers.	5	"I know my numbers and what to do about them"
			7	"I *am able to* take this information to my doctors"
			Total: 14	
Response Efficacy	Believe or feel that something they did worked, helped, fixed a problem.	--	0	--
Risk Perception	Ongoing, continued worry about exposure, long-term health risks, etc.	--	0	--
Private Behaviors	Taking actions that protect oneself or one's family.	Actions taken related to drinking water.	2	"I saw my levels and bought a water filter for my sink."
		Actions taken related to healthcare providers.	6	"I *took* this information to my doctors"
		Private actions taken, broadly.	3	"I am taking actions to protect my family"
			Total: 11	
Public Behavior	Taking actions that contribute to the collective understanding,	Collective understanding of PFAS exposures and risks is a good in and of itself.	18	"I participated in this study and helped researchers

Q5- Satisfaction				
Code	Definition	Themes	Frequency	Example Quotes
	addressing, or mitigating of PFAS risks.			better understand PFAS."
		Improvements to municipal/public water supplies, which could be connected to results from the GenX Study.	6	"This may have been the reason my drinking water got cleaned up."
		The Study's contribution to PFAS knowledge prompts structural or policy changes.	9	"This Study helps hold polluters accountable."
		The Study's contribution to PFAS knowledge may lead to other things with collective benefits.	6	"This put a spotlight on our problem and now maybe it will get better."
			Total: 39	

Q6 – Least Satisfied with GenX Study

Code	Definition	Themes	Frequency	Example Quotes
Factual Knowledge	Stating an objective fact about PFAS, the study, the letter, etc. (ex: they gave me results). Something that we could deem accurate or inaccurate. Mentioning the letter, meeting, results, numbers, levels. Not making definitive links between exposure and health effects.	**Lack of, wishing they had *more information provided* by the Study (that objectively was not covered by the study's report back)**	**16**	**"I wanted more information on each health impact."**
		Wishing they had *more opportunities* to provide information *to* the study.	11	"I want to provide more blood samples more often."
		Mentioning their own results as a source of dissatisfaction.	5	"My results."
		The *time* it took to receive factual information.	2	"It took too long to get them."
			Total: 34	
Subjective Knowledge	Mentions of knowledge or learning that are *not* explicitly outlined in the letter. that are value laden, subjective, or opinionated. Feeling they learned something *beyond what was explicitly outlined* in the letter.	Feeling that there is not enough information about a certain topic, either specifically assigning blame to the study, or speaking more broadly.	7	"Which PFAS are the problem? Not GenX?"
		Not understanding what the results mean for *water*.	2	"So can I drink my water?"
		Not understanding what the results mean for *health.*	**13**	**"What do the high levels in me mean?"**
		Lack of understanding when *reading the letter* (and information therein).	11	"I didn't fully understand the charts."
		Lack of understanding more broadly.	7	"How could this happen, I just moved here!"
			Total: 40	

Q6 – Least Satisfied with GenX Study				
Code	Definition	Themes	Frequency	Example Quotes
Self Efficacy	Feeling they *can't* do something (words like: find out, look for, can't, aren't able to)	Lack of *usefulness* of information provided to *do something.*	7	"I'm not sure what I can do with this information now."
			1	"It's hard trying to find answers"
			Total: 8	
Response Efficacy	Believe or feel that something *won't work*, won't help, won't fix a problem.	--	0	--
Risk Perception	Ongoing, continued worry about exposure, long-term health risks, etc.	Feeling new, continued, or unresolved worry.	6	"I don't know the full scope of this, but my high levels are scary."
		Anger about ongoing risks.	3	"This shouldn't have happened in the first place"
			Total: 9	
Private Behavior	Taking actions (or being unable to) that protect oneself or one's family.	Actions taken in the home.	3	"Is filtering water really all I can do?"
		Actions to reduce body burden.	11	"How can I get PFAS out of my body?"
			7	"I don't know what medical actions to take."
			9	"I need to do something to fix my exposure"

Q6 – Least Satisfied with GenX Study				
Code	Definition	Themes	Frequency	Example Quotes
			Total: 30	
Public Behavior	Actions that contribute to the collective understanding, addressing, or mitigating of PFAS risks.	**Lack of action from the polluters.**	**15**	**"Chemours still hasn't cleaned it up"**
		Time since contamination, or until remediation.	3	"It's going to take a long time to help us."
		Collective access to clean water.	5	"What can be done to get us clean water?"
		Future collective actions and impacts.	3	"What happens next? I don't want people to forget about us."
			Total: 26	

Appendix F

Interview Recruitment Email

Email:
Subject: Share your thoughts on PFAS- Earn a $25 gift card!

Dear GenX Exposure Study participant,

A colleague at NC State, Katy May, is conducting a research study- independent of the GenX Exposure Study- to understand your experience living with PFAS contamination and how you perceive its impact on the environment and human health. As a participant in the GenX Exposure Study and resident of the Cape Fear River basin, you have uniquely important insight on the effects of PFAS.

These interviews are part of her PhD research, and all procedures have been reviewed and approved by NC State's Institutional Review Board. Each interview will last approximately 45-60 minutes, and will be conducted either by phone or Zoom, based on your preference.

Your insights will help researchers better understand what residents of [Pittsboro, Fayetteville, or the Lower Cape Fear] see as opportunities and barriers to addressing PFAS contamination and the role of research studies in that process. In appreciation of taking the time to share their perspectives for the duration of the interview, participants will receive a $25 gift card.

There are only 30 interview spots available and not everyone who volunteers to participate will be selected for an interview. If you would like to learn more and sign up for this research study, please visit this link go.ncsu.edu/pfas_interviews. For questions about this study, contact Katy May: kmay2@ncsu.edu

Thanks,
Jane Hoppin
Principal Investigator, GenX Exposure Study

Appendix G

Interview Consent Form

Title of Study: Environmental Health Literacy and the PFAS Exposure Experience
Principal Investigators: Katy May kmay2@ncsu.edu
IRB Protocol #: 27670
Funding Source: None
NC State Faculty Point of Contact: KC Busch, kbusch@ncsu.edu
Collaborating Researchers: Jane Hoppin, jahoppin@ncsu.edu, 919-515-2918

You are being asked to participate in a research study about PFAS exposure in your community. Participation is strictly voluntary. You must be 18 years of age or older, reside in the United States, and be a participant in the GenX Exposure Study to participate in this study.

If you participate in this study, you will be asked to participate in an individual interview to answer questions about PFAS exposure in your community, and what you perceive are the knowledge, skills, and actions needed address it. Interviews will be conducted either by phone or zoom, depending on your preference. Interviews will be conducted in a private setting where questions and responses will not be overheard.

There are only 30 interview spots. It is possible that not everyone who volunteers to participate will be selected for an interview.

You can choose to not participate in the study or stop participating at any time by selecting the "No I do not consent" option below, or by asking to stop participating during or after the interview.

Participants will be audio recorded. If you are uncomfortable with being recorded, please do not participate in this study. Audio recordings will only be used for transcription purposes and will be deleted after transcriptions have been uploaded and verified.

There are minimal risks to your participation in this study. You may indirectly benefit from participating in this study by contributing to research that is directly relevant to your community, or from having the summary findings reported back to you at the end of the study.

You will receive a $25 gift card for your participation in the recorded interview. In order to receive the gift card, you will need to complete the entire interview, allow the recording to be transcribed and analyzed, and provide an email or mailing address to have your gift card sent.

If you have any questions about the research or how it is implemented, please contact the student researcher, Katy May at kmay2@ncsu.edu and 919-515-2681. You can also contact the faculty advisor for this research, KC Busch at kbsuch@ncsu.edu. Please reference study number 27670 when contacting anyone about this project.

If you have questions about your rights as a participant or are concerned with your treatment throughout the research process, please contact the NC State University IRB Director at IRB-Director@ncsu.edu, 919-515-8754, or fill out a confidential form online at https://research.ncsu.edu/administration/compliance/research-compliance/irb/irb-forms-and-templates/participant-concern-and-complaint-form/

If you consent to participate in this study, please click "Yes, I consent" below and you will be taken to a short form to collect some information. *[See below]*

1. What is your name? [required]

    a. [write in answer]

2. Where do you live? [choose one, required]
    a. Pittsboro
    b. Bladen or Cumberland County
    c. Brunswick or New Hanover County
    d. Other [write in answer]
3. Which of the following racial and ethnic identities best describes you? Select all that apply. [labeled as required, but not set as required in Qualtrics]
    a. Asian / Asian American
    b. Black / African American
    c. Hispanic / Latino
    d. Native American or Alaska Native
    e. Native Hawaiian / Pacific Islander
    f. White
    g. Other - Write in your answer
    h. Prefer not to say
4. What is your gender? [labeled as required, but not set as required in Qualtrics]
    a. Male
    b. Female
    c. Other - Write in your answer
    d. Prefer not to say
5. What is your email address? [required]
    a. [write in answer]
6. What is your phone number?
    a. [write in answer]
7. What is your preferred method of communication?
    a. Email
    b. Phone
    c. Something else

8. Do you need any accommodations to participate in interview? (For example, hearing, visibility) [*Write in your answer]

Only participants who have consented will receive confirmation and reminders with details about the interview, including their unique Zoom link that will take them to the meeting waiting room.

Appendix H

Selection and not Selected Emails to Consented Individuals

Email Script:
Dear [name],
Thank you so much for completing the online consent forms and indicating your interest in participating in an interview as part of my research study on PFAS exposure.

When you have a chance, please reply to this email or give me a call to let me know a few days and times over the next week or so that would be convenient for you to participate in an interview. I expect our conversation to last about 45-60 minutes.

I will send you a calendar invite with a secure Zoom link for our conversation that you can join by computer or phone, depending on your preference.

Please let me know if you have any questions.
I look forward to hearing from you!
Sincerely,
Katy May
kmay2@ncsu.edu
919-515-2681

Dear [name],

Thank you so much for completing the online consent form and indicating your interest in participating in an interview as part of my research study on PFAS exposure.

As of right now, all interview slots have been filled. If a spot opens up, I will be sure to reach back out to you.

Please let me know if you have any questions.
Thanks again,
Katy May
kmay2@ncsu.edu
919-515-2681

Appendix I

Interview Protocol

Introduction Script:

Hello. Thank you so much for taking the time out of your day to talk with me.

I'm Katy May and I am a doctoral student at NC State University. Since 2017, I've been working with researchers at NC State, the GenX Exposure Study, and residents of the Cape Fear River basin to understand and respond to PFAS contamination in drinking water.

My research is interested in understanding what residents of the Cape Fear River basin think is needed to address PFAS contamination at an individual, household, and community level. You are a resident of the river basin and a participant in an ongoing PFAS health study, which makes you uniquely knowledgeable on the lived experience of PFAS exposure. With this study, I hope to understand how communities along the Cape Fear perceive PFAS exposure, remediation, and human health. Results will be shared with researchers and other stakeholders who are working to address PFAS in hopes that their strategies can incorporate your ideas and better respond to your needs.

I know you received an email from me with information about your rights as a participant, but I will review them quickly.

- *Your participation is voluntary and you can stop participating or withdraw consent at any time.*
- *You have agreed to be video-recorded.*
- *I am in a private setting and our conversation will not be overheard.*
- *You will be compensated for your participation with a gift card.*
- *Your name and all other data will be kept confidential by me and we ask the participants to also keep it confidential among this group.*
- *Do you have any questions or concerns about your rights?*

I will begin recording now.

This is a semi-structured interview. I have a list of questions I am interested in but will follow your lead on where to spend the most time during our conversation. I expect this to take between 45 and 60 minutes.

A few quick ground rules before we start:

- *First, there are no right or wrong answers. I'm interested in your perspectives and experiences related to PFAS.*
- *Second, I want you to feel comfortable saying positive things as well as critical things. I'm not here to promote a particular way of thinking, research study, or agenda. I only want to understand your viewpoints.*
- F*inally, since we are Zoom, I hope that we can keep our cameras on as our internet allows. Being able to see each other will help for a more natural conversation.*

Are there any questions or anything you would like to add?
Great, let's get started!

Discussion Script
For today's conversation, I'd like you to think about your experiences as an individual and as a resident of [community name].

1. First, tell me about your community and how long you've lived there.
2. What kinds of health issues do you see in your community? Do you think any of these are related to PFAS contamination?
3. Tell me about PFAS contamination in your community and how you found out about it.

In the years since we learned about PFAS in the Cape Fear River and in [your community's] drinking water, there have been some noteworthy events- the US EPA listed PFAS as hazardous substances and created enforceable standards for six PFAS, the United Nations has accused Chemours of "business-related" human rights abuses in North Carolina, and the National Academies released medical guidance for seven different PFAS. Still, these events do not erase, clean up, or solve the issue of PFAS contamination in your community or its potential impact on human health.

1. Imagine that someone was just moving to [your community] today and asked you about PFAS in your community, what do you consider the most important things for them to know?

2. How would you describe the risk that PFAS poses to you and your family?
    a. Do you think your water is safe to drink?
    b. To your community?
    c. In what ways do you feel that PFAS exposure has impacted your or your family's life?
        i. How has it made you feel?
    d. Did you have any prior experiences that related to or prepared you to deal with an issue like this?

3. **Would you say that PFAS contamination in your community has caused you any stress or worry?**
4. Thinking about your friends and family in the area, how would you describe how *they* perceive or think about PFAS in [your community]?
    a. In what ways do your friends and family shape how you think about contamination?

As I said, you have unique insights into PFAS exposure because you're also a participant in a long-term PFAS health study. I'm interested in hearing more about how you think about PFAS research.

1. How has your participation in the GenX Exposure Study impacted how you think about PFAS?
    a. How have you used the results you've received in letters or at community meetings in the time since you've received them?
        i. Have you changed any of your behaviors because of the results?

   b. What actions are you planning to implement in your family or community in response to the results?
   c. Are there things you'd like to do in response to PFAS contamination but have not done? What are they and why have you not done them?
2. After participating in a research study for multiple years now, what do you feel like researchers "just don't get" when it comes to PFAS in [your community]?
3. I am curious what gaps you see in current PFAS research. In a perfect world, where they could answer it tomorrow, what question related to PFAS do you most wish researchers would find an answer to?

Whether it's through a news story, research study, or information from a friend, once we know about the presence of something harmful in our community, we often want to know how to do something about it.

1. As an individual, what do you see as the most critical step to reduce PFAS exposure and protect you and your family's health?
   a. What kinds of actions have you taken personally or in your home in response to PFAS?
   b. In what ways are you able or unable to do those things?
   c. What kinds of actions have you taken outside of your home in response to PFAS in your community?

2. As a resident of [your community], what do you see as most important for *broadly* reducing PFAS exposure and protecting health in [community] overall?
   a. What things are needed for that to be able to happen?
   b. What actions related to PFAS do you most wish officials at the local, state, or national level would take?
      i. Are there things that you feel like officials who don't live in [your community] don't understand about PFAS contamination here?

3. Is there anything that I haven't asked you about that you would like to speak about? Or is there something you haven't been able to say yet?

Interview Session Conclusion

"Thank you again for your time and sharing your experiences and thoughts. I really appreciate it! I will stop the recording now. I will be conducting similar conversations with residents in [other two communities] over the next few weeks. I'd like to give you a gift card to show my appreciation for taking time out of your day to talk with me. I'll be sending that out shortly using the contact information you provided me previously. If any of your information has changed, please let me know.

Appendix J

Example 2020-2021 GenX Study Report Back Letter

NC STATE UNIVERSITY Center for Human Health and the Environment

GenX Exposure Study
North Carolina State University
Campus Box 7633
Raleigh, NC 27695
Phone: 855-854-2641
https://genxstudy.ncsu.edu/

[Date]

[Street Address]
[City, State, Zip code]

Dear [Participant],

Thank you for participating in the GenX Exposure Study. This study aims to understand human exposure to per- and polyfluoroalkyl substances (PFAS) including GenX in people living in the Cape Fear River Basin, NC, and to learn if this PFAS exposure is associated with health effects. You are part of an important health study which will help understand the long-term health consequences of PFAS exposure.

What are PFAS and where did PFAS in the Cape Fear River Basin, NC, come from?

- PFAS are human-made chemicals that have unique properties that make them resistant to heat, water, and grease. Because of these properties, they have been used to make a large variety of products including non-stick cookware, fast-food packaging, rain gear, stain- and water-resistant carpeting and upholstery, paint, and fire-fighting foams. PFAS last for a long time in the environment and can accumulate in plants, animals, and people.
- Sources of PFAS contamination in the Cape Fear River Basin include textile and furniture manufacturing, use of sludge from wastewater treatment plants as fertilizer, and use of fire-fighting foams at airports.
- Additionally, discharges into water and air emissions from the Fayetteville Works facility near Fayetteville, NC, have contaminated the Fayetteville area and lower Cape Fear River Basin with PFAS.

What did we do?

- From November 2020 to November 2021, we enrolled volunteers from three regions of the Cape Fear River Basin in NC into the GenX Exposure Study. People from the lower Cape Fear River Basin and Pittsboro were served by public utility water, while people from the Fayetteville area were served by private wells.

  - In November 2020, we collected blood samples from 282 people who lived in the lower Cape Fear River Basin (specifically, New Hanover and Brunswick Counties).
  - In June and July 2021, we collected blood samples 300 people in the Fayetteville area (Bladen, Cumberland, and Robeson Counties),
  - In September and October 2021, we collected blood samples from another 232 people in the lower Cape Fear River Basin, and
  - In November 2021, we collected blood samples from 206 people in Pittsboro (Chatham County).
- We tested participants' blood samples for 44 PFAS. The list of all PFAS we tested for is on our website (https://genxstudy.ncsu.edu/). The blood samples were analyzed at NC State University.
- This letter describes the results from all blood samples collected in 2020 and 2021. **In addition, your individual PFAS blood results are on Pages 5-11.**

What did we find in blood samples collected in 2020 and 2021?

- We detected 4 PFAS (PFOS, PFOA, PFHxS, and PFNA) in almost everyone who participated no matter where they lived in the Cape Fear River Basin. These 4 PFAS are also commonly detected in people living in the United States. The concentrations for people in our study were higher than the United States national averages.
- We detected 2 PFAS (Nafion byproduct 2 and PFO5DoA) in most people in the lower Cape Fear River Basin in 2020 and 2021, and some people in the Fayetteville area in 2021. Nafion byproduct 2 and PFO5DoA concentrations decreased in the lower Cape Fear River Basin between 2020 and 2021.
- We rarely detected Nafion byproduct 2 and PFO5DoA in people in Pittsboro.
- We did not detect GenX in blood samples. GenX does not last in blood for a long time so even though people in the Lower Cape Fear River Basin and some people in the Fayetteville area were exposed to GenX, it was not present in blood when samples were collected in 2020 and 2021.

Is there any medical guidance for people exposed to PFAS?

- Yes, in July 2022, the National Academies of Science, Engineering, and Medicine (NASEM) released a report based on an unbiased review of the human data for PFAS exposure and health. This report provides recommendations for medical follow-up for people exposed to PFAS. The summary of the NASEM report is available online (bit.ly/PFAS-guidance).

- The NASEM panel recommended that exposed people get their blood tested for PFAS to inform medical decisions. They recommended certain health-based actions depending on the summed concentration of 7 PFAS (PFOS, PFOA, PFHxS, PFNA, PFDA, PFUnDA, and MeFOSAA) in blood. We tested for these PFAS in the blood samples and these PFAS were detectable in most study participants in 2020-2021.
- About 30% of people in our study had summed PFAS concentrations above 20 ng/mL. This level was associated with the highest risk for adverse health effects based on the NASEM 2022 guidance.
- The current guidance from NASEM are recommendations. At this time, there is no money set aside to help people pay for PFAS blood testing or health testing. However, many of these recommendations are things that are included in regular check ups with your health care providers.

What's on the following pages of this letter?

- **Page 5-6** shows your individual concentrations and the sum concentration of the 7 PFAS in your blood sample in a small table next to the recommended medical action based on the current NASEM guidance.
- **Pages 7-10** show stripcharts for several PFAS. A stripchart is a picture showing your blood result and the blood results for all people in your community. You will also see the median concentration (half of the participants are above this value, half of the participants are below) of the results for each PFAS.
- **Page 11** is a table of all your PFAS results and the method reporting limits for our PFAS blood testing.

What's next?

- Please join us for a webinar to learn more about these results. We will also have a question-and-answer period. The webinar is scheduled for October 18th, 2022, 6-8pm, and here's the link to join (https://ncsu.zoom.us/s/92719272112 | +1(312)626-6799 |ID: 92719272112).
- We plan to come to your communities in person to share these results with the public and answer any questions. Below are the details for currently scheduled community meetings. We hope you will attend at least one of these meetings and bring others who are not study participants but would like to know what we are learning.

Oct 19th, 2022, 6-8pm, Chatham County Agriculture & Conference Center
1192 US Hwy 64 West Business, Pittsboro, NC, 27312

Nov 2nd, 2022, 6-8pm, Grays Creek Community Center
3024 School Rd, Hope Mills, NC, 28348

Nov 10th, 2022, 6-8pm, Cedar Creek Baptist Church
4170 Tabor Church Rd, Fayetteville, NC, 28312

We're in the process of finding a location for a meeting in the New Hanover and Brunswick County area. We will announce details on our website and through social media.

- Please check our study website (https://genxstudy.ncsu.edu/) or the NC State Superfund website (superfund.ncsu.edu) for more information about the webinar and in-person meetings.
- If you have questions about these results, the GenX Exposure Study, or the NASEM recommendations, please contact our study office by phone (855-854-2641) or email (genx-exposure-study@ncsu.edu).

In the next few weeks, you will receive a post card and a survey questionnaire from independent researchers at NC State University. These researchers will be evaluating our community engagement efforts in the GenX Exposure Study.

Once again, we thank you for your participation in the GenX Exposure Study.

Sincerely,

Jane Hoppin, ScD
GenX Exposure Study, Principal Investigator

NC STATE UNIVERSITY
Center for Human Health and the Environment

GenX Exposure Study
North Carolina State University
Campus Box 7633
Raleigh, NC 27695
Phone: 855-854-2641
https://genxstudy.ncsu.edu/

Clinical Guidance for PFAS Exposed People

In July 2022, the National Academies of Science, Engineering, and Medicine (NASEM) published recommendations for medical monitoring based on the total (sum) concentration of 7 specific PFAS in blood.

The table below shows the levels of 7 PFAS we measured in your sample from [year], and the sum ofthese 7 PFAS in the blood. On the right, current NASEM recommendations based on the sum PFAS are shaded with a **bold box** around them.

PFAS	Your blood result (ng/mL)
PFOS	2.0
PFOA	2.0
PFHxS	3.0
PFNA	0.3
PFDA	0.1
MeFOSAA	0.1
PFUnDA	0.0
Your sum	**7.5**

2022 Guidance on PFAS from the National Academies of Sciences, Engineering, and Medicine

Sum PFAS More Than 20 ng/mL

Associated with higher risk of adverse effects. You should...
- Reduce PFAS exposure (see other side of page)
- Speak with your medical provider and ask them to check cholesterol levels, hypertensive disorders of pregnancy, breast cancer, thyroid function, kidney and testicular cancer, and ulcerative colitis, as per NASEM guidance.

Sum PFAS Between 2 and 20 ng/mL

Associated with potential for adverse effects in sensitive populations. You should...
- Reduce PFAS exposure (see other side of page)
- Speak with your medical provider and ask them to check cholesterol levels, hypertensive disorders of pregnancy, and breast cancer, as per NASEM guidance.

Sum PFAS Less Than 2 ng/mL

Health effects not expected at this time. You should...
- Maintain usual medical care.

What can you do with this information? You can discuss these PFAS blood results and the NASEM recommendations with your clinician to decide whether you would benefit from specific medical tests.

If your clinician has questions about PFAS, they can refer to the NASEM report (bit.ly/PFAS-guidance) or to a memo from the North Carolina Department of Health and Human Services (https://bit.ly/DHHSMemo). If you would like us to email you a copy of the NASEM report, please contact our study office. These recommendations do not mean that insurance will pay for any additional PFAS or clinical testing at this time.

If you are underinsured or noninsured and are seeking primary care services, please contact one of the following resources.
For Lower Cape Fear River Basin Region, NC, contact Cape Fear Health New (Phone: 910-399-2751; Website: http://www.capefearhealthnet.org/getting-care/). Note that Novant outpatient clinics have assistance places for low-income and uninsured people.

For Fayetteville area, NC, contact Stedman-Wade Health Services, Inc., 7118 Main St., Wade, NC, 28395 (Phone: 910-483-6694).

For Pittsboro, NC, contact Siler City Community Health Center, 224 S. Tenth Ave., Siler City, NC, 27344 (Phone: 919-663-1744) OR Moncure Community Health Center, 7228 Moncure-Pittsboro Road, Moncure, NC, 27559 (Phone: 919-542-4991).

What about other PFAS, besides these 7? The 2022 NASEM recommendations are based on the sum of 7 PFAS in blood. These 7 PFAS have been monitored by the Centers for Disease Control and Prevention in Americans for the past 20 years. Health screening recommendations for people exposed to PFAS may change as scientists learn more about the health effects of PFAS.

How can you reduce your PFAS exposure? The PFAS in your blood tells you about the PFAS that you are currently exposed to and what you were exposed to in the past. Many people in the Cape Fear River Basin have been exposed to PFAS through contaminated drinking water. Recently, municipal water suppliers have worked to remove PFAS from drinking water. The Sweeney Water Treatment plant in New Hanover County, the Brunswick County's Northwest Water Treatment Plant, and the Town of Pittsboro have installed treatment technologies to remove PFAS from drinking water sources.

If you use well water, you may want to have your water tested for PFAS and, if PFAS are detected, install filtration at your sink to reduce PFAS exposure. Private well owners in the Fayetteville area may be eligible for water testing and remediation (https://bit.ly/DEQGenX).

To learn what more you can do to reduce PFAS exposure, please visit this website (https://bit.ly/ATSDRPFAS). You can also contact our community partners: Cape Fear River Watch for Lower Cape Fear River Basin (https://capefearriverwatch.org/; phone: 910-762-5606), Sustainable Sandhills for Fayetteville area (https://sustainablesandhills.org/; phone: 910-484-9098), and Haw River Assembly for Pittsboro (https://hawriver.org; phone: (919) 542-5790).

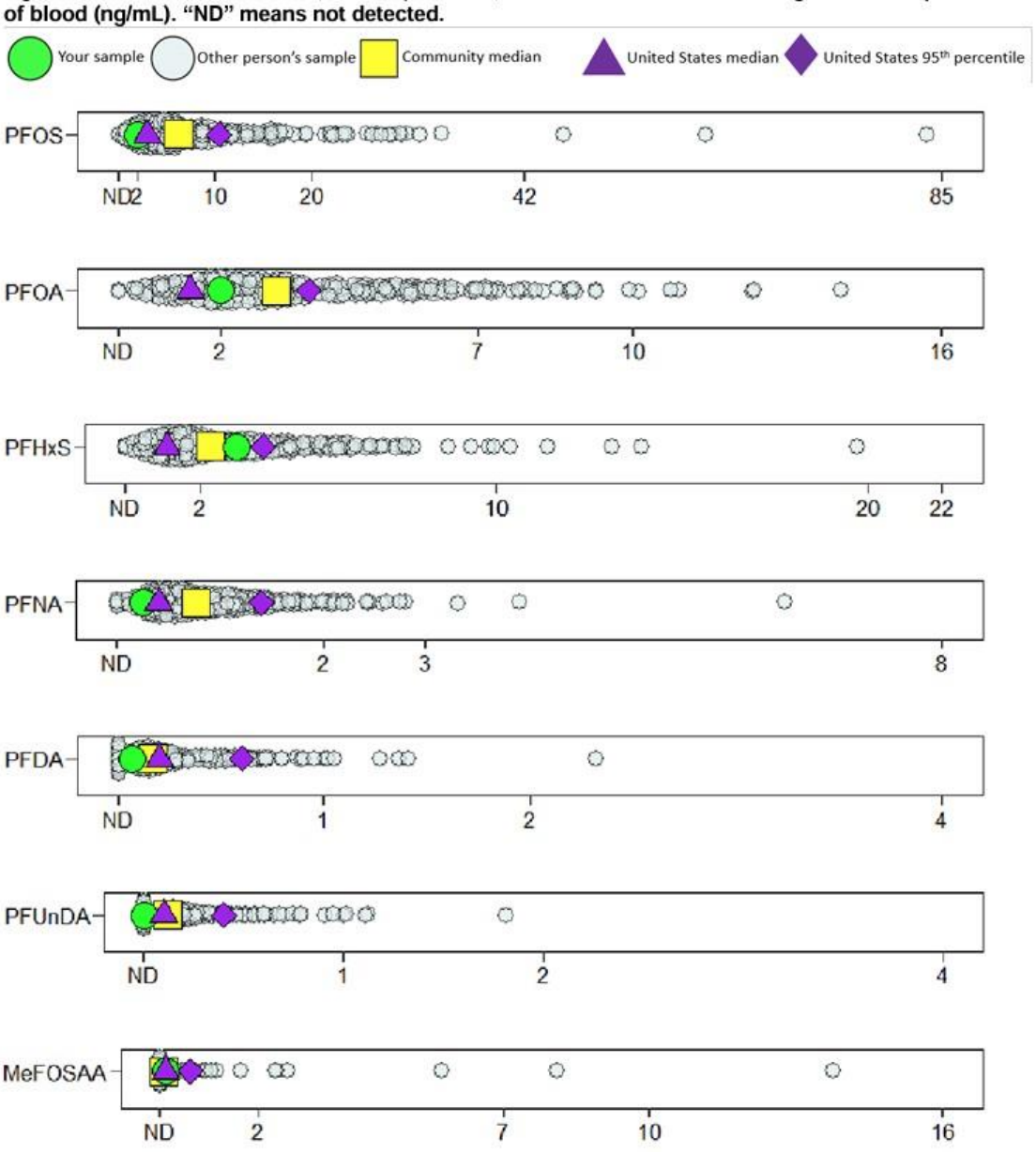
What if you have more questions about the GenX Exposure Study?
Please contact our study office by phone (855-854-2641) or email (genx-exposurestudy@ncsu.edu) and visit our study website (genxstudy.ncsu.edu).

We thank you for your participation in the GenX Exposure Study.

Sincerely,

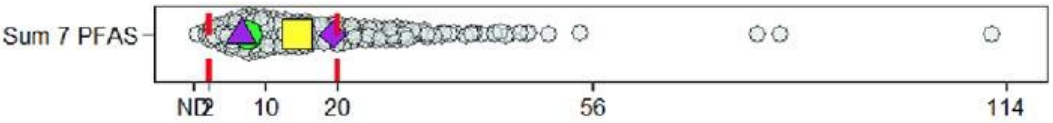
Jane Hoppin, ScD
GenX Exposure Study, Principal Investigator

Below are your blood results for the sample you provided in [year]. Each stripchart shows results for all [total] people who lived in Lower Cape Fear River Basin Region, North Carolina, and provided a blood sample in [year]. For PFAS measured by the Centers for Disease Control and Prevention (CDC) in 2017-2018, we show the median and 95th percentile for United States residents. These values show you how your sample compares with the average United States resident (the purple median) and someone who has a blood level higher than 95% of US residents (the 95th percentile). **All concentrations are nanograms PFAS per mililiter of blood (ng/mL). "ND" means not detected.**

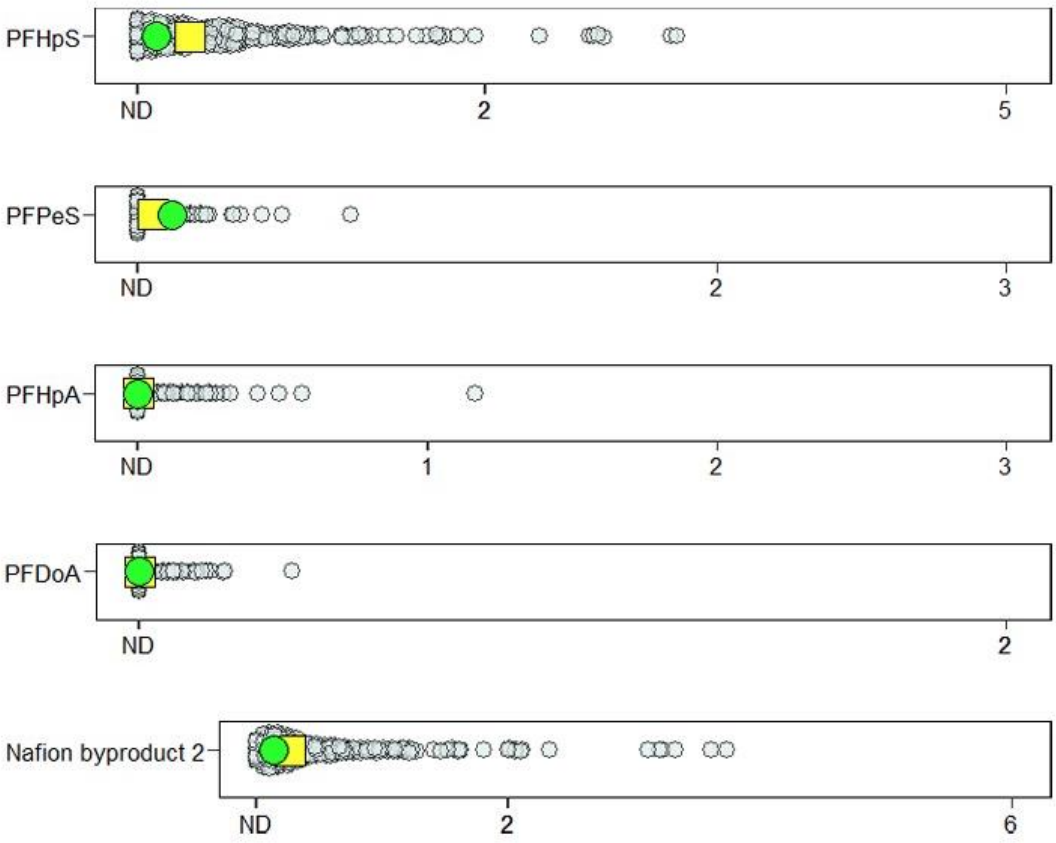


The National Academies of Sciences, Engineering, and Medicine recently published guidelines for PFAS blood levels based on the summed blood concentration of 7 PFAS (PFOS + PFOA + PFHxS + PFNA + PFDA + PFUnDA + MeFOSAA). **The stripchart below shows your blood's sum for these 7 PFAS in your sample from [year] and the sums for samples from all [total] people in Lower Cape Fear River Basin Region, NorthCarolina, in [year].** You can also see how your sample compares with the average United States resident (the purple median) and someone who has a blood level higher than 95% of US residents (the 95th percentile). **Theconcentrations are nanograms summed PFAS per milliliters of blood (ng/mL). "ND" means not detected.**

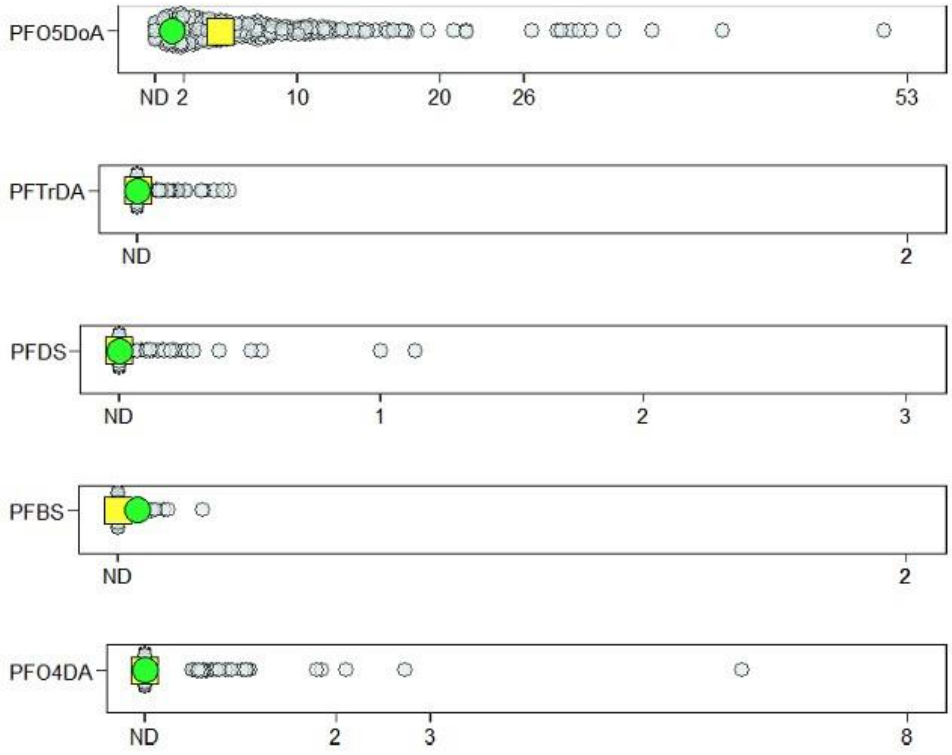
According to the National Academies report, sum PFAS between 2 and 20 ng/mL is associated with potential for adverse health effects in sensitive populations, and sum PFAS greater than 20 ng/mL is associated with higher risk of adverse health effects. We marked 2 ng/mL and 20 ng/mL with red, dotted lines on the stripchart below. See page 5 for more information about your sum and the National Academies' recommendations.



The stripcharts below are for other PFAS frequently detected in Lower Cape Fear River Basin Region, North Carolina, in [year]. The United States median and 95th percentile are not shown on these stripcharts because CDC did not test for these PFAS in blood samples collected 2017-2018. **All concentrations are nanogramsPFAS per milliliter of blood (ng/mL). "ND" means not detected.**



The stripcharts below are for other PFAS frequently detected in Lower Cape Fear River Basin Region, North Carolina, in [year]. The United States median and 95th percentile are not shown on these stripcharts because CDC did not test for these PFAS in blood samples collected 2017-2018. **All concentrations are nanogramsPFAS per milliliter of blood (ng/mL). "ND" means not detected.**



Appendix K

Combined Full Codebook and Coding Scheme

LIVED EXPERIENCE
Comm Time
Recent Transplants- Describe having (relatively) recently moved to the area *"I have been there since 2017"*
10+ years- Describe having lived there for awhile, but having moved from somewhere else *"I've been here since January of 2001"*
Whole life- Mention having lived there their whole life, having family history in the area, etc. *"I was born and bred right here in Wilmington, lived in, lived in the inner city pretty much all my life."*
Comm Physical
Affective -Subjective descriptions of the community and its people. Can't be measured. *"It's been absolutely the best place to grow up."*
Descriptive- Objective descriptions about the community's size, location, demographics, etc. *"It's a small community of about 92 houses"*
Nature- Describing their relationship to nature, the outdoors, agriculture as a motivation for moving there, something they like about it, or their history of it. *"during my years of growing up we farmed and we fished, and we were poor, but we thought we were rich because we ate from the ocean. We went to the river, and my dad fished."*
Toxicity Continuum
Ignorance- describing a lack of knowledge or awareness of PFAS altogether. Could be about themselves or their perception of others. *"I don't think people know about it"*
Invisibility and Downplaying- they know about PFAS and they may be worried about it, but it's not at the top of their mind, it's not high priority, they don't think about it all the time. They may downplay the severity in comparison to other contamination examples ("*at least it's not Flint*") or other demographics ("*I'm old already*"). Relatively lower risk perception. *"I've never been fearful about taking a bath, I mean, I don't want to seem flippant"*
Suffering- they know about PFAS and they're worried. It's front of mind, an ongoing source of fear, anxiety, stress. High perceived risk
Concern for animals- discussing illness and other impacts to pets and livestock from a welfare and wellbeing perspective, not economic impacts.

"Let's put it this way. I have a pet cemetery with about 15 animals in it right now that have all died at fairly young ages of cancers and liver issues and heart issues."
Exposure anxiety- discussing worry or fear that they are still being exposed, being exposed in new ways, are unable to prevent the exposure itself. *"if it's coating my dishes. What's it doing to me."*
Fear of drinking water- discussing ongoing fear of drinking water, despite filtration options. *"I think the water may even be worse right now." "it just makes me feel vulnerable. Having bad water"*
Fear of uncertainty- using words like "the unknown" "uncertainty" or describing uncertainty and lack of information as a source of stress and worry. *"I still don't know really necessarily long term effects. And what this means for us. So yeah, there's just a lot of unknown"*
General worry and hurt- negative emotions related to PFAS and their situation not covered by the above. *"It's scary to live here. And that is sad."*
Cancers- describing known cases of cancer in themselves, their loved ones, or stories they've heard. *"But the young people, the young people dying of stomach cancer and breast cancer and pancreatic cancer. the young people dying."*
Caused by PFAS- specifically making a link between a health effect and PFAS exposure *"I believe my autoimmune issues have been from that."* *"People getting sick, you know, from the chemicals. They're dying,"*
Children's health- specifically citing worry about PFAS impacts on children. If it's health effects about kids it goes here. *"especially for my kids. You know, they go to public schools, and there's no filtration system that I am privy to at the school system. So I mean our kids should have access to clean water during the day."*
Death- referencing death and dying in their community, even if they don't specifically say "and it was caused by PFAS." Documenting loss in the community. *"We know we've lost quite a few friends"*
Other health effects- mentioning other specific health effects they see in their communities that aren't cancer (autoimmune, thyroid, kidney, etc.) *"I know a tremendous number of people who have thyroid issues. underactive thyroids"*
Illness anxiety- describing fear and worry about getting sick ***in the future***, not describing current illnesses. *"thank God, my cancer was caught early and taken care of. But what's next?"*
Women's health- specifically describing women's health issues (pregnancy, PCOS, etc.) *"I've been diagnosed with PCOS. A lot of people I know have been diagnosed with PCOS."*

"I have 3 grown daughters. They're 36, 39 and 41 between my 3 daughters. I've lost 7 grandchildren to miscarriage. Miscarriages never ran in my family or my husband's family."
Lack of trust and disappointment- describing past actions and experiences that have caused them to feel mistrustful of institutions and actors (water utilities, government) or disappointed in feeling under/unprotected *"I'm still like, very distrustful of just water utilities in general."*
Feeling minimized- having their concerns minimized by those in power, contradicting what they see and feel. *"They told me there's nothing to worry about."* *"when you're nonchalant about it, and you just don't care it just the nerve with me majorly."*
Other's don't get it- describing the feelings or perceived misconceptions people have about them, their community, or their experience related to PFAS *"They need to walk a mile in our shoes. They need to see what it is to have to buy a whole bunch of bottled water."*
Refusal- their worry and anger about PFAS motivates them to act and organize. Refusal to accept current conditions. Describing the feelings and desire to contribute to collective actions, civic engagement. high perceived risk **.** *"I called newspapers. I called like I just made a big fuss about it because I was just like, why is no one talking about this."*
Resignation- they know about PFAS, they're worried, but they feel a lack of personal and collective agency ("*What am I going to do? I have to wait. I don't have another option"),* they don't believe there is a solution to the problem ("*I don't think it's ever going to go away*")
ENVIRONMENTAL HEALTH SCIENCES RESEARCH
Participating in research- describing the impact that participating in the GenX Study has had on them affectively ("*it's been eye opening" or "I'm so glad I did it")*
Helping the science- scientific research is a good in and of itself that people want to contribute to. Science as a public good. Participating in research studies as a service to others. *"when I heard about I thought, great sign me up. so I wanted to assist the science"*
Difficulties and barriers- things that make it hard for people to participate in research in theory or that they saw when participating in the GenX study *" I was a little disappointed when I couldn't participate in the exposure study like follow up that they did this fall because of my pregnancy."*
Diversity- specifically mentioning the role of demographics as a motivation or factor in research participation. *" I wish that there had been a lot more initially participation from my community than I saw when I 1st got involved."*
Wanted to know more- viewing participating in the study as a source of information they wanted access to *"I really want to find out exactly how this has affected all of us." "We just don't know, which*

is why I signed our family up for the study, because I think the more information we can get, the better"
Report back- discussing the process of receiving information from the GenX Study (or other research projects if applicable). Discussing the information itself. *"I like their objectivity because, they're not biased"*
PFAS levels- describing their personal measurements and any related emotions *" it's made me very well aware that it is in my blood at very high levels."*
RB Use
Haven't used- specifically saying how they have not used their report back letter or the info therein for anything *"Honestly, I have not really used that information."*
Other behaviors- citing other behaviors they have changed, or ways they've used the study information to inform other actions *"now I can look up these specific compounds and try to identify where those where they're like suggested to be like the source for some of these specific compounds."*
Personal comparisons- describing the way they use their letter as comparing their own levels over time, comparing to others in their family, comparing to threshold values *"after what we just did recently we should get another letter that says how the numbers look, and then I can compare. So I'm looking forward to that letter, so I can see if there is what the difference is."*
Shared info with others- describing how they used their letter when talking about PFAS with others. *"I've been able to, you know, anecdotally talk with friends and neighbors"*
Took to doctor- specifically saying that they took the letter to their doctor *"I have talked and talked to my doctor. I even let him see the results too."*
ENVIRONMENTAL HEALTH LITERACY
Knowledge
PFAS Know- Describing what they know about PFAS. Using this code to generate a picture of how impacted residents make sense of PFAS contamination and science. Objective and subjective knowledge statements included. Statements like "I know that _____" or "it's my understanding that _____". *" I've been doing some reading on bottled water, and that's not even safe anymore."* *"I know that there's this class of chemicals there's like thousands of and like they're testing for, I don't know, 30 of them and they're unregulated"*
PFAS Tell- describing how they SHARE information about PFAS *"Everybody's always helping each other, and so we help in sharing what little information we have."*

PFAS Learn- describing how they learned about PFAS, how they found information or who from. Helps show flow of information within the communities. *"Through the news, of course."*
Behaviors- Exposure Reduction and Lifestyle Changes
ER bottled water- buying bottled water or big jugs of water, not using water from their sink for drinking. *"I drink bottled water at home."*
ER filtered water- talking about different types of water filtration for removing PFAS from drinking water. Can be in-home methods, or municipal. If talking about municipal treatment, needs to be specifically talking about filtered water as related to exposure reduction (not in relation to institutional processes more generally) *"We got the under sink filter which we have the little faucet at the sink, but because we have the whole house filter, it's double filtered. I'll use that water for like boiling to cook with but we don't drink it. We don't even give it to our dogs."*
ER general reduction- describing general behaviors they take that can have a **direct** impact on reducing their exposure to PFAS. Not related to water, food, or purchasing. *"I've like tried to think about where those exposures are coming from, and how I can begin to limit and reduce those specific exposure sources"*
ER LACK of- describing specific actions that they do NOT take that would otherwise reduce their exposure *"when I'm at home, I still drink tap water. I haven't taken many steps to. I guess. Lessen the amount of pfas I'm probably taking in."*
ER avoid local foods- discussion changes to what they eat because of local PFAS contamination. Locally grown and caught things like fish, vegetables, milk, honey. NOT grocery shopping. *"I eat fish and seafood that comes from other States. I listen to the advisories. I won't eat anything that comes from the Cape Fear River."*
ER purchasing choices- changes to purchasing habits to buy things with less or no PFAS (like cookware, outdoor gear, etc.), specifically for the purpose of not being **exposed to** PFAS. Not discussing broader lifestyle changes. Grocery shopping goes here. *"we shifted to the non teflon pans"*
LC financial- discussing increased out of pocket costs that are a direct result of PFAS contamination. Paying for filtration or bottled water, property values, extra testing, etc. *"there's also like the money side of things, too. Like I, I go get my 5 gallon water things filled up. And it's like, you know, you're just always paying extra for more things."*
LC General- broader lifestyle changes as a result of PFAS. Changes to how they think about and interact with different systems (ecological, financial, social, political) *"I know we eat better. We try to get more exercise. we're very cognizant of, I think how short life is now."*

LF hardship- discussing ways life has become more difficult in small and large ways as a direct result of PFAS contamination. Tasks we take for granted becoming more difficult. *"Pretty frustrating that you that you'd like move into a house, and then a month later, you can't use the water"* *"they didn't deliver that consistently, either. Sometimes they would just stop delivering for months, and you'd have to call them back up and say, Hey, where's my water?"*
LC privileged- discussing the way access to resources or exposure reduction requires levels of privilege (financial, etc.). *"that's a privilege you have to have the money and resources and time and the home infrastructure to put in a home filtration system."*
LC Legal and civic actions- discussing filing or joining lawsuits directly related to PFAS (needing to find a lawyer, class action, etc.). describing actions they take or ways they have become civically engaged directly related to the issue of PFAS. (calling elected officials, writing letters, going to public meetings). Describing this as things they currently do, not describing them as broader solutions. *"our names are in a couple of different lawsuits"* *"it's made me attend these other meetings, whether it's for mainly for information, and to be able to attend and be with other people whose interests are the same as mine."*
LC moving- discussing moving away because of the PFAS issue *"we're considering moving, but we have to settle with the lawsuit"*
LC interactions with nature- describing changes to how they interact with nature, the outdoors (hunting, fishing, swimming, gardening) *"I definitely know people who no longer swim in the ocean here because of it, and they have changed their habits in that way, and they no longer enjoy the water the way that they used to."*
PFAS SOLUTIONS
More research- more/continued research needed. Questions they still want answers to
Exposure sources- wanting more research on other ways people may be exposed to PFAS *"I think there needs to be more research done on all of the sources of it"* *"where is the most PFAS are coming from?"*
Health effects- "*does this definitely cause cancer. And if so, how do we fix it?"*
Ongoing testing- *"I think having. like the community, should have access to being able to have their levels tested too."*
Reducing body burden- *"How to get it out of the body of the people that are already affected"*
Water and Environmental quality- *"I would like to see a little more research about are these carbon filtration and reverse osmosis systems, are they truly enough?"* *"What is coming out of that company in Fayetteville now? Is someone testing those waters now to see if pfas is still coming out of that company and releasing downstream?"*
Proof- more research seen as source of certainty, proof of harm, proof of causation. Belief that some type of data will be "enough" to effect change.

"Can you give us more concrete evidence? Can you show, you know how this is affecting people's lives, how it has? Is it affecting people's lives," *"if we were armed with this in the information, we can share it with others- this is what happened. This is what's been conclusively found out."*
Research for action- related to proof, but specifically talking about how research prompts change. Not necessarily because it is without uncertainty, but the generation of data can be USED for other actions (regulation, litigation, etc.) *"So if they come back and they have data that shows that people are being adversely impacted. Then, hopefully we'll finally get something done"*
Collective action- describing the process of addressing PFAS contamination as a collective effort. Specifically using "we" and collective language when describing what they feel should happen. *"I think it takes everybody"* *"it's very short sighted to not understand that even if it's not directly coming out of your water faucet, it's still affecting your life, because it's affecting us citizens, whether they're in your county. your city, your town, your state, we're all in it together"*
Corporate accountability- the belief that the polluters (either in the abstract or specifically naming them) should "take responsibility" "be held accountable" or pay for remediation and clean up. *"the company specifically caused this so they should be taking the oversight and fixing it, really fixing the damage that they've done."*
Litigation- belief that lawsuits and court systems are the only way to effect change. *"Only through the courts."*
Mitigation- describing the need to REDUCE harm from what has already happened. How to be proactive with medical tests and treatments, look for medicines to "reverse" impacts from current exposures. Telling new neighbors to test/filter/change drinking water. *"figure out a way to dispose of waste without it getting into the water,"* *"if over time, it turns out that pfas ingestion puts you at higher risk of liver cancer, then you need to talk to your doctor about how to stay alert to the development of liver cancer just as an example."*
Prevention- describing the need to stop any further use/production of PFAS, preventing any industrial uses or emissions, and using different chemicals instead of PFAS. *"stop those sources long term"* *"It needs to be illegal to release that stuff into the environment, whether it's in the water in the land, whatever."*
Regulation and Enforcement - the need for governmental entities to oversee and enforce. Financial penalties, emission limits, monitoring. *"there should be fines that are happening with these companies that are, you know polluting the waters this way."* *"More federal regulation and state level regulation"*
Remediation- describing the need REMOVE PFAS contamination from the environment (water, soil) and our bodies. *"we need to install some kind of filters, or something that would take it out of our daily lives"*

"having systems to deal with what we have in place, whether or not that's filtering"
Education and outreach
Answerable questions- specific questions people have that we already have answers to. Flagging as opportunities for immediate outreach and engagement efforts by academics, community groups, etc. *"for right now, I'm not sure where it's coming from, but we're getting water. I know I'm billed by a company out of Sanford…"* *"What are they even making there? Because some people are saying it's for gore-tex raincoats, and some people say it's for nonstick pans and other people say it's like weapons or something. No one knows. I don't know."*
Broad ed and outreach- specifically citing the need for more awareness as a means to solving the problem., the need to reduce perceived ignorance among residents, the need to address perceived differences in education levels. Information sharing and outreach seen as a solution or vehicle for the above solutions. *"right now, I guess I would want to be armed with you know more knowledge. So that I could do more"*
For doctors- the lack of awareness currently among healthcare providers and/or the need to educate them *"the lack of knowledgeable doctors and nurses in giving information, and like, I guess, even like testing for things like knowing what to test, for ordering labs, to test, for things like that would be an area where I definitely like more information"*
Building trust and transparency- Describing the need for more transparency from various actors *"Transparency. If you're doing something, let us know exactly what it is that you're doing. Because I could not pinpoint to you at this very moment that I know that there is some kind of system going on."* *"You could tell us that the levels are going down, but I don't see anything on my bill that says anything"*