

Non-stick science: Sixty years of research and (in)action on fluorinated compounds
Social Studies of Science 48(5): 691-714.

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Abstract

Understandings of environmental governance both assume and challenge the relationship between expert knowledge and corresponding action. We explore this interplay by examining the context of knowledge production pertaining to a contested class of chemicals. Per- and polyfluorinated alkyl substances (PFASs) are widely used industrial compounds containing chemical chains of carbon and fluorine that are persistent, bioaccumulative and toxic. Although industry and regulatory scientists have studied the exposure and toxicity concerns of these compounds for decades, and several contaminated communities have documented health concerns as a result of their high levels of exposure, PFAS use remains ubiquitous in a large range of consumer and industrial products. Despite this significant history of industry knowledge production documenting exposure and toxicity concerns, the regulatory approach to PFASs has been limited. This is largely due to a regulatory framework that privileges industry incentives for rapid market entry and trade secret protection over substantive public health protection, creating areas of *unseen science*, research that is conducted but never shared outside of institutional boundaries. In particular, the risks of PFASs have been both structurally hidden and unexamined by existing regulatory and industry practice. This reveals the uneven pathways that construct issues of social and scientific concern.

Keywords

lay discovery, unseen science, ignorance, emerging contaminants, fluorinated compounds

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Introduction

A group of seemingly new chemical contaminants has recently gained significant international attention. Research by toxicologists, epidemiologists, chemists and exposure scientists has burgeoned. State agencies have developed and lowered advisory levels, and even set regulatory levels in one case. Newspapers, online news sites and eco-blogs have featured stories about poisonous pizza boxes, toxic microwave popcorn bags, and unhealthy exercise clothes. Yet chemical manufacturers and some environmental regulators have been aware of the exposure concerns of these substances for decades, and the exposure pathways described in media headlines do not do justice to the ubiquitous daily exposures all people experience through consumer products, food, drinking water and other pathways. The chemicals of concern are PFASs – poly- and perfluorinated alkyl substances – a class of thousands of human-made chemicals containing chains of carbon and fluorine atoms (Wang et al., 2017). PFASs have received relatively little attention outside of small scientific and industry circles, despite a series of contamination episodes across the United States, Europe and China, lawsuits against some of the world’s largest chemical corporations, and scientific knowledge of pervasive global exposure in humans, wildlife and drinking water. Why does this class of chemicals remain relatively unknown to concerned consumers and even environmental health advocates, despite a long and involved history of industry and regulatory research and legal action? Is this lack of broader attention unique and surprising for a class of chemicals with a long scientific and industrial history, or does it represent a more typical lack of awareness and concern around chemicals to which we are ubiquitously exposed?

This paper investigates the rise of scientific interest in the class of PFAS compounds across a number of settings. In particular, we focus on two related research questions: 1) How

have the scientific dangers of PFASs been produced, interpreted, shared, concealed and acted upon by industry, regulatory, scientific and advocacy stakeholders and organizations? 2) What accounts for decades of contested social and scientific concern around the environmental and human health risks of these chemicals?

In this paper, we present an overview of sociological research on environmental health risks and describe PFASs as a class of ‘re-emerging contaminants’. We draw on Krimsky’s (2000) work tracing the origins of what he terms a *public hypothesis*, to account for scientific knowledge production involving multiple stakeholder groups and significant public engagement. We are interested in how characteristics of PFASs as a chemical class came to be scientifically understood, and the conditions under which lay concerns over the impacts of contamination became avenues for new scientific knowledge production. After briefly outlining the methodological approach of our research project, we offer in-depth descriptions of three episodes that characterize negotiated scientific knowledge production (Brannigan, 1981). Our focus is on how research findings do and do not inspire broader awareness and concern on the part of various publics or state agencies, and when embodied health mobilizations in turn catalyze scientific research knowledge sequestration (Frickel and Edwards, 2014) or undone science (Frickel et al., 2010; Hess, 2009). We conclude by discussing the implications of these findings for environmental governance and for social science theories of knowledge and non-knowledge production.

Contested scientific knowledge production

Scholarship in Science and Technology Studies (STS) has long examined the multifaceted production and mobilization of science across institutional contexts (Haraway, 1989; Jasanoff,

2003; Latour, 1987; Murphy, 2006; Wynne, 1996). Science is central to contemporary policy debates about chemicals, and is increasingly required in a variety of non-scientific spheres, including the regulatory, legal and social movement arenas (Frickel, 2004; Habermas, 1970; Michaels and Monforton, 2005). Kinchy (2012: 25) defines this process of *scientization* as ‘the transformation of political conflict ... into a debate among scientific experts, ostensibly separate from the social context in which it unfolds’. Critics contend that scientization excludes lay voices and structures debates in a way that perpetuates the regulatory status quo and the interests of industry (Morello-Frosch et al., 2006). The matter of who is in a position to produce, interpret, and validate data is highly contested in research on non-voluntary chemical exposures and adverse health effects (Brown, 2007; Dumit, 2006; Murphy, 2006; Sellers, 1997). While institutional contexts are important in scientific production, equally central are complex historical relationships that structure the landscape of empirical norms and possibilities.

Drawing on Krimsky’s (2000) work on the lay origins of scientific hypotheses, this paper focuses on the contexts of knowledge production and awareness pertaining to PFASs. Since the late 1970s, STS scholars have critically examined the interpretive practices used by scientists to construct particular forms of rationality, reach scientific consensus and establish boundaries around what ‘counts’ as legitimate science (Brannigan, 1981; Shapin and Schaffer 1985; Gieryn, 1983; Shwed and Bearman, 2010). Scholarship in this tradition has emphasized the social-structural factors involved in research practices and scientific knowledge production. Brannigan (1981) argues that predominant theories of scientific practice typically assume an individual-level genius and/or a seemingly natural, inevitable event. For Brannigan, the task is to investigate how particular events become labeled as new scientific knowledge or discoveries, in light of social context. From this perspective, the uneven history of environmental health

knowledge production across stakeholder groups can be understood as the mobilization of contested knowledge claims.

The construction and mobilization of scientific claims are studied by a variety of theoretical STS traditions. Scientific research never operates independently of social forces, and despite popular discourse the implications of science are neither readily obvious nor directly translated into public policy. Rather, a number of social forces channel science in different directions for distinct purposes, and thus the boundary between science and social fields is permeable, contested and inseparable (Gieryn, 1983). Scholars of the 'New Political Sociology of Science' highlight the political-economic forces that shape the conceptualization, funding, production and dissemination of science (Frickel and Moore, 2006; Kleinman and Suryanarayanan, 2013). Much as Latour and Woolgar (1986) point to the need for scientists to engage in recruitment in order to persuade others to believe in and implement their innovations, Krimsky (2000) traces how scientists actively translate their research to engage various publics. All invested actors engage in 'strategic science translation' (Cordner, 2015) to interpret and communicate scientific evidence to an intended audience for the purposes of advancing certain goals and interests. These processes demonstrate how the separation between scientists and non-scientists and between the scientific and the social are overlapping, blurred and challenged.

Citizen science and community-based participatory research make many contributions to scientific knowledge (Corburn, 2005; Kinchy, 2012; O'Fallon and Deary, 2002). Residents of contaminated communities have conducted popular epidemiology to research the locations and consequences of environmental hazards (Brown, 1987). Crowdsourced data has contributed to fields as diverse as wild bird counts and water pollution from hydraulic fracking (Cavalier and Kennedy, 2016; Dickinson and Bonney, 2012; Irwin, 1995; Wylie et al., 2014). Requests by

affected residents and community leaders can prompt government scientists to carry out surveillance or research, thus increasing scientific knowledge production oriented towards characterizing the health and environmental impacts of a compound. This often involves *undone science*, areas of research that are of concern for residents, workers, or other members of the public, yet are not an area of focus for academic, government or industry researchers, often due to deliberate or tacit avoidance (Frickel et al., 2010; Hess, 2009).

The institutional structures that affect scientific knowledge production are often obscured or guarded from public view, leading to significant data gaps, uncertainties, and areas of undone science regarding environmental health hazards (Allen et al., 2016; Cordner and Brown, 2013; Frickel et al., 2010). To understand the emerging public understanding of the endocrine disruptor hypothesis, Krimsky (2000) focuses on the growing awareness by a broad group of stakeholders and publics, not just practicing researchers, of a previously unrecognized or poorly understood social problem, disease, environmental hazard or social phenomenon. Such awareness in the public sphere can be impeded in several ways: by government agencies who fear the burden of dealing with contamination, by industries who claim research on their products as ‘confidential business information’, or by scientists who resist the input of affected residents. Exemplified by the experience of Lois Gibbs uncovering contamination in Love Canal, NY in the 1970s (Gibbs, 2002; Levine, 1982), lay people affected by pollution in countless locations have detected contamination and/or health effects and pressed for remediation, prevention, and legal and judicial action. Lay involvement in producing a public hypothesis involves struggles between countervailing forces under public scrutiny (Krimsky, 2000).

When chemical hazards are involved, corporate-sponsored science is well known for promoting and emphasizing scientific uncertainty and ‘manufacturing doubt’ in order to delay or

prevent regulatory or public-sphere activities that would limit production (Markowitz and Rosner, 2002; Michaels, 2005; Proctor and Schiebinger, 2008; Shapiro, 2014). While these patterns of scientific manipulation are common, data gaps and ignorance can also result from institutional and structural features of the scientific and regulatory fields. As Frickel and Edwards (2014) show in their study of exposure research following Hurricane Katrina, organized institutional ignorance can be a product of regulatory science. Institutional ignorance can also be an outcome of industry science. This can be intentional, as when a company stops studying a topic because they do not want to discover further cause for concern, or can emerge from disciplinary habits or structural considerations, as when researchers investigate birth defects by looking at maternal exposures but very rarely paternal exposures.

Particularly relevant here is the difference between production-oriented science, which ‘aims to generate deliverables’ such as new product development, and impact-oriented science, ‘which enhances our understanding of environmental and human health impacts of production processes, products, and externalities’ (Gould, 2015: 3; see also Schnaiberg, 1977). Industry research is primarily production-oriented. When impact-oriented science is conducted by corporations to evaluate the risks of their own products, it carries significant potential for conflict of interest in the production and interpretation of scientific data. For example, within the environmental regulatory context, the norms of production-oriented science often prevent research scientists from obtaining information on new chemical structures or accessing existing industry testing due to claims of ‘confidential business information.’ In this instance, science is not only undone, but unseen, which is a major feature of PFAS research. “Unseen science,” the scientific knowledge kept from public and professional view, is a major feature that we discuss in greater detail below.

Scientific knowledge production can lead to a more widespread public awareness, as was the case with hormone disrupting chemicals (Krimsky, 2000) and flame retardant chemicals (Cordner, 2016). Public interest in these classes of chemicals was spurred by growing knowledge that many contaminants were ubiquitous in the population, as shown by federal surveillance through the Centers for Disease Control and Prevention's (CDC) National Health and Nutrition Examination Survey and through numerous biomonitoring and household exposure studies conducted by academics and advocacy groups. A growing corps of scientists who employ community-engaged research and community-based participatory research approaches deliberately partner with local community groups or exposed lay people. This sometimes involves sharing surveillance and exposure data with participants with high chemical exposure levels (Brody et al., 2014), prompting activists and officials to take on a research role. In the United States, such surveillance is necessary since government chemical monitoring is inadequate and further exacerbated by weak policy that leaves most chemicals underregulated and understudied.

However, the relationship between scientific knowledge production and attendant policy or public health interventions cannot be assumed (Brannigan, 1981). When impact-oriented science occurs in institutional sites that do not publicly share research findings, regulatory agencies, environmental health scientists, and different publics lack access to research that might motivate rapid replication and further investigation. In the case of PFASs, we find that the production of scientific knowledge varies greatly depending on the institutional location of the research itself and whether the research aims are public or private in nature. In this paper, we present three episodes from the history of PFASs that demonstrate different possible entanglements between impact- and production-oriented scientific discoveries. In the first case

presented below, we find points of private scientific knowledge production that do not trigger regulatory responses or allow for public attention, but instead represent areas of *unseen science*. In contrast, in the second and third cases examined below we find significant interplay between scientific and lay knowledge production, leading to more public health and impact-oriented research in regulatory research labs, independent academic labs, and in partnership with exposed communities.

Emerging contaminants and per- and polyfluorinated alkyl substances

Environmental sociology and STS have a significant history of investigating contaminated communities, regulatory failure and corporate mishandling of data pertaining to environmental pollution. Researchers focused on toxics and health have examined broad exposure to individual chemicals such as BPA (Vogel, 2009), high profile community contamination from specific industrial sources (Brown, 1997; Bullard, 1990; Erikson, 1976), discrete grassroots campaigns against unwanted land use (Cole and Foster, 2001), and mobilization around adverse health effects such as asthma and endocrine disruption (Brown, 2007; Krimsky, 2000; Langston, 2010).

This article offers a relatively novel approach to studying contamination, shifting from single chemical or case analysis toward an investigation of an entire class of industrial chemicals (Cordner, 2016; Howard, 2011). In the United States, the regulatory structure around industrial chemicals supports the rapid approval and production of new chemicals (US Congress, 1976). Thus, when an existing chemical is found to have concerning health or environmental effects, it is common for a chemical manufacturer to develop or market a replacement compound with a similar but distinct chemical structure as a ‘safe’ alternative (Vogel, 2009). The Environmental Protection Agency (EPA), the agency charged with reviewing newly developed industrial

chemicals before they can be sold or distributed, must rely on a limited amount of data to evaluate the risks of new chemicals and is widely viewed as having lost its authority to regulate existing chemicals in a timely or protective way (Geiser, 2015; Vogel and Roberts, 2011). Given the general assumption of upfront chemical safety conceded to US chemical manufacturers, investigating classes or groups of chemicals instead of individual chemicals is beneficial for environmental scientists, regulators and social science analysts alike.

The ubiquity of industrial chemicals threatens both environmental quality and human health. The vast majority of the more than 84,000 industrial chemicals registered in the United States with the EPA lack any data on how people are exposed to them, at what levels, and with what consequences (Egghy et al., 2012; Judson et al., 2009; US EPA, 2010). Furthermore, while exposure to many chemicals is ubiquitous, exposure is also unequal, with communities of color, the poor and people living near and working in industrial facilities all facing disproportionately high chemical exposures (Mohai et al., 2009). Although there is a common expectation in the United States that the EPA fully assesses the safety of all chemicals that are in use, in practice this is far from the case. Industrial chemicals are regulated by the Toxics Substances Control Act (TSCA), but significant limitations in both the original 1976 bill and a recently-passed TSCA reform bill mean that the regulation of most chemicals, especially those in production before 1976, is woefully inadequate (Geiser, 2015; US EPA, 2009b; Vogel and Roberts, 2011). Exposures to chemicals are complex and often are poorly understood. This is particularly the case for chemicals that are considered ‘emerging contaminants’. A chemical may be ‘emerging’ for a range of reasons, including that: available data and links to potential human health are concerning but limited, there are new modes of production, use and disposal, or

technical detection-limits change what levels of exposure researchers and regulators are able to ‘see’ through laboratory analysis.

Among the over 3,000 estimated distinct PFAS compounds (Lau, 2015), two specific compounds are most widely known: perfluorooctanic acid (PFOA, also called C8 because of the eight-carbon chain in the chemical formula), which was used in the manufacture of Teflon cookware coatings and is a byproduct of many other chemical processes, and perfluorooctane sulfonate (PFOS), used in Scotchgard fabric protectors, firefighting foam and in semiconductor devices. While PFOA was first synthesized by DuPont chemists in 1938, first used in commercial products in 1949, and studied by DuPont for toxicological and exposure concerns starting in the 1960s (Lyons, 2007), significant awareness of PFASs within the regulatory and academic science community did not occur until decades later.

There is no available data about total PFAS production, in part because no regulatory agency systematically keeps track of these chemicals as a class (US EPA, 2009). For example, no PFASs are included on the Toxics Release Inventory, a program maintained by the EPA that tracks releases of approximately 700 chemicals of concern (US EPA, 2017a). The general public’s exposure to multiple PFAS compounds is ubiquitous: The CDC’s NHANES national biomonitoring program measured 212 chemicals, including 12 PFAS compounds, in a nationally representative sample of 2,500 US residents, and found four PFASs in the serum of over 98% the people tested (Calafat et al., 2007; CDC, 2009). Academic, advocate and regulatory studies documenting widespread exposure have brought PFASs to the attention of a new audience of environmental health scientists and involved laypeople, especially residents whose drinking water is contaminated with PFASs (Environmental Working Group, 2017; US EPA, 2017b).

Though median NHANES exposure levels are lower than levels typically used in animal toxicology studies or documented in contaminated communities, ubiquitous PFAS exposure is particularly concerning because the entire population is exposed to these chemicals, which do not naturally degrade in the environment and have concerning health effects (Post et al., 2012). As we discuss in greater detail below, the C8 Science Panel, a large epidemiological study in Ohio and West Virginia of residents who drank PFOA-contaminated water, linked PFOA exposure to high cholesterol, ulcerative colitis, thyroid disease, testicular and kidney cancers, and pregnancy-induced hypertension (C8 Science Panel, 2011, 2012a, 2012b, 2012c, 2012d). Other suspected health impacts of exposure to certain PFASs include endocrine disruption, obesity, reproductive problems, birth defects, other types of cancer, stroke and developmental problems in children (Lau, 2015). While PFOA and PFOS are no longer produced by manufacturers in the US, replacement compounds called ‘short-chain’ PFASs are widely used in spite of concerns about exposures and toxicity (Danish Ministry of the Environment, 2015; Rae et al., 2015; Sun et al., 2016; US EPA, 2017c). Given the ubiquity of exposure and the rising number of communities with high level PFAS contamination, the scientific, legal and regulatory responses across public and private stakeholders serve as important entry-points into strategic scientific production and translation.

Data and methods

This paper is part of a larger project on PFAS compounds, and focuses on two related research questions: (1) How have the dangers of per- and polyfluorinated compounds been discovered, interpreted and acted upon by industry, regulatory, scientific and advocacy stakeholders and organizations? (2) What has accounted for decades of contested social and scientific concern around the environmental and human health risks of these chemicals? Following Corder and

Brown's previous research project on flame retardants (Cordner, Brown and Mulcahy 2013; Cordner, Brown, and Mulcahy 2015; Cordner 2015), the data collected for the project include in-depth, semi-structured interviews, observations at scientific and advocacy conferences on PFASs, and ongoing participant observation across a range of involved parties, including regulatory agencies, government research laboratories, affected residents, advocacy organizations and university research settings. In addition to interviews and observations, we draw on ongoing in-depth historical analysis, as well as document and media analysis pertinent to PFASs compounds. This research was approved by Institutional Review Boards at Northeastern University and Whitman College.

We conducted 78 interviews between July 2015 and October 2017. Interview subjects include scientists in academia (n=9), government (n=20), state regulators (n=5), federal regulators (n=11), chemical industry scientists and representatives (n=3), journalists (n=2), affected community residents (n=15) and advocacy organization scientists and staff (n=13). Interviews were conducted in person (n=53) when possible, and otherwise by phone (n=33). Interviews were recorded, stored electronically as encrypted files and later transcribed. Additionally, we wrote up and de-identified observational notes from those interviews.

Our approach towards data analysis is guided by the concept of *relational ethnography* focused on studying how scientific knowledge is produced and contested across time and space (Desmond, 2014). Thus, we use a mixed methodological approach that includes multi-sited participant observation. Between July 2016 and February 2017, we completed seven months of participant observation to learn how scientists, industry, regulators and contaminated communities are dealing with PFASs. Drawing on the model of the prior flame retardant project, the relational ethnography approach was both feasible and a rich source of data. Sites studied

include the two offices at the EPA (Office of Research and Development, and Office of Pollution Prevention and Toxics) and various locations in Minnesota, a site of historic PFAS contamination and the location of a major PFAS manufacturer's headquarters. Additionally, we have observed industry stakeholders at EPA's Toxic Substances Control Act 2016 public meetings and multiple scientific conferences related to PFASs. Research assistants collected observational data at public meetings regarding local PFAS contamination throughout New England between June 2015 and October 2017. Archival research was conducted through digital EPA dockets on PFAS-related litigation and subsequent TSCA-related investigations, and at the Minnesota Historical Society collection of 3M company archives in Saint Paul, Minnesota.

A research assistant tracked coverage of PFASs contamination sites globally through Google media alerts, Environmental Health News' daily newsletter, and Lexis-Nexis. This led to the creation of a spreadsheet of all known contamination sites that is available on our public project website (pfasproject.com). When we launched this database in March 2017 it had 52 sites, and by August 2018 this has increased to 180 sites. To our knowledge, it is the only comprehensive and publicly available source of information on PFAS-related contamination sites, litigation and exposure. Based on this data, we constructed an in-depth timeline tracing pertinent developments in peer-reviewed literature, media coverage of contamination discoveries, litigation and policy changes involving PFASs. The timeline assists in comparison of how actors respond to various scientific findings, moments of discovery, legal and regulatory decisions, and is available on our project website. We analyzed interview transcripts, fieldnotes, newspaper coverage and archival documents through multiple readings to iteratively identify themes and patterns related to social and scientific discovery.

Three episodes of contention in knowledge production

The production of knowledge surrounding PFASs is an ongoing and contentious process, stretching over decades and involving a variety of stakeholders, including academic, industry and regulatory agency scientists, as well as contracted laboratories and consultants. However, lay stakeholders have played the central role in generating visible knowledge of the environmental, human and animal health consequences of PFASs contamination. As with other chemicals, adverse animal and human health effects were and remain proverbial ‘canaries in the coal mine’ – or in this case, canaries in the kitchen, as cooking with Teflon cookware is well known to kill pet birds (Shusterman, 1992). In a chemical regulatory system that presumes pre-1976 chemicals to be safe and permits rapid new chemical production with little to no environmental or health data, the most likely source of data is observed harmed people and animals – ‘bodies in the street’, in the words of epidemiologists and occupational health specialists (Michaels, 2008). Just as Rachel Carson (1962) observed decades ago in her work on pesticides, characterizing the human health effects of pesticide exposure by farmworkers as anecdotal dismisses not only our best source of information, but sometimes the only source of evidence we have (Nash, 2006).

This section examines the factors that contribute to the shifting patterns of knowledge production across institutions and stakeholder groups. Out of a more than sixty-year history of scientific controversy on the environmental and health impact of the most widely studied PFAS compounds, PFOA and PFOS, we focus on three episodes: (1) a 1981 private industry finding in a laboratory that was shared with another company, (2) a 1990 episode of lay knowledge on a farm that initiated significant regulatory action and academic scientific research, and (3) a series of scientific findings between 2000 and 2012 that led to wider public awareness in the Mid-Ohio Valley. Notably, internal documents reveal that PFAS chemical manufacturers had evidence indicating adverse human and animal health effects of these compounds as early as the late

1960s and early 1970s (Grandjean 2018). The three select examples illustrate the complexity and range of contexts that explain why knowledge pertaining to this class of compounds has not substantially altered the dominant misperception of this class as ‘emerging’ or led to more systematic restriction of their use at the federal level. We argue that such persistent lack of knowledge is the result of a political process, owing not to a paucity of data, but to the intentional production and reproduction of ignorance by inadequate chemical regulatory framework and by chemical companies and their networks of consultants, lobbyists and trade associations. While the production of scientific denial in agnotology studies has been the subject of significant research (Proctor 2008; Oreskes and Conway 2010), the PFAS case reveals that an important aspect of the production of ignorance involves preventing the production of evidence that powerful actors might eventually need to deny.

Episode 1: Industry knowledge of health effects in labs and workers

In addition to the product research and development conducted by chemical manufacturers, such companies also engage in evaluative or impact-oriented science to characterize any potential health risks a substance may pose, including laboratory studies to identify chemical properties, exposure characteristics and toxicological endpoints. Under TSCA’s Section 8(e), chemical manufacturers are required to report to the EPA any research results indicating actual or potential health harms related to their products (US Congress, 1976). Interviews and internal documentation reveal that 3M and DuPont, the two major US manufacturers of PFOA, took notably different approaches towards complying with this TSCA requirement in the 1980s and 1990s (Lyons, 2007).

Early knowledge of the risks from PFAS exposure at 3M and DuPont came from laboratory studies of health effects in rodents and primates, and from observations of factory workers. Litigation has revealed that in the late 1960s and early 1970s, academic researchers notified 3M that they had found organofluorine compounds in human blood that they suspected were linked to 3M commercial products (Taves, 1968; Guy et al., 1976). In 1978, two industry primate studies found adverse health effects and mortality in monkeys exposed to PFOS (Goldenthal et al., 1978a; Goldenthal et al., 1978b). In 1981, an internal laboratory study at 3M found that pregnant rats exposed to PFOA experienced severe birth defects in their rat pups (Hegg, 1981). The company then removed thirteen female employees from their Decatur, Alabama chemical plant, reporting to the press that company doctors detected ‘organic fluorides’ in the workers’ blood and that ‘some’ of these chemicals may cause cataracts in rat fetuses (Associated Press, 1981). 3M shared these internal results with both DuPont and the EPA.

While 3M engaged in partial disclosures pertaining to PFOA (US EPA, 2006), DuPont failed to disclose internal research documenting potential human health risks to EPA as required by TSCA. Internal documents reveal that DuPont reviewed the 1981 3M studies, concluding that the rat birth defects were due to PFOA exposure (Blake, 2015; 3M, 1981). In January of 1981, a DuPont employee in the Teflon division, Sue Bailey, gave birth to a baby with severe eye and nostril deformities, similar to those found in the rat studies. A colleague put Bailey in touch with another female worker in the Teflon division who gave birth to a baby with eye deformities. In 1981, while Bailey was on leave, DuPont removed all female staff, a total of seven women, from the Teflon unit (Karrh, 1981; Lerner, 2015). In December of 1981, 3M and DuPont produced new lab studies concluding that PFOA did not cause rat pup birth defects (Blake 2015; Burger, 1981). In 1982, DuPont officials met with the EPA to share this new animal data, but did not

disclose any information about employees' children with birth defects (Blake, 2015; McKusick, 1982). DuPont documents from that meeting reveal that EPA staff expressed concern about the reversal in birth defect study findings, but sought no regulatory action (Blake, 2015; McKusick, 1982).

The birth defects experienced by female DuPont employees working in the Teflon division were rendered imperceptible for regulatory scientific investigation or broader public inquiry, due to industry sequestration of employee medical information from the employees themselves and from EPA. Furthermore, DuPont withheld its concerns about exposure and risk from most employees and from local communities in the Mid-Ohio Valley. Thus scientific findings were shared with the EPA in such a manner that the research could not influence other scientists, regulators or public officials, nor contribute to a greater scientific or public awareness, nor allow for external investigation of potential harms to exposed workers.

This episode illustrates the structurally hidden paths of industry knowledge production, combined with the withholding of findings from regulators. Scientific findings took a circuitous path moving from 3M to DuPont to EPA, with the two companies then producing additional data they used to deny the relationship between PFOA exposure and birth defects. We view this as the production of unseen science, as we discuss in the conclusion. This temporarily secured the companies' legal invulnerability and apparent compliance with TSCA, while facilitating the continued growth of PFOA production for decades. This case illustrates how the industry strategy of selectively sharing impact science while leaving some science unseen simultaneously truncates further impact science capable of implicating a product.

Internal DuPont documents confirm this conclusion. By 1984, the company was testing tap water in communities near the Washington Works facility in West Virginia without public

knowledge (Lyons, 2007); this research would not be made public until a class-action lawsuit against DuPont began in 2001. In a confidential memo, DuPont recognized that ‘off plant’ and consumer PFOA exposures needed to be eliminated, though the memo author suggests the costs of eliminating exposure would be too great: ‘Currently, none of the options developed are ... economically attractive and would essentially put the long-term viability of this business segment on the line. From a broader corporate viewpoint the costs are small’ (DuPont, 1984, cited in Lyons, 2007: 31). The memo concludes that eventually legal and medical branches of the company will ‘take a position of total elimination’ regarding PFOA, while the products branch will argue against elimination because of the costs of doing so. DuPont did not begin to phase-out PFOA production until 2006, as we describe in Episode 2 below.

Episode 2: Lay awareness on the farm

A second episode of knowledge production on PFOA toxicity demonstrates the potential for lay awareness to inspire significant scientific research and regulatory action. In 1980, DuPont purchased a portion of a farm in West Virginia owned by the Tennant family, agreeing to use the land for disposal of non-hazardous materials (Blake, 2015; Lyons, 2007). However, this property became a central disposal location for PFOA waste from DuPont’s Washington Works Plant, a large chemical manufacturing plant on the Ohio River in Parkersburg, WV, which produced Teflon starting in the 1950s. Initially, the Tennant family noticed the disappearance of minnows from their creek and death of wild deer on their property, and by 1990 their entire herd of 280 cattle died from a mysterious ‘wasting away’ sickness (Lerner, 2015; Lyons, 2007). After years of unsuccessful outreach to DuPont and local regulatory agencies, in 1999 the Tennants hired attorney Rob Bilott to represent them in a lawsuit against DuPont. The dramatic death of the

cattle, the Tennant family's long-term presence on their farm and expertise in cattle ranching, DuPont's violation of their agreement that the farmland would only be used for non-hazardous waste, and DuPont's sole ownership of the landfill created a unique alignment of legal and scientific conditions that supported the Tennants' legal standing and nuisance claims against DuPont.

The lay discovery of PFOA contamination followed a path described by Brown (1987) as *popular epidemiology*, in which lay people – often residents in contaminated communities – identify illness rates and clusters linked to a polluter of concern. The Tennants' successful 1999 lawsuit led directly to the knowledge that PFOA was the main chemical disposed of near their farm (Lyons, 2007; Lerner, 2015). Throughout the lawsuit DuPont attempted to limit the scope of information they disclosed to data on already-regulated chemicals, which would have excluded PFOA. However, after Bilott read that PFOA-contaminated sludge was disposed of near the Tennant farm, he requested all DuPont's documentation on this essentially unknown, unregulated compound (Lyons, 2007). It was only through the legal discovery process that DuPont's internal data on PFOA came to light (Blake, 2016).

Because of the Tennants' lawsuit, EPA learned of DuPont's failure to disclose data on female employees' birth defects, and the Agency determined that DuPont had violated reporting requirements under section 8(e) of TSCA. Attorney Bilott shared 900 pages of internal DuPont documents acquired through the legal discovery process with EPA in March 2001 (Blake, 2016). This led to a \$10.25 million civil settlement with the EPA and an additional \$6.25 million for supplemental environmental projects, as well as an attempted but ultimately unsuccessful criminal lawsuit pursued by the EPA (Savan, 2007; US EPA, 2005b). At the time, the fines were the largest administrative penalty ever paid to the EPA, though short of the \$300 million that was

possible (Lerner, 2015). One year later in 2006, 3M paid \$1.5 million in TSCA-related violations, mainly pertaining to reporting on PFOA and PFOS (US EPA, 2006). That same year, instead of facing potential restriction or bans of their products by the EPA through TSCA, the manufacturers of PFOA and PFOS agreed to completely phase out production of these long-chain PFASs by 2015 (US EPA, 2017).

Episode 3: Epidemiological findings from settlement-funded research

Our third episode stems from actions in part inspired by the second one, and involves the scientific investigation and wider public awareness of probable health effects of PFOA exposure. Prior to the Tennants' litigation, very limited independent or academic research on the health or environmental impacts of PFOA or other PFASs had been conducted. This is due to a confluence of factors, including corporate proprietary trade secrets on in-use chemicals, the legally unregulated status of PFOA, and a lack of institutionally mandated impact-oriented science. For example, researchers studying the presence of *fluoride* in human blood consistently found the widespread *fluorine* present as early as the 1960s and 1970s, and suspected the source was consumer products (Guy et al., 1976). After successfully representing the Tennant family, Bilott organized a 2001 class action lawsuit representing approximately 80,000 residents of the Mid-Ohio Valley with PFOA-contaminated drinking water (Bilott, 2013). As with the 1999 Tenant family case, DuPont chose to settle the lawsuit rather than go to trial. The company agreed to pay up to \$70 million for a health study of exposed residents, with an additional \$235 million in potential class compensation if the chemical were proven to cause health harm (Jack W. Leach, et al. v. E.I. du Pont de Nemours & Company).

The epidemiological approach of the health study was designed to obtain the highest number of participants in the most culturally appropriate manner (Frisbee et al., 2009). The first

phase of the C8 Health Project entailed comprehensive medical study for as many members of the class as possible. To lead the health study independent of its corporate funder, the court appointed a local physician, Dr. Paul Brooks. Brooks first held local focus groups to ascertain the best approach for attracting regional participation. As Lyons (2007) describes, this approach was ‘a cultural and anthropological phenomenon’:

The effective and simple marketing made its way beyond the typical venues of media and into some of the most remote areas of Ohio and West Virginia. In some cases, the people invited to participate were unaware that they were eligible for the class action suit. Many simply did not realize that C8 was present in their drinking water until they were approached about signing up for the C8 health project. (Lyons, 2007: 88)

The structure of the health study adapted successfully to the cultural, financial and geographic needs of this region, enlisting over 69,000 participants within a year of its start in 2005. The C8 health study held local town hall sessions throughout the region, as much of the population was unaware of the contamination, the class action lawsuit or the court-mandated health study. This may have been due to lack of internet access, illiteracy rates and poor media coverage (Lyons, 2007: 88). The health study employed local staff to conduct participant interviews in six modular unit trailers spread throughout the region. After study officials notified participants that ‘there are no normal values as in high or low’, many community members mobilized others to participate and share results with each other in an attempt to make sense of their PFOA measurements (Lyons, 2007:93).

In addition to the litigation-funded health research, public concern led to a community-based exposure research project funded by the National Institute of Environmental Health Sciences (NIEHS), in which the University of Pennsylvania partnered with the Decatur Community Association. Researchers tested blood serum in a stratified random sample of 370 community members who received water between 2004 and 2005 from the Little Hocking Water

Association (LHWA), the water district most affected by the Washington Works contamination. The study found PFOA blood levels 60 to 75 times higher than the national average (Emmett et al., 2006a, 2006b). On the day in August 2005 when these results were shared at a community meeting, DuPont announced delivery of free bottled water to LHWA municipalities, implicitly recognizing the company's role in the contamination and representing an important gain for the residents. Follow-up testing two years later showed that PFOA concentrations in participants' blood serum fell 26%, a change attributed to widespread behavioral changes as a result of the report-back of individual exposure data (Emmett et al., 2009; Judge et al., 2016).

Following the success of the C8 Health Project in its overall exposure and health assessment of over 69,000 participants, the C8 Science Panel was appointed to identify potential 'probable links' between PFOA exposure and negative health outcomes (e.g. C8 Science Panel, 2012a). These exposure, health and epidemiological studies provided affected residents with multiple forms of new scientific information about their health and extent of environmental contamination. Three independent epidemiologists were appointed to lead the analysis of the data. This expert-derived knowledge production was necessary for understanding a chemical like PFOA for several reasons: (1) an individual cannot see, taste or smell the substance, and thus understanding exposure required sophisticated analytical chemistry technologies that did not exist until the late 1990s; (2) the human health effects from low-dose exposure are often latent, not acute, and can emerge following low-dose exposure; and (3) until 2000, there was little public or regulatory knowledge of this substance due to the grandfathering in of pre-1976 chemicals under TSCA. With over 69,000 participants, this was an exceptionally large study and hence able to identify exposure-disease relationships that are difficult to observe through smaller sample sizes. By 2012, the C8 Science Panel had released a series of results from their

epidemiological study, finding probable links between exposure and six diseases: testicular cancer, kidney cancer, ulcerative colitis, thyroid disease, pregnancy-induced hypertension and hypercholesterolemia (C8 Science Panel, 2011, 2012a, 2012b, 2012c, 2012d). Additional adverse health effects have since been linked to PFOA exposure, and in February 2017 DuPont and its spin-off Chemours settled lawsuits with 3,500 individuals diagnosed with one or more of these probable link illnesses (Rinehart, 2017).

The Tennant family's success in court, and the resulting release of internal industry documents, led to in-depth, independent scientific investigation of the presence and health effects of PFOA by academic and regulatory scientists. Medical monitoring, the C8 Science Panel, and possibility of financial compensation contributed to the development of a critical public hypothesis by residents of the Mid-Ohio Valley. This was more than two decades after DuPont had suspected significant rates of employee birth defects in 1981 and confirmed PFOA contamination in public drinking water in 1984.

Discussion and conclusion

Science is often characterized by the media, regulatory agencies and dominant industries as continually progressing, with significant research findings necessarily leading to regulatory action. That perspective is persistently invoked by the both the chemical industry and EPA. However, science is embedded in social contexts, and scientific discoveries and their applications are neither linear nor inevitable (Cordner, 2015; Jasanoff, 2003; Latour, 1987). As is clear in the case of PFAS, the relationship between scientific knowledge production and public awareness regarding health impacts is multifaceted, and at times intentionally incapacitated (Sedlak, 2016). Indeed, after sixty years of industry, lay and regulatory knowledge production around the risks of PFASs, it is only recently that US state and federal environmental agencies

have moved forward with voluntary or, in rare cases, regulatory drinking water guidelines (US EPA, 2017d; State of New Jersey Department of Environmental Protection, 2017).

In this paper we have described three episodes of knowledge production and dissemination that demonstrate how scientific knowledge production can be connected to multiple actors and settings. This case illustrates how undone science may sometimes be better conceived of as *unseen science*, research conducted but never shared outside of institutional boundaries. The unequal ability to access or withhold information that creates and perpetuates areas of unseen science results from unequal distributions of power and resources, or from benefits regarding knowledge access and protection that are codified in rules, regulations and laws. For example, federal regulations protecting industry confidential business information facilitates the protection of unseen science by chemical companies. Although we have focused here on unseen science produced by industry stakeholders, unseen science is common in other areas of knowledge production, such as in purported national security issues (e.g., nuclear release and waste issues surrounding the Manhattan Project) or in academic research that produces null findings or failed replications of prior research. Further unpacking different forms and functions of unseen science is an important topic for future STS scholarship.

Our research shows that chemical companies intentionally sequestered data that was concerning. Presumed data gaps thus reflected hidden data that was unseeable by those outside of industry. While it is clear that undone science may function as a liability protection in the form of ‘plausible deniability’ of health effects, efforts by industry to guard already-conducted research as invisible and thus unknowable may serve similar functions. Indeed, one finding from our analysis is that regulatory action and public awareness has been limited *despite* the existence

of consequential industry scientific findings regarding adverse health effects and significant public exposure to toxic chemicals.

The pathways of scientific knowledge production described in these three episodes provide insight into the compromised capacity of the US chemical regulatory framework to protect public health. US regulatory infrastructure privileges corporate discretion regarding the extent and meaning of industry research. At present, production science logics, industry withholding of research, and the protection of confidential business information limit the state's capacity to conduct the impact-oriented science required by EPA's authority and mandate. This is possible in part due to assumptions that the institutional interests of scientists or their employers do not affect the outcomes of research. This belief persists in spite of extensive research documenting the clear relationship between funding sources and scientific findings (Cosgrove and Krimsky, 2012; Kleinman and Suryanarayanan, 2013; Krimsky, 2005). Despite concerns about conflicts of interest in the design, conduct and interpretation of industry-funded research (Michaels, 2008; Michaels and Monforton, 2005), current regulatory arrangements allow private institutions to evaluate impact-oriented science on the environmental and health consequences of their products. Our findings bring renewed attention to conflicts of interest, showing that it took decades for industry's undisclosed PFASs exposure data and health effects to come to public light. The selective production of science thus undergirds both unseen and undone science, enabling both the production and maintenance of regimes of imperceptibility (Murphy, 2006).

Other forces are positioned to challenge areas of undone and unseen science. Improved knowledge on PFASs brought out by the episodes we address are the result of entanglements of lay observation and understanding, legal action, independent science, media coverage and

growing public awareness. The first episode demonstrates how knowledge production can be stalled, remaining unseen outside of institutional boundaries. Thus an internal industry scientific conclusion that PFOA caused rat pup birth defects and that PFOA exposure might cause birth defects in worker pregnancies did not lead to external independent research or regulatory action. This is partly due to deliberate concealment by companies, and partly due to structural features of the US Federal chemicals policy. The incomplete disclosure of research findings by PFAS manufacturers to the EPA took multiple forms, including technical compliance with EPA reporting requirements, qualifications and explanations that downplayed health effects, and the outright withholding of relevant research findings. This illustrates how the process of scientific knowledge production is made uneven and often impeded due to a theoretically predictable pattern of institutional conflicts of interest.

In contrast, the second and third episodes demonstrate the interplay between information uncovered by lay publics, regulators and industry and government scientists. The second episode describes the emergence of an area of formerly unseen science following the lay observation and mobilization. In response to the discovery of wildlife and cattle deaths on private land abutting an identifiable site of industry waste disposal, impacted residents sought legal action. Their success in litigation – specifically in the discovery process requiring internal document disclosure – enabled further scientific and regulatory action. In the final episode, the production of new knowledge about PFASs became possible because of court-mandated medical monitoring and the C8 Science Panel. Since then, public-oriented scientific research on PFASs in peer-reviewed scientific journals has grown rapidly, from fewer than 300 studies published prior to the year 2000, to over 3,000 studies by 2015 (Lau, 2015). This research led to wider regional

awareness among a large population previously unaware of the contamination of their drinking water, illustrating an uneven path of knowledge production unfolding among stakeholders.

Research into the EPA docket containing material from the DuPont settlement demonstrates decades of cover-up and the careful production of unseen science. Litigation has been a central stimulus for many delayed environmental and public health research interventions, as with tobacco, lead and polyvinyl chloride (Markowitz and Rosner, 2002). In the case of PFASs, the litigation-prompted C8 Health Study led to a significant body of health research and the linking of health effects to PFOA exposure (Judge et al., 2016). Since litigation often results from lay and worker exposure experiences, popular epidemiology and community advocacy, environmental health research initiatives and continued chemical regulatory reform should include systematic public input and mechanisms for responding to community-identified contamination.

Litigation is but one piece of the interplay of social institutions that have shed light on PFAS compounds. The research from the DuPont lawsuit produced one of the largest epidemiological studies on environmental contamination, which laid the groundwork for additional federally-funded research, conferences and position papers. That chain of research and related activities provided scientific basis for EPA to lower its drinking water advisory levels for PFOA and PFOS, for numerous states to reduce their drinking water advisory levels, and for New Jersey to adopt a regulatory level for PFOA in drinking water. The action of affected people in the mid-Ohio Valley provided evidence and inspiration for many affected communities to take up the issue of PFAS contamination resulting in further research, government and industry clean-up, and recent attention to over 600 military sites, airports and fire-training areas that are highly contaminated with PFAS used in firefighting foams (McDaniel and McCrystal, 2016). US

Senators and Congressional Representatives amended the omnibus Defense Authorization Act to provide significant funding for PFAS exposure research on military sites (US Congress, 2017). Environmental engineers are developing new approaches to remediation and evaluating the efficacy of filters to remove PFASs from drinking water (Xiao et al., 2017). Resident activists have formed national networks to help each other in the many processes of research, remediation, and prevention (Highly Fluorinated Compounds National Conference, 2017; Toxics Action Center, 2017). Environmental advocacy groups have pressured major retailers to reduce or abandon PFAS in products (GSPI, 2017). As a result of the complex processes of social action and scientific research, these outcomes have occurred with a class of chemicals of which few people had heard five years earlier.

Despite the successes noted above, the existence and health impacts of these chemicals are structurally obscured, largely because knowledge about chemical formulations, usage and health and environmental impacts remains tightly controlled, and often concealed, by the PFAS industry and the US regulatory system tasked with overseeing chemical safety. In our study, we find that initial pathways of knowledge production flowed through animal and human bodies sufficiently contaminated and uniquely positioned to render harms visible, and secure necessary legal standing to pursue institutional recourse through litigation. Had the Tennants not successfully sued DuPont and not requested all documents mentioning PFOA, the extent and risks of contemporary PFAS contamination could still be unknown to the public. Industry science could have remained unseen given the regulatory status quo. Other sites of lay awareness became possible only because of the scientific research produced related to DuPont's West Virginia facility. For example, the 2014 discovery of water contamination in Hoosick Falls, New York was identified by a resident who was concerned with prevalent cancers and who found

online information on PFOA and associated health effects from the C8 Science Panel studies (Associated Press, 2016). This more recent investigation contributed to the EPA setting chronic exposure drinking water guidelines, industry-funded water filtration in many contaminated communities, state regulatory and legislative activities, and a class-action lawsuit in Hoosick Falls.

Thus, on the basis of previous episodes of knowledge production, cases of PFOA contamination can now be identified even if they are less clearly embodied in animal or human victims, and government institutions can substantively respond to the presence of concerning levels in drinking water. Yet even with a growing volume of peer-reviewed scientific research on the human and animal health effects of PFAS exposure, the current US chemical regulatory system is unable to enforce the EPA's mandate to monitor, track, investigate and remediate chemicals of concern. Scientists around the world studying consumer exposures, oceans, and wildlife continue to be confronted with unknown PFAS compounds. This case illustrates the risks of a regulatory structure that assumes chemicals are safe until proven harmful, and places the burden of proof of harm on residents and agencies ill-equipped to produce scientific knowledge on chemical compounds only substantively known by their private producers. Despite the obstacles, local actors and networks of concerned scientists and advocates have made PFAS contamination more visible through research, litigation, public policy, demands for remediation, and pressure on manufacturers and retailers. As with other chemicals, it is engaged members of the public and social movements who ultimately discover unseen science and shift regulatory institutions towards addressing undone science and the implementation of more precautionary environmental policy.

Acknowledgements

The authors thank Stephanie Knutson for her editorial assistance, and members of the Social Science Environmental Health Research Institute at Northeastern for their helpful feedback. We express our sincere thanks to all those we have interviewed and spent time with during our research.

Funding Acknowledgment

Research for this paper was made possible through a grant by the National Science Foundation (SES-1456897).

References

3M (1981) 3M TSCA Section 8(e) notice submitted to US EPA. (EPA Docket AR-226-1373). Washington: US EPA.

Allen B, Ferrier Y, and Cohen A (2017) Through a maze of studies: health questions and ‘undone science’ in a French industrial region. *Environmental Sociology*, 3(2), 134-144.

Associated Press (1981) 3M moves workers after tests. St. Paul Sunday Pioneer Press. Available from 3M Company Archives Minnesota Historical Society, St. Paul, MN.

Associated Press (2016) In Upstate NY village of Hoosick Falls, a trail of cancer leads to tap water. *Syracuse.com*, 26 January.

Bilott RA (2013) *Letter to Bruce Tierney at the Agency for Toxic Substances and Disease Registry*. EPA Docket AR-226-1372.

Blake M (2015) Welcome to Beautiful Parkersburg, West Virginia. Home to one of the most brazen, deadly corporate gambits in US history. In The Huffington Post. Available at: <http://highline.huffingtonpost.com/articles/en/welcome-to-beautiful-parkersburg/> (accessed 1 January 2016).

Brannnigan A (1981) *The Social Basis of Scientific Discoveries*. Cambridge: Cambridge University Press.

Brody J, Dunagan S, Morello-Frosch, et al. (2014) Reporting individual results for biomonitoring and environmental exposures: Lessons learned from environmental communication case studies. *Environmental Health*. 13: 40. Published online 2014 May 26. doi: 10.1186/1476-069X-13-40

Brown P (1987) Popular epidemiology: Community response to toxic waste-induced disease in Woburn, Massachusetts. *Science, Technology, and Human Values* 12(3): 78-85.

Brown P (2007) *Toxic Exposures*. New York: Columbia University Press.

Brown P and Mikkelsen EJ (1997) *No Safe Place: Toxic Waste, Leukemia, and Community Action*. Berkeley, CA: University of California Press.

Brown P, McCormick S, Mayer B, et al. (2006) ‘A lab of our own’: Environmental causation of breast cancer and challenges to the dominant epidemiological paradigm. *Science, Technology & Human Values* 31(5): 499–536.

Brown P, Morello-Frosch R, and Zavestoski S (2012) *Contested Illnesses: Citizens, Science, and Health Social Movements*. Berkeley: University of California Press.

Bullard R (1990). *Dumping in Dixie: Race, class, and environmental quality*. Boulder, CO: Westview Press.

Burger RJ (1981) C-8 (FC-143) Status Report. Internal DuPont Memo to Fluoropolymers Supervision.

C8 Science Panel (2011) Probable Link Findings Pregnancy Related Diseases. Available at: http://www.c8sciencepanel.org/pdfs/Probable_Link_C8_PIH_5Dec2011.pdf (accessed 23 April 2014).

C8 Science Panel (2012a) Probable Link Findings Heart Disease. Available at: http://www.c8sciencepanel.org/pdfs/Probable_Link_C8_Heart_Disease_29Oct2012.pdf (accessed 23 April 2014).

C8 Science Panel (2012b) Probable Link Findings Cancer. Available at: http://www.c8sciencepanel.org/pdfs/Probable_Link_C8_Cancer_16April2012_v2.pdf (accessed 23 April 2014).

C8 Science Panel (2012c) Probable Link Findings Autoimmune Diseases. Available at: http://www.c8sciencepanel.org/pdfs/Probable_Link_C8_Autoimmune_Disease_30Jul2012.pdf (accessed 23 April 2014).

C8 Science Panel (2012d) Probable Link Findings Thyroid Disease. Available at: http://www.c8sciencepanel.org/pdfs/Probable_Link_C8_Thyroid_30Jul2012.pdf (accessed 23 April 2014).

Calafat AM, Wong L, Kiklenyik Z, Reidy JA, and Needham LL (2007) Polyfluoroalkyl Chemicals in the US Population: Data from the National Health and Nutrition Examination Survey (NHANES) 2003–2004 and Comparisons with NHANES 1999–2000. *Environmental Health Perspectives* 115(11):1596-1602.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2072821/> (accessed 2 December 2017).

Carson R (1962) *Silent Spring*. Washington: Georgetown University Press.

Cavalier D and Kennedy EB, eds. (2016) *The Rightful Place of Science: Citizen Science*. Tempe, AZ: Consortium for Science, Policy, and Outcomes.

Centers for Disease Control and Prevention (2009) *Fourth National Report on Human Exposure to Environmental Chemicals*. Atlanta, GA: Centers for Disease Control and Prevention.

Cole L and Foster S (2001) *From the Ground Up: Environmental Racism and the Rise of the Environmental Justice Movement*. New York: NYU Press.

Corburn J 2006. *Street Science: Community Knowledge and Environmental Health Justice*. Cambridge MA: MIT Press.

Cordner A (2015) Strategic Science Translation and Environmental Controversies *Science, Technology & Human Values*. 40: 915-938.

Cordner A (2016) *Toxic Safety: Flame Retardants, Chemical Controversies, and Environmental Health*. New York: Columbia University Press.

Cordner A and Brown P (2013) Moments of Uncertainty: Ethical Considerations and Emerging Contaminants. *Sociological Forum* 28(3): 469–494.

Cordner A, Brown P, Mulcahy M (2015). ‘Playing with fire: Flame Retardant Activists and Policy Arenas. In *Players and Arenas: The Interactive Dynamics of Protest*. Jan Willem Duyvendak and James Jasper, Eds. Amsterdam University Press. 211-228.

Cordner A, Mulcahy M, Brown P (2013) Chemical Regulation on Fire: Rapid Policy Advances on Flame Retardants. *Environmental Science & Technology* 47:7067-7076.

Cosgrove L and Krimsky S (2012) A comparison of DSM-IV and DSM-5 panel members’ financial associations with industry: a pernicious problem persists. *PLoS Med*, 9(3), p.e1001190.

Danish Ministry of the Environment. 2015. Short-chain Polyfluoroalkyl Substances (PFAS). A literature review of information on human health effects and environmental fate and effect aspects of short-chain PFAS. (accessed 1 December 2017)

Desmond M (2014) Relational ethnography. *Theory and Society* 43(5): 547–579.

Dickinson J and Bonney R (2012) *Citizen Science: Public Participation in Environmental Research*. Ithaca, NY: Cornell University Press.

Dumit J (2006) Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social science & medicine*. 62(3), 577-590.

Egeghy P, Judson R, Gangwal S, et al. (2012) The Exposure Data Landscape for Manufactured Chemicals. *Science of the Total Environment* 414(1): 159–166.

Emmett E, Shofer F, Zhang H, et al. (2006b) Community Exposure to Perfluorooctanoate: Relationships between Serum Concentrations and Exposure Sources. *Journal of Occupational and Environmental Medicine* 48(8):759–70.

Emmett E, Zhang H, Shofer F, et al. (2006a) Community Exposure to Perfluorooctanoate: Relationships between Serum Levels and Certain Health Parameters. *Journal of Occupational and Environmental Medicine* 48(8):771–9.

Emmett EA, Zhang H, Shofer FS, et al. (2009) Development and Successful Application of a ‘Community-First’ Communication Model for Community-Based Environmental Health Research. *Journal of Occupational and Environmental Medicine*. 51(2): 146–156.

Environmental Working Group (EWG) (2017) Mapping a Contamination Crisis. Available at: <https://www.ewg.org/research/mapping-contamination-crisis> (accessed 28 November 2017).

Erikson KT (1976) *Everything in its path: Destruction of Community in the Buffalo Creek Flood*. New York: Simon and Schuster.

Frickel S (2004) Just Science? Organizing Scientist Activism in the US Environmental Justice Movement. *Science as Culture* 13(4): 449–469.

Frickel S and Moore K (2006) *The New Political Sociology of Science: Institutions, Networks, and Power*. Madison: University of Wisconsin Press.

Frickel S and Edwards M (2014) Untangling Ignorance in Environmental Risk Assessment. In: Boudia S and Jas N (eds) *Powerless Science?: Science and Politics in a Toxic World* New York : Berghahn Books, 215-233.

Frickel S, Gibbon S, Howard J, et al. (2010) Undone Science: Charting Social Movement and Civil Society Challenges to Research Agenda Setting. *Science, Technology, & Human Values* 35(4): 444–476.

Frisbee SJ, Brooks AP, Maher A, Flensburg P, et al. (2009) The C8 health project: design, methods, and participants. *Environmental Health Perspectives*. 117(12):1873-82.

Geiser K (2015) *Chemicals without Harm: Policies for a Sustainable World*. MIT Press.

Gibbs L (2002). Citizen activism for environmental health: The growth of a powerful new grassroots health movement. *The Annals of the American Academy of Political and Social Science*, 584(1), 97-109.

Gieryn T (1983) Boundary-work and the demarcation of science from non-science: Strains and interests in professional ideologies of scientists. *American Sociological Review* 48(6);781-795.

Goldenthal EI, Jessup DC, Geil RG, Mehring JS (1978a) Final report, ninety day subacute rhesus monkey toxicity study. *International Research and Development Corporation*, study no. 137–090. U.S. EPA Administrative Record, AR226–0447. Washington, DC: US EPA.

Goldenthal EI, Jessup DC, Geil RG, Mehring JS. (1978b) Ninety-day subacute rat toxicity study, with Fluorad® Fluorochemical Surfactant FC-95, *International Research and Development Corporation*, project No. 137–085. U.S. EPA Administrative Record, AR226–0137. Washington, DC: US EPA.

Gould K (2015) Slowing the nanotechnology treadmill: Impact science versus production science for sustainable technological development. *Environmental Sociology* 1(3): 143–151.

Grandjean P (2018) Delayed discovery, dissemination, and decisions on intervention in environmental health: A case study on immunotoxicity of perfluorinated alkylate substances. *Environmental Health* 17(1): 62.

Green Science Policy Institute (GSPI) (2017) <http://greensciencepolicy.org/>. (accessed 19 November 2018).

Grandjean P (2018) Delayed discovery, dissemination, and decisions on intervention in environmental health: A case study on immunotoxicity of perfluorinated alkylate substances. *Environmental Health* 17(1): 62

Guy WS, Taves DR, and Brey Jr WS, (1976) Organic fluorocompounds in human plasma: Prevalence and characterization. In: Filler R (ed) *Biochemistry Involving Carbon-Fluorine Bonds*. American Chemical Society. 117-134.

Habermas J (1970) *Toward a Rational Society: Student Protest, Science, and Politics*. Boston: Beacon Press.

Haraway DJ (1989) *Primate visions: Gender, Race, and Nature in the World of Modern Science*. New York; Routledge.

Hegg GL (1981) Section 8(e) Toxic Substances Control Act (TSCA) Perfluoroalkane Carboxylic Acids and Corresponding Ammonium Carboxylates. St. Paul, MN: 3M Commercial Chemical Division.

Hess D (2009) The Potentials and Limitations of Civil Society Research: Getting Undone Science Done. *Sociological Inquiry* 79(3): 306–327.

Highly Fluorinated Compounds: Social and Scientific Discovery. Conference at Northeastern University June 2017. Presentations available: <https://pfasproject.com/conference-presentations/>

Howard J (2011) Environmental nasty surprise, post-normal science, and the troubled role of experts in sustainable democratic environmental decision making. *Futures*, 43(2): 182-195.

Irwin A (1995) *Citizen Science: A Study of People, Expertise and Sustainable Development*. London: Routledge.

Jasanoff S (2003). Technologies of humility: Citizen participation in governing science. *Minerva* 41:223-244.

Judge M, Brown P, Brody J, et al. (2016) The Exposure Experience: Participant Responses to a Biomonitoring Study of Perfluorooctanoic Acid (PFOA). *Journal of Health and Social Behavior* 57: 333-350.

Judson R, Richard A, Dix D, et al. (2009) The Toxicity Data Landscape for Environmental Chemicals. *Environmental Health Perspectives* 117(5): 685–695.

Karrh B (1981) Ammonium Perfluorooctanoate FC-143_C-8 Compounds. DuPont ‘Personal & Confidential’ Memo. (EPA Docket AR-226-1375). Washington: US EPA.

Kinchy AJ (2012) *Seeds, Science, and Struggle: The Global Politics of Transgenic Crops* Cambridge, MA: MIT Press.

Kleinman DL and Suryanarayanan S (2013) Dying Bees and the Social Production of Ignorance. *Science Technology & Human Values* 38: 492-517.

Krimsky S (2000) *Hormonal Chaos: The Scientific and Social Origins of the Environmental Endocrine Hypothesis*. Baltimore: Johns Hopkins University Press.

Langston NN (2010) *Toxic bodies: Hormone disruptors and the legacy of DES*. New Haven CT: Yale University Press.

Latour, B (1987) *Science in Action: How to Follow Scientists and Engineers Through Society*. Cambridge, MA: Harvard University Press.

Latour B and Woolgar, S (1986) *Laboratory Life: The Construction of Scientific Facts*. Princeton, NJ: Princeton University Press.

Lau C (2015) Perfluorinated Compounds: An Overview. In: DeWitt JC (ed) *Toxicological Effects of Perfluoroalkyl and Polyfluoroalkyl Substances*. Switzerland: Springer International Publishing.

Lerner S (2015) DuPont and the Chemistry of Deception. *The Intercept*, 11 August, Available at: <https://theintercept.com/2015/08/11/duPont-chemistry-deception/> (accessed 20 December 2015).

Levine A (1982) *Love Canal: Science, Politics, and People*. Lexington, MA: Lexington Books.

Lyons C (2007) *Stain-Resistant, Nonstick, Waterproof, and Lethal: The Hidden Dangers of C8*. Westport, CT: Praeger Publishers.

Markowitz G and Rosner D (2002) *Deceit and Denial: The Deadly Politics of Industrial Pollution*. Berkeley, CA: University of California Press.

McDaniel J and McCrystal L (2016) Nearly 400 military bases must be tested for drinking water contamination – and it will take years. *The Philadelphia Enquirer and Daily News* 21 April.

McKusick BC (1982) Report of FC-143 Tetratogenic Studies to EPA. Dupont Memo to Raines JW. (EPA Docket AR-226-1396). Washington, DC: US EPA.

Michaels D (2008) *Doubt Is Their Product: How Industry's Assault on Science Threatens Your Health*. New York: Oxford University Press.

Michaels D and Monforton C (2005) Manufacturing Uncertainty: Contested Science and the Protection of the Public's Health and Environment. *American Journal of Public Health* 95(S1): S39–48.

Mohai P, Pellow D, and Roberts JT (2009) Environmental Justice. *Annual Review of Environment and Resources* 34: 405–430.

Morello-Frosch R, Zavestoski S, Brown P, et al. (2006) Embodied Health Movements: Responses to a 'Scientitized' World. In: Frickel S and Moore K (eds) *The New Political Sociology*

of Science: Institutions, Networks, and Power. Madison: University of Wisconsin Press, pp.244-271.

Murphy M (2006) Sick building syndrome and the problem of uncertainty: Environmental politics, technoscience, and women workers. Duke University Press.

Nash LL (2006) *Inescapable Ecologies: A history of Environment, Disease, and Knowledge*. Berkeley, CA: University of California Press.

O'Fallon L, Deary A (2002) Community-based participatory research as a tool to advance environmental health sciences. *Environmental Health Perspectives*. 110 (Suppl 2):155-159.

Oreskes N and Conway EM (2010) *Merchants of Doubt: How a Handful of Scientists Obscured the Truth on Issues from Tobacco Smoke to Global Warming*. New York: Bloomsbury Press.

Post GB, Cohn PD, and Cooper KR (2012) Perfluorooctanoic acid (PFOA), an emerging drinking water contaminant: a critical review of recent literature. *Environmental Research* 116: 93-117.

Proctor R and Schiebinger L (2008) *Agnotology: The Making and Unmaking of Ignorance*. Stanford: Stanford University Press.

Rae, JC, Craig L, Slone TW, Frame SR, Buxton LW, Kennedy GL. (2015) Evaluation of chronic toxicity and carcinogenicity of ammonium 2, 3, 3, 3-tetrafluoro-2-(heptafluoropropoxy)-propanoate in Sprague–Dawley rats. *Toxicology Reports*, 2, 939-949.

Rinehart E (2017) DuPont to Pay \$670 Million to Settle C8 Lawsuits. *The Columbus Dispatch* 13 February.

Savan, L (2007) Teflon is Forever. *Mother Jones*. Available at: <https://www.motherjones.com/environment/2007/05/teflon-forever/> (accessed 19 August 2018).

Schnaiberg A (1980) *The Environment: From Surplus to Scarcity*. Cambridge: Oxford University Press.

Sedlak D (2016) Fool Me Once. *Environmental Science & Technology*, 50(15), 7937.

Sellers CC (1997) *Hazards of the job: from industrial disease to environmental health science*. Durham NC: University of North Carolina Press.

Shapin S, Schaffer S (1985) *Leviathan and the Air-Pump: Hobbes, Boyle, and the Experimental Life*. Princeton NJ: Princeton University Press.

Shapiro N (2014) Un-Knowing Exposure: Toxic Emergency Housing, Strategic Inconclusivity and Governance in the US Gulf South. In: Cloatre E and Pickersgill M (eds) *Knowledge, Technology and Law*. New York: Routledge.189-205.

Shusterman DJ (1992) Polymer fume fever and other fluorocarbon pyrolysis-related syndromes. *Occupational medicine* 8(3): 519-531.

Shwed U, Bearman P (2010) The Temporal Structure of Scientific Consensus Formation. *American Sociological Review*. 75, 6: 817-840.

State of New Jersey Department of Environmental Protection (2017) Christie Administration Takes Action to Enhance Protection of New Jersey's Drinking Water. Available online: http://www.nj.gov/dep/newsrel/2017/17_0104.htm. (accessed 2 December 2017).

Sun M, Arevalo E, Strynar M, Lindstrom A, Richardson M., Kearns, et al. (2016) Legacy and emerging perfluoroalkyl substances are important drinking water contaminants in the Cape Fear River Watershed of North Carolina. *Environmental Science & Technology Letters*, 3(12), 415-419.

Taves DR (1968) Evidence that there are two forms of fluoride in human serum. *Nature*. 217(5133):1050-1.

Toxics Action Center (2017) Available at: <https://toxicsaction.org> (accessed 19 August 2018).

US Congress (1976) Toxic Substances Control Act. *15 USC 2601-2692*. US Congress (2017) House of Representatives. National Defense Authorization Act for Fiscal Year 2018, H.R. 2810. 115th Congress.

US EPA (2005) EPA Settles PFOA Case Against DuPont for Largest Environmental Administrative Penalty in Agency History.

US EPA (2006) EPA Settles Case Involving 3M Voluntary Disclosures of Toxic Substances Violations. Available at: https://archive.epa.gov/epapages/newsroom_archive/newsreleases/440f8e8e3e28707e8525715b007186f7.html

US EPA (2009a) Long Chain Pefluorinated Chemicals (PFCs) Action Plan. Available at: http://www.epa.gov/oppt/existingchemicals/pubs/pfcs_action_plan1230_09.pdf (accessed 15 July 2014).

US EPA (2009b) *Essential Principles for Reform of Chemicals Management Legislation*. Washington, DC: US EPA.

US EPA (2010) What Is the TSCA Chemical Substance Inventory? Available at: <http://www.epa.gov/oppt/newchems/pubs/invntory.htm> (accessed 10 December 2010).

US EPA (2013) 2010/2015 PFOA Stewardship Program. Available at: <http://www.epa.gov/oppt/pfoa/pubs/stewardship/> (accessed 10 July 2013).

US EPA (2017a) Toxics Release Inventory. Available at: <https://www.epa.gov/toxics-release-inventory-tri-program/tri-listed-chemicals>. (accessed 2 December 2017).

US EPA (2017b) [Fourth Unregulated Contaminant Monitoring Rule](https://www.epa.gov/dwucmr/fourth-unregulated-contaminant-monitoring-rule). Available at: <https://www.epa.gov/dwucmr/fourth-unregulated-contaminant-monitoring-rule> (accessed 28 November 2017).

US EPA (2017c) PFOA Stewardship Program Baseline Year Summary Report. Available at: <https://www.epa.gov/assessing-and-managing-chemicals-under-tsca/pfoa-stewardship-program-baseline-year-summary-report> (accessed 28 November 2017).

US EPA (2017d) Drinking Water Health Advisories for PFOA and PFOS. Available at: <https://www.epa.gov/ground-water-and-drinking-water/drinking-water-health-advisories-pfoa-and-pfos> (accessed 2 December 2017).

Vogel SA (2009) The politics of plastics: the making and unmaking of bisphenol a ‘safety’. *American Journal of Public Health* 99(S3): S559-S566.

Vogel SA and Roberts JA (2011) Why the Toxic Substances Control Act Needs an Overhaul, and How to Strengthen Oversight of Chemicals in the Interim. *Health Affairs* 30(5): 898–905.

Wang Z, DeWitt JC, Higgins CP, et al. (2017) A Never-Ending Story of Per- and Polyfluoroalkyl Substances (PFASs)? *Environmental Science & Technology* 51(5): 2508-2518.

Wylie S, Jalbert K, Dosemagen S, and Ratto M (2014) Institutions for civic technoscience: How critical making is transforming environmental research. *The Information Society* 30(2): 116-126.

Wynne, B (1996). May the sheep safely graze? A reflexive view of the expert-lay knowledge divide. In: Lash S, Szerszynski B, Wynne B (eds) *Risk, Environment and Modernity: Towards a New Ecology*. New York: Sage. 44–83

Xin Xiao X, Ulrich BA, Chen B, and Higgins C (2017) Sorption of Poly- and Perfluoroalkyl Substances (PFASs) Relevant to Aqueous Film-Forming Foam (AFFF)-Impacted Groundwater by Biochars and Activated Carbon. *Environmental Science & Technology*. 51 (11), pp 6342–6351 DOI: 10.1021/acs.est.7b00970

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