Breathing Injustice

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Redesigning Asthma as a Collective Illness Experience

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Thesis presented by Todd Linkner
to the Department of Art + Design

In partial fulfillment of the requirements
for the degree of Master of Fine Arts
in Information Design and Visualization
in the Graduate School of
the College of Arts, Media and Design

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Northeastern University
Boston, Massachusetts
May, 2020

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Abstract

Asthma is a powerful lens to explore the intersections of pollution, social geography, and the long-standing impacts of structural racism. The burden of asthma is unequally distributed across geographies characterized by race, ethnicity, and economic status. While health professionals widely accept that outdoor air quality and indoor environmental conditions aggravate asthma symptoms, this contributes to a biomedicalized view of the disease that treats its symptoms but fails to address its root causes. With the biomedical view, patients or parents of children with asthma are given the responsibility for managing their illness by maintaining constant vigilance to avoid environmental triggers. We can instead cultivate a focus on the root causes in the environment for which we have a shared societal responsibility. Research shows that the triggers that exacerbate the symptoms of asthma don't represent the full extent of the environmental causes. Because the contributing causes and impacts reach beyond the individual, asthma is best understood as an illness that affects communities. The sociologically produced disparities of the disease are exposed in the environment and can be addressed by collective action.

I have designed an open-source workshop centered around a simple device to explore asthma as a sociologically produced disease using the breath as a physical interface. The workshop simulates spatialized socioeconomic and environmental factors and their impact on the experience of asthma. This approach is intended to build social cohesion around the root causes by framing asthma as a collective illness, rather than one affecting isolated individuals. To facilitate the workshops, I designed a kit that includes a curriculum guide for health advocacy organizations and activists. The Breathing Injustice Workshop encourages people to understand asthma from an environmental perspective in order to form publics that can advocate for communities facing an increased burden of the disease.

Aknowledgements

This thesis would not have been possible without the support, influence, and insights of many people. I want to thank my advisor, Tad Hirsch, for his guidance through each stage of the process, and for encouraging a practice of politically engaged design. I thank Sara Wylie for her valuable insights and for helping me navigate environmental health and tactical media.

I'm incredibly appreciative of my reviewers, who took time out of their busy lives to share their expertise: Carl Di Salvo, Julian Drix, and Ty-Eisha Rivera.

To the CAMD faculty and my colleagues in the MFA program, it has been a privilege to share this journey with you.

I am grateful to my parents, Herb and Karla, whose teachings I carry with me always. To my daughters, Camille and Iris, thank you for distracting me and making sure I had fun. And finally, Becky, without whose support, encouragement, and sacrifice this would not have been possible.

Contents

1 **Introduction** 1

- 1.1 *Asthma and Individuals* 4
- 1.2 *Asthma and Society* 8
- 1.3 *Framing a Collective Illness Experience* 10

2 **Perspectives on Health and the Environment** 13

- 2.1 *Individuals* 14
- 2.2 *Communities* 15

3 **Giving Form to Complexity** 21

- 3.1 *Empathy in Design* 21
- 3.2 *Making Visible* 25
- 3.3 *Participation and Engagement* 28
- 3.4 *Summary* 31

4 **Understanding Asthma through Design** 33

- 4.1 *Challenging Design Orthodoxies* 34
- 4.2 *Discursive Design* 34
- 4.3 *Adversarial Design* 35
- 4.4 *Situated Design* 35
- 4.5 *Tactical Media* 36

5 **A Social Design Process** 39

- 5.1 *Finding a Context for Change* 40
- 5.2 *Synthesizing Research and Framing a Problem* 40
- 5.3 *Generating Ideas for Ways to Address the Problem* 41
- 5.4 *Sharing My Ideas and Getting Feedback* 42
- 5.5 *Evaluating Feedback* 42

6 **Preliminary Design Experiments** 45

- 6.1 *Personal Air Quality Map* 47
- 6.2 *Human-Made Weather Report* 47
- 6.3 *Constriction Diagram* 48
- 6.4 *Data Straw* 49
- 6.5 *Wheezing Map* 52
- 6.6 *Breathing Map* 53
- 6.7 *Air Hunger Device* 54
- 6.8 *Learning from My Experiments* 55

7 **Case Study: Breathing Injustice** 57

- 7.1 *The Asthmaker Device* 58
- 7.2 *Workshop Guide* 68
- 7.3 *Expert Review* 75
- 7.4 *Reflection on Expert Evaluations* 80
- 7.5 *Evaluation Plan* 81

8 **Conclusion** 83

Appendix A: Audio Guide Scripts 87

Appendix B: Workshop Evaluation Questionnaire 95

References 99

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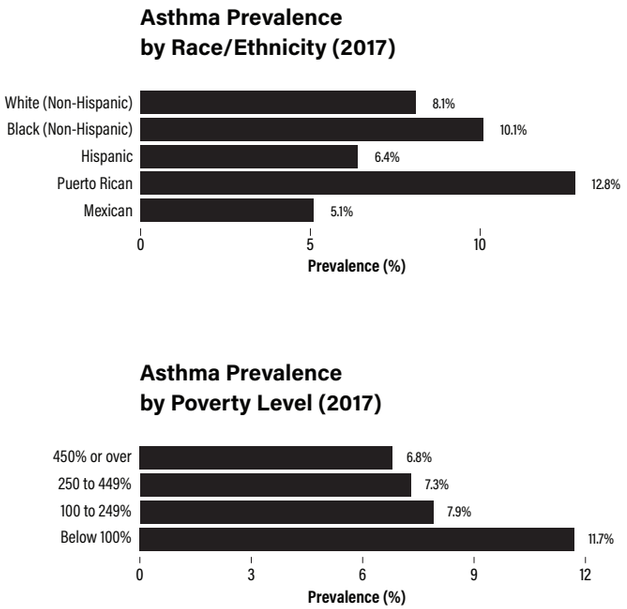
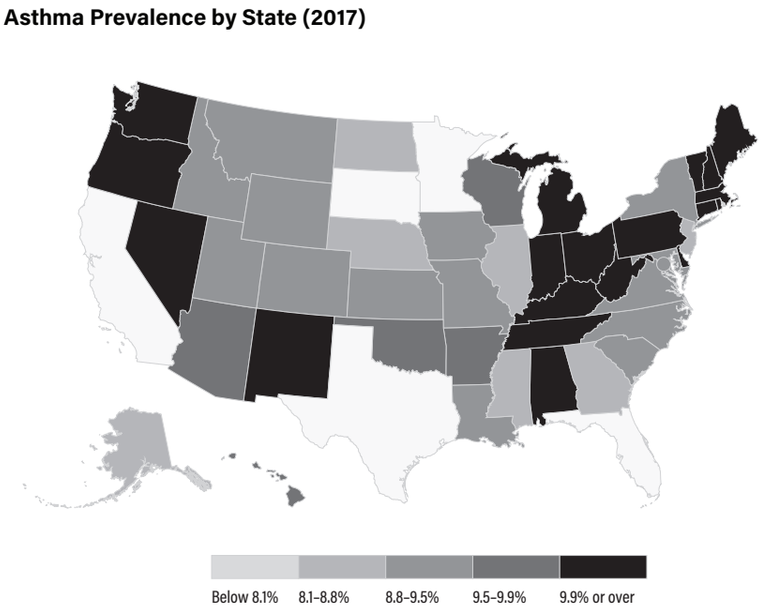
1 Introduction

Who should be able to breathe? The *Principles of Environmental Justice* drafted at the First National People of Color Environmental Leadership Summit in 1991 proclaimed clean air, land, water, and food to be a fundamental right ("Principles of Environmental Justice" 1991). The Principles are an affirmation of the rights to an equitable distribution of environmental benefits and burdens. Yet the actual distribution of either is far from equitable in the United States, as the summit highlighted, with the benefits tending to accumulate to whiter, wealthier communities and the burdens to lower-income and minority communities. Among the burdens that polluted environments impose on communities is poor health outcomes, which occur at the intersections of pollution, social geography, and the long-standing impacts of structural racism.

Asthma is a powerful lens through which to examine these intersections. More than one in ten people living in the United States have asthma, a respiratory illness that is exacerbated by environmental conditions, including air pollution. The burden of asthma is unequally distributed across geographies characterized by race, ethnicity, and economic status (Brown et al. 2003; Williams, Sternthal, and Wright 2009).

To breathe as another breathes is a way to connect the breath to the body and the body to the community. In this thesis, I explore ways in which design might help communities facing an increased burden of asthma from environmental factors. I primarily focus on design interventions that expose the illness as a socio-environmentally induced





CDC asthma prevalence data reveals disparities by race/ethnicity, poverty level, and geography

condition. This view of asthma is useful in promoting a collective understanding of the illness so that communities can advocate for change together. To accomplish this, I have designed an open-source workshop centered around a simple breathing device using the breath as a physical interface.

Asthma data collected by public health organizations show clear disparities. Asthma disproportionately affects lower-income and minority communities. While the prevalence among white non-Hispanics was 8.1% in 2017, it was 10.1% among non-Hispanic Black Americans, and 12.8% among Puerto Ricans (CDC 2019). Differences are apparent, but the resolution of these data is coarse. Some stories are not revealed. For example, the local environmental factors that contribute to illness in individual communities are missing.

When asthma data by race and ethnicity is intersected with socioeconomic status and geographic location, the picture of the disparity comes into focus. The asthma rate for Americans below the poverty level is 11.7%, whereas those at or above 450% of the poverty level, the rate is 6.8% (CDC 2019). If we look at the geographic distribution of asthma prevalence, the highest rate is in lower-income neighborhoods near busy roadways, industry, and waste facilities.

The effect of these combined factors can be seen in a comparison of asthma mortality rates. Non-Hispanic Black Americans die from asthma at a rate 2.8 times greater than non-Hispanic white Americans. In the United States, health disparities between racial and ethnic groups are often the result of disparities in access to quality health care and disproportionate environmental exposures based on socioeconomic status (Forno and Celedón 2012). The specific stresses of living in a racist society also contribute (Williams and Mohammed 2013).

Children are another subpopulation that is disproportionately affected by asthma. In 2017 child asthma rates were higher than adult asthma rates for non-Hispanic Black Americans and various Hispanic groups, while child asthma rates for white non-Hispanics were slightly lower than adult

asthma rates (CDC 2019). Air pollution has a more severe effect in children than in adults. Children typically spend more time outside than adults and engage in more physical activity, which yields increased respiration: a combination that results in greater exposure to airborne toxicants. Because children are growing, they are more susceptible to respiratory infection and damage from pollutants (Brasier 2013).

1.1 Asthma and Individuals

Asthma is a chronic inflammatory disease of the airways. The most common effects are shortness of breath, coughing, and wheezing. During an asthma attack, the airways become constricted, reducing the amount of air that can enter and exit the lungs. The wheezing comes from air trapped in the lungs that is trying to escape. Asthmatic reactions are often triggered by substances in a person's environment. Common triggers in the natural environment are air pollutants such as particulate matter, ozone, and nitrogen dioxide, as well as pollen and mold. In the built environment, irritants such as volatile organic compounds (VOCs) in building materials or cleaning products, low or high humidity, and extreme temperatures—can trigger asthma events. So can allergens such as roach droppings, dust mites, mold, and pet dander (Matsui et al. 2008; Brown et al. 2011, 109). Asthma can also be triggered by non-environmental factors, such as exercise (Brasier 2013). The exact mechanisms are not well understood, and vary by individual (Brasier 2013, 43).

There is no cure for asthma, only management through medication and avoidance of triggers. Typically, medicines to treat asthma serve one of two roles: control and rescue (RI DOH 2014). Control medications such as corticosteroids and long-acting beta-agonists reduce inflammation and mucus production and relax the smooth muscle tissues of the lungs. Biologic drugs help prevent inflammation by targeting responsible proteins. Leukotriene modifiers block the inflammatory response (Brasier 2013). Rescue medications are fast-acting bronchodilators that provide relief by relaxing the muscles in the airways, including short-acting beta-agonists and anticholinergics. Most asthma medications are delivered directly to the lungs through an inhaler or nebulizer, although some control medications come in pills, shots, or liquid forms (Asthma and Allergy Foundation of America 2018).

Asthma can be costly. In 2013, the total economic cost of asthma in the US was estimated to be $81.9 billion. This figure factored the cost of treatment, lost productivity, and mortality (Nurmagambetov, Kuwahara, and Garbe 2018). The same study reported that the average annual cost for individuals with asthma was $3,266, of which $1,830 was for prescription drugs to manage the condition.

When managed with a regimen of medications, most people with asthma can lead productive lives. However, asthma is an illness that has impacts beyond its symptoms. In addition to requiring costly treatment, especially without health insurance, it means frequent visits to healthcare providers. Asthma can result in missed school or work or difficulty participating in social activities. It requires continual watchfulness to spot possible hazards from asthma triggers in places most other people see as safe. The stigma associated with the illness can drive individuals to isolation and depression.

The Centers for Disease Control and Prevention (CDC) coordinates the surveillance of asthma in the US. The CDC monitors asthma through two surveys. According to the National Center for Health Statistics (NCHS), which reports data from healthcare provider records, the lifetime prevalence of asthma for adults was 13.3% in 2017 (CDC 2017a). In another CDC study of self-reported lifetime adult asthma called the Behavioral Risk Factor Surveillance System (BRFSS), the prevalence was 14.1% for the same year (CDC 2017b).

This difference between doctor-diagnosed and self-reported asthma rates may be explained through the asthma experience of individuals, who are often keenly aware of their condition because of the many ways it impacts their quality of life. Yet the medical community describes asthma as an atopic allergic reaction. The word "atopic," meaning "without place," reveals the historical bias toward the disease (Oxford English Dictionary, n.d.). Since medicine couldn't locate a cause of asthma, practitioners often attributed it to the individual. Asthma was long framed as a psychogenic illness brought on by uncontrolled emotions and overbearing mothers (Fortun et al. 2014; Brasier 2013).

Childhood asthma prevention public service announcements from the Ad Council and EPA describe asthma as a threatening monster.

In the US, asthma is considered a preexisting condition (Brookes 1994; Cigna 2019). Although current laws prevent medical insurers from discriminating against people with preexisting conditions, life insurance companies still do, charging higher premiums to cover people with asthma. Asthma can also generate unconscious biases in schools and workplaces, limiting opportunities. The design and operations of many public spaces don't consider their impact on people with asthma. HVAC, fragrances, cleaning products, solvents, dust, and particulate all have the potential to trigger attacks.

In recent decades, the practice of medicine has undergone a techno-scientific shift known as biomedicalization. The term refers to the systematization of medicine as practiced in large institutions that are interested in managing risk and achieving predictable outcomes (Clarke et al. 2003). The biomedicalization of asthma places the burden of managing the illness on the individual. Patients or parents of children with asthma are given the responsibility to maintain constant vigilance to avoid environmental triggers. Susceptibility to environmental factors that are unseen by most people results in asthma being framed as a disability. While focusing on in-home conditions that affect asthma is pragmatic—home environments are something individuals can change—this messaging has the effect of ignoring the broader social and environmental factors that increase the prevalence of asthma in particular communities.

Medical and public health organizations have cultivated the expectation that individuals are responsible for managing their illness. For example, public service announcements from the EPA and the Ad Council remind parents of household cleaning procedures that reduce allergens "because their next breath is in your hands" (Ad Council and EPA 2010). Public health messaging frames a child's experience in terms of fear and uncertainty: "for a child with asthma, it can seem like monsters are everywhere" (Ad Council and EPA 2010). These kinds of messages never call out the root causes that must be addressed to prevent illness in the first place. If this individualized experience of asthma can be cultivated, or designed, it is also possible for alternative frames. We can instead develop a focus on the root causes in the environment for which we have a shared societal responsibility.

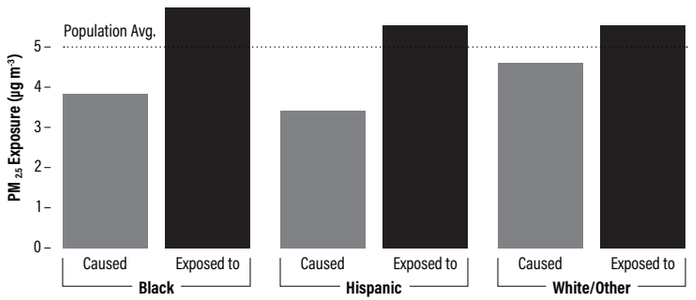
1.2 Asthma and Society

Health professionals widely accept that indoor environmental conditions aggravate asthma symptoms. Research by David R. Williams at the Harvard School of Public Health shows that outdoor air quality and sociodemographic factors also contribute to the illness. He also finds that social factors that increase stress—such as violence in a community—correlate with asthma prevalence (Williams et al. 2009). Other economic and social stressors such as food and housing insecurity also correlate with an increase in asthma prevalence. Research has also shown that stress can be passed down through generations. The infants of stressed mothers typically have lower birthweights.

Polluting industries are often located near lower-income neighborhoods and communities of color. In fact, in 1978, the United Church of Christ Commission for Racial Justice found that the location of waste sites correlates with the location of minority communities. The finding was reinvestigated twenty years later and still holds true (Bullard et al. 2008). Another significant cause of air pollution that disproportionately affects lower-income neighborhoods, and communities of color is transportation. Low-cost housing is often situated near busy roadways. Exposure to fine particulate from combustion engines is known to have cardiovascular and respiratory effects (US EPA 2015). Chemical irritants coming from highways and power plants also irritate the lungs.

Regulatory noncompliance is another discriminatory practice that subjects lower-income and communities of color to increased environmental exposures (Pulido 2015). Communities near polluting industries can be left out of regulatory protection when companies make an economic calculation that the cost of defying regulations is less than the cost of compliance. Laura Pulido speculates that in these cases, companies deem the communities that lack the political and economic power to be expendable. Pulido documented this practice in a case study of Exide Technologies, a corporation that operated a battery recycling plant in Vernon, California (Pulido 2015). Decades of local pollution due to regulatory noncompliance subjected the surrounding low-income, Latinx communities to chemicals that increased

Average $PM_{2.5}$ Exposure Caused and Experienced by Race/Ethnicity



Average amount of PM2.5 that different groups cause via consumption of energy and manufactured goods vs. the average amount they are exposed to in the environment. (Tessum et al. 2019)

respiratory ailments and elevated their risk of cancer. Exide continued this practice for nearly four decades, receiving 44 citations, which it often resolved via financial settlements in court rather than by altering its operations to reduce pollution. Besides the company, Pulido reports that regulators, courts, and the state were complicit in a culture of lax regulatory enforcement that showed indifference to the health and wellbeing of the communities affected by what she regards as environmental racism.

Asthma represents injustice manifest in the environment. The various external factors that contribute to the asthma experience intersect and have more significant impacts than any isolated factor. Race, ethnicity, gender, wealth, class, and geographic location are all factors that are related yet reveal specific pathways to the causes and exacerbation of asthma. In the study of public and environmental health, the environment refers to the natural, built, and social environments (Frumkin 2016). This contrasts with the nostalgic 19th century notions of the environment as a place wholly insulated from human influence. Since the definition of the Anthropocene, nature and human activity are seen as inextricably intertwined. The effects of human life impact nature just as nature impacts human life.

A study led by Christopher Tessum describes "pollution inequity," an exposure to higher amounts of pollution than one causes by consuming energy either directly

or as a byproduct from manufacturing the goods one consumes (Tessum et al. 2019). In this study, the research team measured PM2.5, a fine particulate known to aggravate asthma. They found that Black Americans were exposed to 56% more air pollution relative to their consumption than white non-Hispanics. Hispanics were exposed to 63% more air pollution relative to their consumption than white non-Hispanics.

1.3 Framing a Collective Illness Experience

Sociologist Phil Brown of Northeastern University has written extensively on health social movements (Brown and Gibbs 2007; Brown et al. 2011). These are social movements promoting social or political action around health issues, such as the environmental breast cancer movement. In the medical system, doctors treat asthma as a personal illness. In health social movements, activists frame illness differently, as a collective illness experience. This model treats the individual illness as an embodiment of its social and environmental causes. In other words, personal illness represents the state of the environment. Social and environmental health factors are connected to political concerns, such as the distribution of power, resources, and stewardship of the environment. Biomedicine and health social movements represent competing ways of knowing health and the environment.

To know and understand asthma one must see the space differently. On one hand, the biomedical view would have the asthma patient constantly monitoring their surroundings on the lookout for immediate triggers. On the other, health social movements focus their analysis on disparities in the geographic distribution of pollution and resources that affect the prevalence of asthma across communities.

In this thesis, I explore ways in which design might help communities facing an increased burden of asthma from environmental factors to form a collective understanding of the illness as a shared socio-environmentally induced condition so that they can advocate for change together. *In Chapter 2: Perspectives on Health and the Environment,* I show examples of how the relationship between health and the environment are communicated through different disciplinary lenses. *Chapter 3: Giving Form to Complexity* presents a range of approaches artists and designers have taken to help audiences develop empathy and engagement around health and the environment. In *Chapter 4: Understanding Asthma through Design,* I develop a design brief that frames the key issues and criteria for a design intervention that can create an understanding of asthma that is situated in the environment. In *Chapter 5,* I describe *A Social Design Process*. In *Chapter* 6, I document my *Preliminary Design Experiments.* Next, in *Chapter 7: Case Study: Breathing Injustice*, I present the Breathing Injustice Workshop. Finally, in *Chapter 8: Conclusion*, I reflect on the outcomes of my design and describe opportunities for further work.

"I wouldn't find answers to my own asthma without learning more about what was happening in the world of asthma at large, and it was possible—and presumptuous; but then I had nothing to lose—that my own asthma might hold some answers to the larger questions."

— Tim Brooks (1994)

2 Perspectives on Health and the Environment

We naturally want to understand our health. From grade school through our adult lives, we learn through the study of science that if we slice up a problem into small enough bits and study them in isolation, we will be able to begin understanding our health. The *New York Times Magazine* even has a popular column devoted to this form of biomedical detective work, "Diagnosis: Unsolved Cases." Each week the authors present a new mysterious case for readers to speculate on until the actual rare, single cause is revealed in the style of a serial who-done-it drama. Narratives such as these invite us to engage in the fantasy that scientific explanations can reveal a singular missing piece to the puzzle of illness. The reality is rarely so simple.

In this chapter, I explore alternative and underrepresented perspectives on illness and the environment that contrast with biomedical approaches. In *Individuals*, I discuss ways in which people make sense of their health conditions from their conscious and bodily experiences. In *Communities,* I discuss how, when individuals come together, people combine local knowledge with a desire for change, which can lead to new relationships between communities and science.

2.1 Individuals

In *Catching my Breath*, radio commentator Tim Brooks chronicles his quest to make sense of his asthma (1994). He describes years of frustration as he pursues a variety of etiological narratives and treatments. In the process, he amasses a nearly encyclopedic knowledge of the disease as he researches the history, pathology, treatment, and culture of asthma to better understand his condition. The book concludes with Brooks believing he has finally found the one trigger and cause of his asthma. Once identified, he believes his life will return to normalcy. His hypothesis: the coloring in his antacids is causing his asthma attacks. After setting up a trial in the safety of his doctor's office, Brooks takes the antacid. Nothing happens, dashing his hypothesis, and hopes of relief.

In some ways, the scientific approach of emphasizing a singular cause can distract from the knowledge an individual has about their illness. Brooks observes that while doctors have the advantage of "seeing" health in a literal sense of the word—they learn from cadavers and x-rays of actual bodies and tissues—patients have an understanding of a disease that comes from their internal sensations of it. Brooks believes that medical professionals are unprepared to make use of the patient's nuanced knowledge of their conditions, depending instead on evidence they gather from their observations as outsiders.

In "Attuning to the Chemosphere: Domestic Formaldehyde, Bodily Reasoning, and the Chemical Sublime," author Nicholas Shapiro documents cases where the individual may not even know consciously what their bodies know. Shapiro records the experiences of people who have been subjected to chemical exposures in their homes (Shapiro 2015). From FEMA trailers to new homes of the wealthy, formaldehyde off-gassing can cause a host of debilitating physical symptoms. Prolonged exposure can also awaken an unnamed sensory ability to detect the presence of chemicals. Shapiro calls this "attuning to the chemosphere," and argues that people who experience chronic exposure develop a different understanding of their environment.

The body can be a highly sensitive sensor. Shapiro recounts how the activist Linda Kincaid found that she could detect exposure in her body just as well as her formaldehyde meter could. She could even associate consistent symptoms with specific concentrations of the chemical. The notion of the body knowing something is wrong before the mind does is essential to Shapiro's concept of bodily knowledge. Chemical traces excite perceptual pathways within the body. Shapiro says this sensation is specific to our post-industrial environment. He studies this phenomenon as evidence of an invisible chemical world we inhabit. It is a different way of knowing and relating to space.

Coping with asthma causes individuals to look at space differently. The first line of asthma treatment is to avoid triggers. First, the individual must pay close attention to exposures in their environment to identify triggers. Sensing is an essential way they participate in their treatment. It also requires them to continually form, test, and evaluate causal narratives as they encounter foods, environmental conditions, and various physical and emotional states.

From Brooks and Shapiro, I gained an understanding that the embodied experience is a vital part of understanding illness and the environment. People with asthma are more susceptible to the effects of air pollution, and that makes them attuned sensors of environmental conditions that affect everyone.

2.2 Communities

Communities have knowledge of asthma that comes from their lived experiences, and it differs from the public health and biomedical narratives. Since no single factor causes asthma, there is space for multiple narratives to explain its prevalence.

Sometimes the stories coming from official sources have unintended consequences, as Julie Sze reveals in "Gender, Asthma Politics, and Urban Environmental Justice Activism" (2004). Public health messages can unintentionally appear to shift the blame for illnesses onto the most affected populations. For instance, when the *New England Journal of Medicine* reported in 1997 that cockroaches might be the primary cause of childhood asthma, community members widely interpreted the report as implying that their homes were unclean and that mothers, most often the primary housekeeper, bore some responsibility. Another unintended

consequence emerged when chemical companies began marketing pesticides to affected communities as a protective measure against exacerbating asthma. In reality, chemical exposures from the pesticides also pose a risk to people with asthma (Sze 2004).

A tactic that many community organizations use is to take the focus away from individual cases and focus on external factors that affect many people in the community. While poor indoor air quality and allergens are known to aggravate asthma, outdoor air quality does too, and it is something the community experiences collectively. Additionally, children who spend more time outside have higher exposures to toxicants in the air. Politicization is a tactic the South Bronx Clean Air Coalition (SBCAC) and West Harlem Environmental Action (WEACT) deployed in campaigns against polluting facilities in New York's predominantly minority neighborhoods in the 1980s and 90s (Sze 2004).

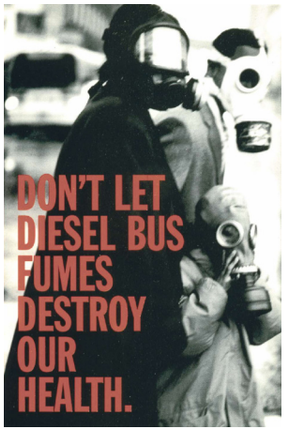
Across the East River in Brooklyn's Greenpoint and Williamsburg neighborhoods, the community-based environmental justice coalition El Puente ("The Bridge") engaged residents in creating an evidence-based understanding of asthma (Corburn 2005). El Puente used community-based participatory research (CBPR) methods that included several surveys of health and the environment. The group worked with outside organizations to train community members in the survey techniques. The group found that asthma varied among specific Hispanic and Latinx groups in the Greenpoint and Williamsburg neighborhoods, with Puerto Ricans having the highest rates. El Puente also revealed skepticism and distrust of health officials among homogenous ethnic communities. El Puente's health surveys found conflict between religious and traditional medicine and contemporary biomedicine (Corburn 2005, 135).

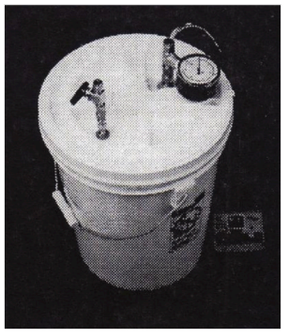
In *Street Science*, Jason Corburn documents some action research methods that allow communities to maintain their autonomy while benefiting from the collection of knowledge (2005). The goals of action research methods are positive change and participation by the community in setting the research agenda and collecting and evaluating data. Community involvement helps gain buy-in and dissolves the division between subject and observer. Most importantly, it respects the experiences of the individuals and values their expertise about their lives.

Public participatation in research is a form of public engagement. It is inclusive of a diverse base of perspectives that can help set agendas and anticipate consequences. It also empowers individuals to investigate their environment without permission from official sources. The Louisiana Bucket Brigade (LABB) is an example of an activist organization that enlists the public as the front-line observers of environmental threats (Brown et al. 2011, 60). The *iWitness Pollution* feature of the group's website aggregates citizens' observations and evidence of pollution in the Gulf Region of the southern US. LABB evolved out of efforts in the 1990s by communities near petrochemical plants to document air quality conditions believed to be responsible for a disproportionately high number and severity of health problems such as respiratory illness, cancer, and neurological disorders. To do this, LABB used an inexpensive, low-tech bucket device to collect air samples for laboratory analysis (CBE 1999). Notably, the EPA approved the device as a valid instrument for collecting air samples, which gave authority to the data collected by citizens.

Citizen science expands the models of participation in scientific knowledge to communities. It invites democratic participation. Increasingly, the government is neglecting its obligations for environmental oversight and stewardship. For instance, in late 2019, the *New York Times* documented 95 environmental rules and regulations that the Trump administration had rolled back (Popovich et al. 2019). In March 2020, the administration effectively suspended the Environmental Protection Agency's oversight of polluting industries in response to the COVID-19 pandemic (Friedman 2020).

In *Fractivism*, Sara Wylie sees citizen participation in monitoring polluting industries as essential to maintaining the integrity of regulation (2018). She calls for a decentralized system of open-source monitors, with data to be collected, maintained, and analyzed by a coalition of communities, academics, regulatory agencies, journalists, and lawyers (Wylie 2018, 303). To facilitate this, community groups





WEACT Dirty Diesel campaign poster.

EPA-approved air collection bucket used by community air sampling programs.

need accessible tools and infrastructure to collect and share data. Public Lab is a nonprofit that fills this need by providing access to research tools created by community members and academic researchers and through a website that hosts research projects and data.

I build on this work to respond to messaging from the biomedical perspective that each individual is responsible for managing their own asthma. I aim to contribute to a redesign of our perception of asthma to that of a collective experience—one that reaches beyond the affected individuals. When we address asthma collectively, we have the power to engage with the social and political systems involved. I also note that many of the tactics used in citizen science produce knowledge through action that is conducted by and intended to benefit the community.

Christopher Samuel. *Welcome Inn. 2019.*

Pierre-Laurent Cassière. *Schizophone.* 2006.

Andreas Heinecke. *Dialogue in the Dark.* 1990.

3 Giving Form to Complexity

Design has a role in providing an embodiment of complex problems. It provides physical forms for ideas so people can relate to them through emotional connections, multi-sensory experiences, spatial reasoning, and movement. I'll describe three design approaches that create embodiments of health or environmental issues: *Empathy in Design, Making Visible*, and *Participation and Action*.

3.1 Empathy in Design

Empathy can motivate people to act on behalf of others because it can expose people to the situated perspectives of others. Sociologist Richard Sennett draws a distinction between sympathy and empathy that is useful in clarifying how empathy can be used to bring people into dialogue (2013). Both are ways of attending to another's experience. Sympathy conveys emotion between people that draws on each one's own experience to find a similarity. Empathy is a sharing of experience based upon an understanding of another's perspective. According to Sennett, empathy is a more demanding practice but also more powerful. When an empathic connection is made, "me" becomes "we." While empathy and sympathy both show recognition of another person, only empathy allows a person to align their actions with those of another by providing access to the other's perspective. Feeling sorry for someone (sympathy) is less productive than acting on behalf of another in a way that is consistent with their positionality (empathy).

In design disciplines, empathy can help workers and designers access a set of considerations outside their personal experiences. It can help public employees better understand the needs of people with disabilities, and help designers consider additional constraints that people with different abilities have when using consumer products and public spaces. Prostheses can alter the wearer's abilities and simulate different physical and perceptual limitations, such as the effects of age, disability, limited range of motion, and pregnancy. An example is Ford's empathy belly, which helps designers understand the unique constraints that pregnant women have on space, balance, and mobility in automobiles. Another example is Suit GERT, a prosthesis system that simulates the effects of age on vision, hearing, and movement.

The use of empathy in design has critics. Some argue that temporarily "trying on" a disability for a day is a superficial experience because the subjects know they can return to their normal state when they take off the prosthesis (Nario-Redmond et. al., 2017). Critics also say that such experiences can have unintended negative consequences that come from an incomplete understanding of social and emotional effects that cannot be simulated by merely donning a prosthesis (Ibid). The role of the designer, in this case, is different than that of people training specifically for empathy, such as customer service workers. Designers need to consider users' abilities so that their products don't pose barriers to use and may even help users overcome difficulties. In product design, empathy is about expanding the range of design constraints and considerations. Since the designer is embedding this knowledge in objects, I disagree with the objections to the practice of design for empathy. Designers aren't attempting to inhabit someone's experience, but rather to address factors that constitute that experience.

Artists and designers sometimes invoke empathy in their work to highlight differences in experiences and reveal ableism: a cognitive bias that favors non-disabled people. Artist Christopher Samuel designed a hotel room to translate the frustration he felt while staying in a supposedly accessible hotel room that had many features he could not access (Samuel 2019). Samuel uses a wheelchair and had no choice but to sleep in his chair because he could not get into the bed that was supposed to be accessible to him. In the installation *Welcome Inn*, Samuel placed the light switches near the ceiling, trapped the toilet behind the bathroom door, and surrounded the raised bed with a padded wall.

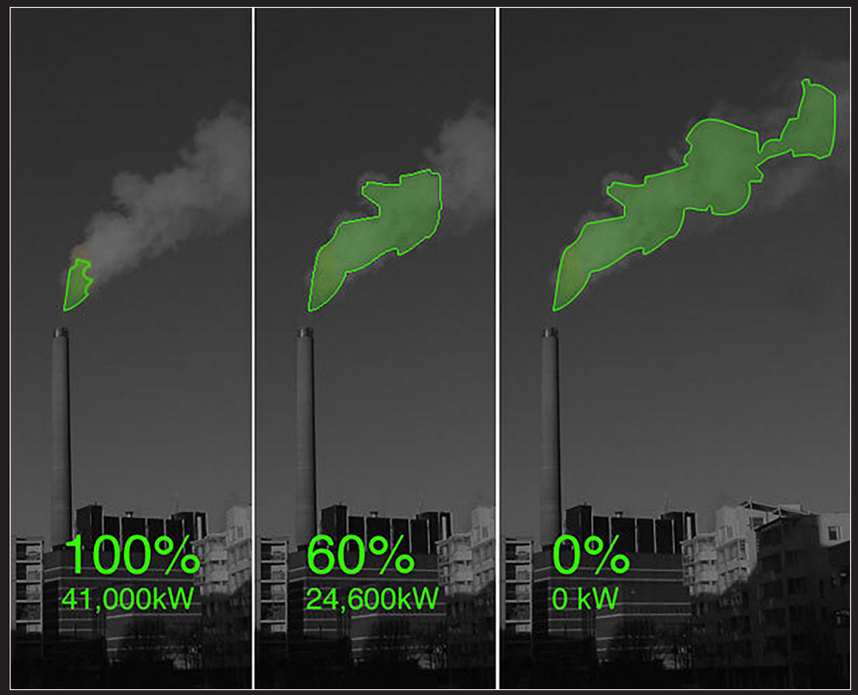
Artist Pierre-Laurent Cassière created the *Schizophone* to reveal the difficulties people with psychotic disorders experience (Cassière 2006). The *Schizophone* makes it challenging to focus selectively on auditory stimuli. It is a pair of headphones that isolates sound available to each ear and disrupts the spatial relationships. Like *Welcome Inn*, the *Schizophone* helps wearers appreciate the different relationship to space that people with disabilities confront daily.

Dialogue in the Dark is another designed experience intended to create understanding through empathy (Heinecke 1990). In the exhibition, sighted visitors navigate a series of spaces and activities with the help of a white cane and a guide while in complete darkness. The exhibition employs blind people as guides, so in this environment, those who live with the disability are the experts. *Dialogue in the Dark* was conceived by the social entrepreneur Andreas Heinecke in 1988. Heinecke uses empathy to promote a broader understanding of diversity and inclusion concerns.

My design work aims to engage its audience through empathy and motivate them to act on behalf of others. Using the breath, I train audiences to perceive environments in terms of their air quality. In my design explorations I make use of the breath as an interface to help participants attune to internal sensations so that they might better understand the experience of respiratory illness.

Daniel Goddemeyer. *Smoke Doll*. 2006.

Daniel Goddemeyer and OFFC. *Urban Canaries*. 2017.



Helen Evans and Heiko Hansen. *Nuage Vert*. 2008.

Andrea Polli. *Particle Falls*. 2010.

Dietmar Offenhuber. *Staubmarke*. 2019.

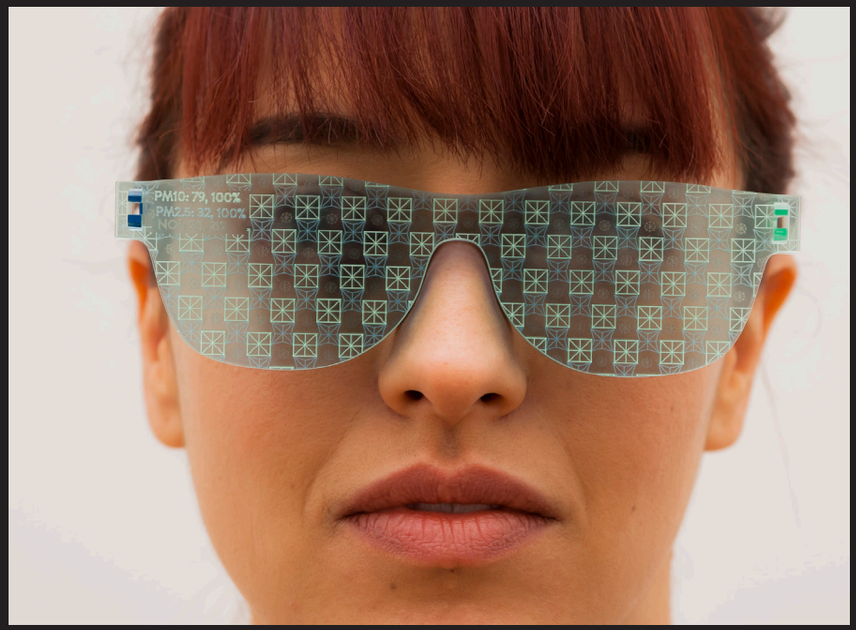
3.2 Making Visible

Typically, air pollution is invisible. Designers have taken a variety of approaches to reveal air pollution in its context: the cities where we live. Strategies include encoding data in objects, situating data visualizations in public space, and activating senses other than sight: touch, hearing, smell, and taste (Moere 2008).

In *Particle Falls*, Andrea Polli constructed a large projected-light visualization of real-time measurements of particulate matter that was displayed on the side of a building. Helen Evans and Heiko Hansen superimposed data onto the environment in an even more direct way. In *Nuage Vert*, they used lasers to project data about the city's current energy usage onto a power plant's smokestacks in Helsinki, Finland. Residents reduced their power consumption as a result of the visualization.

These representations of air quality tell us about the current state of the environment; however, they don't express the long-term cumulative effects. By using a stencil to remove layers of particulate that had accumulated on concrete, Dietmar Offenhuber's *Staubmarke* ("Dust Mark") is a form of visualization that works in reverse (Offenhuber 2019). This is an installation in Stuttgart, Germany. As time passes, the new particulate will erase the graphics. The accumulation of data is compared to the baseline of the particulate "patina."

In *Seeing Air*, Stefanie Posavec and Miriam Quick made glasses printed with graphic patterns representing air quality to create a disturbing visual representation. By making the microscopic particulate and ozone large enough to obstruct the vision, the glasses heighten the feeling of threat. The pollution is impossible to ignore because it occludes the viewer's vision. *Soundscapes of Smog* allows the listener to "hear" air quality (Isaacman and Reuben 2012). The designers call attention to the data by creating an experience that is unusual and uncomfortable. The sound representation is not harmonious. The designers have chosen to embed a point of view in their representation.



Stefanie Posavec and Miriam Quick. *Air Transformed: Seeing Air.* 2014.

Zack Denfeld and Cat Kramer. *Smog Tasting.* 2011.

Janet Cardiff. *Her Long Black Hair.* 2004.

As the Center for Genomic Gastronomy, Zach Denfield and Cat Kramer created *Smog Tasting* to explore ways of communicating local air quality through taste. They capture local smog by whipping egg whites near busy streets. Once baked, the particulate from the air is suspended in the meringue. This project is low-tech and direct. The material choice of whipped egg whites is appropriate—they appear like fluffy clouds. Structurally they depend on the trapped air. *Smog Tasting* presents food as a sampling method for environmental pollutants, which can be sensed in the body. The social proposition of knowingly consuming pollution makes people a bit uncomfortable. The meringues are a materialization of the invisible issue of air pollution.

Personal air quality monitoring devices such as the Atmotube and Plume Labs' Flow let people know when their immediate environment is hazardous. Two other projects take an approach to product design that brings data collection and air quality warnings closer to a vulnerable audience: children. Daniel Goddemeyer's *Urban Canaries* and *Smoke Doll* disguise air quality sensors as toys to place them near children, one of the populations most vulnerable to the health impacts of pollution. Both products employ an embodiment strategy that invokes familiarity through anthropomorphism to encourage acceptance by children.

Artist Janett Cardiff activates the senses using narrative and sound. She is known for her audio-guided walks. In her work, she employs spatial cues, stereo sound imaging, and descriptive narration (Cardiff 2004). An example is *Her Long Black Hair*, in which the narrator, searching for meaning in found photographs, guides the listener on a journey through Central Park that retraces the footsteps of an unidentified woman. At the end of the audio program, the narrator makes an additional sensory connection with the listener: "I want you to do one last experiment … match your breathing to mine."

Air quality is typically experienced through symptoms affecting the respiratory system. Breathing could be considered a human interface for connecting the body to the air. In her performance *It takes 154,000 breaths to evacuate Boston,* Catherine D'Ignazio measured the distance of the city's evacuation routes in human breaths.

The presence of a health intervention can imply the presence of a risk. Matt Hope's *Breathing Bike* is an air filtration

system attached to a bicycle with a mask for the rider. We can't see the pollution, but it is uncommon to see a bicyclist wearing a breathing apparatus—bicycling is typically considered a healthy activity. The *Breathing Bike* indirectly calls attention to an invisible threat.

Bjorn Franke's imaginary device, *Pace Maker*, fits under the design practice known as discursive design. The device consists of a pedometer and a mechanical valve. If the wearer is not meeting the target running cadence, the valve begins to restrict air. Restricting air is an intentionally extreme mechanism for workout motivation. Air hunger is the urgent sensation a person feels when they are not receiving enough oxygen; it conveys a genuine threat to life. It is a sensation that is very real to people with asthma and described in great detail by Brooks in *Catching my Breath*.

Like these projects that in various ways physicalize the invisible phenomenon of air pollution, I seek to make air pollution perceptible through my design work. I employ multi-sensory stimuli to communicate the ways that threats to those with asthma exist in the spaces we inhabit.

3.3 Participation and Engagement

In commercial applications, there is often a clearly defined "designer" and "user," in other words: an "us" and a "them." Art and design practices have been questioning this separation and the ways in which we define participation in public spaces for decades (Bishop 2012). Recent design practices build on this tradition. For example, in *Designing Publics*, Christopher Le Dantec describes figurative spaces with porous boundaries, where participants share the production and consumption of information (Le Dantec 2016). Participation is motivated by attachment to issues. The following are three examples of designs that engage audiences or communities in the production of knowledge through emergent outcomes that the designer doesn't entirely control.

PigeonBlog questions the priorities of regulators by presenting an alternative, community-based air quality monitoring technique. Beatriz Da Costa used homing pigeons fitted with low-cost sensors to detect carbon monoxide, nitrogen oxides, temperature, altitude, and location. The flight of the pigeons mapped data to locations that air quality monitoring stations placed by regulatory agencies didn't cover. Community-initiated air-quality monitoring like this provides a situated perspective that offers a contrast to the regulatory data. It can be used to validate the scientific interpolation models and compare them to the lived experience of the community. The pigeons were also more visible than the stationary air-quality monitoring stations, calling attention to the act of monitoring.

PigeonBlog is an example of a hybrid scientific and artistic approach to environmental health. The performative aspect of the approach can draw attention and interest because it is outside of the distant, esoteric practices of science. However, the resulting data is useful and comes from a vantage point that scientists may not have chosen: pigeons.

Natalie Jeremijenko's *Environmental Health Clinic* "re-scripts" health and environmental problem spaces. Jeremijenko used the familiar biomedical concept of a health clinic but redefined health as something that is outside an individual instead of inside, as the biomedical point of view posits. This reframing of health encourages people to reflect on ways they are collectively responsible for environmental factors that affect them. An "impatient" comes to the clinic for solutions to environmental anxieties. The prescriptions are specific actions or referrals to art, design, government, or local civic groups. The clinic services also generate data about community concerns that are useful to local activists and advocacy groups. This broad conception of health and the environment means that healing actions benefit more than the individual; they impact the surrounding communities. Healing one heals many. Many seemingly small actions can amount to meaningful effects when we engage in cooperative behavior. Jeremijenko's projects use science and technology to configure social events that encourage collective actions. It is a practice Jeremijenko calls the "eco-mindshift." The practice

Catherine D'Ignazio. *It takes 154,000 breaths to evacuate Boston*. 2009.

Bjorn Franke. *Pace Maker*. 2005.

Matt Hope. *Breathing Bike*. 2013.

Beatriz da Costa, Cina Hazegh, and Kevin Ponto. *PigeonBlog*. 2006.

Natalie Jeremijenko. *Environmental Health Clinic*. 2007.

Critical Art Ensemble, Beatriz da Costa, and Shyh-shiun Shyu. *Free Range Grain*. 2003

involves questioning the assumptions we have about issues and finding a way to reframe them from a different perspective to open opportunities for different solutions.

Similarly, *Free Range Grain* was a live performance where artist-biologists from the Critical Art Ensemble (CAE) tested foods brought by audience members for genetically modified (GM) content. The European Union had established laws to regulate the import, sale, and labeling of GM food. To demonstrate the futility of the effort, CAE revealed GM content in conventional food products.

This performance made the issue of GM food pollution material through a public scientific process. The performance invited the audience to speculate about the scientific process, the results, and their implications. Because audience members had a personal interest in the exhibition—their health and food—they were quickly drawn in and exposed to the more significant issue at hand. The show also revealed what is invisible to consumers and raised suspicions about corporate ethics.

These works expose unarticulated rules about science, our environment, and society. They disrupt our expectations by reconfiguring relationships between observers and the observed, between patients and clinicians, and between consumers and regulators. Similarly, in my work, I relinquish control that designers traditionally cherish to create an experience that participants are free to interpret and draw their own conclusions from.

3.4 Summary

The tension between science and action can be articulated by examining design approaches to communicating the relationship between the environment and public health. Scientific studies require focus and objectivity. However, there are times when the possible effects on human health from toxic exposures are well known. These moments call for action driven by ethics. These actions are often political and require a different rhetorical approach in the design to communicate and motivate the public.

"When asthma symptoms start, you don't know when your next full breath of air is going to come. It almost feels like you're drowning. I don't think until you've walked in the shoes of someone with respiratory issues (that) you really understand how scary that can be."

— Tim Seib as reported by Sandee LaMotte (CNN 2020)

4 Understanding Asthma through Design

In previous chapters, I've described two ways of looking at asthma: the biomedical lens places the responsibility of illness on individuals, and the sociological lens identifies factors in the built, social, and natural environments that contribute to disparities in the burden of the disease. Which way of looking at the illness intersects with the strengths of design?

The biomedical view treats the immediate symptoms, while the sociological perspective calls for change. Design is a change-oriented practice: therefore, design fits with the sociological viewpoint. The biomedical view treats individual cases. The sociological view asks communities to advocate for change. Design enables communication: therefore, design fits with the sociological viewpoint. In the biomedical perspective, expertise is distant from the individual because it is hidden away in the laboratory or clinic, disembodied. In the sociological view, community knowledge of the environment is privileged. Through design, ideas can be embodied, making ideas concrete and actionable.

As design disciplines evolve, so do the opportunities for designers to apply their skills beyond commercial applications. In this chapter, I will describe my process and tactics for exploring asthma and the environment through design.

4.1 Challenging Design Orthodoxies

*"Economics, and its associated retinue of skills and trades: accounting, marketing, **design**, merchandising, business organization study and so on—do not make a science studying a material world, but rather, a set of disciplines in charge of extracting from the social and natural world—another world that would have remained transcendent without this violent act of performation."*

—Bruno Latour (2014)

In this generalization of commercial design practices, Latour alleges that design is part of an extractive industry, one that mines and appropriates culture to manufacture desire for products that exist solely to fulfill the manufactured desire. While I find this summation to be a bit overzealous, there is a case for studying how design might be reconfigured to counteract the figurative violence and calculated act of cultural extraction.

Critical design includes a loosely defined group of practices that question the values, role, and ethics that dominate commercial design practices. These practices can be regarded as experiments whose outcomes reveal new tactics to create meaningful impact in commercial and social applications. I'll describe a few of these practices and note aspects that I find useful for addressing complex environmental health issues. Many of these practices came out of industrial and product design, so the orthodoxies they react to come from designing manufactured products or designing to manufacture desire for products.

4.2 Discursive Design

In discursive design, designers examine society's relationship with objects and our assumptions about aesthetics and utility (Tharp and Tharp 2019). Discursive designs are products that have the purpose of communicating ideas rather than serving a function. Daniel Goddemeyer's works described in Chapter 3 are examples of this. Discursive designs retain certain familiar links to the vernacular of consumer products while making changes to the form or function to draw attention to our assumptions and expectations of the role of objects in our lives. These changes in form or function often introduce ambiguity. In commercial design, ambiguity is typically avoided. In discursive design, ambiguity shifts the relationship between the product and the user from one of production and consumption to one of discourse. From discursive design, I adopt the tactic of materializing issues in objects and the notion of productive ambiguity.

4.3 Adversarial Design

Adversarial design examines the relationship of design to democracy and power (DiSalvo 2012). It provokes engagement in the political by exposing expressions of power embedded within designed objects, such as the competing interests of producers and consumers in the marketplace. An adversarial design reflects the notion that political contest is productive to democracy. Desigers use tactics such as uncovering obscured influences, giving privilege to what is commonly excluded, and articulating the unseen rules governing links between parts of political or economic systems.

In adversarial design, the purpose of the models of power is to enable a pluralistic public space. The models themselves don't follow ideas of the political left or right. They do not reward, punish, or prescribe defined outcomes. Instead, they instigate active participation in the political by exposing situations that could be otherwise. From adversarial design, I borrow the tactics of exposing contested power dynamics that are embedded in our environment.

4.4 Situated Design

Situated design is inspired by Donna Haraway's situated knowledges (Nielsen et al. 2014). In situated design, the perspective and authority of design is the subject of criticism. For Haraway, knowledge is always partial because

each person is limited by their situation. Knowledge is also incomplete because a person cannot possibly know all situations, which is why Haraway uses the plural, knowledges.

Situated design reflects on the role of the planning process. In *Situated Design Methods*, Jesper Simonsen et al. write that "plans are seen no longer as set procedures simply to be acted out but as guidelines that can be altered in accordance with the situation at hand" (Nielsen et al. 2014, 5) . In other words, the planning aspect of design is replaced by activities that are responsive to the moment and place where they are happening. Design, in this way, is a cycle of continuous adjustment and improvisation. Like critical design, situated design embraces ambiguity.

I take from situated design the challenge of acknowledging the partiality of my knowledge as a designer interacting with communities. I accept the challenge to reflect on the ways my experiences differ from the communities I may work with to ensure that my work is inclusive and respectful. I also interpret this as an opportunity to facilitate and embrace unplanned interpretations that emerge from people interacting with my work.

4.5 Tactical Media

Tactical media is an approach to political and activist art. Practitioners borrow from the disruptive techniques of the Situationist International movement: détournement and dérive. Détournement is an act that rearranges the meaning of a popular message to create a new, subversive message (Thompson, Noordeman, and Massachusetts Museum of Contemporary Art 2004). It is a deliberate trespass on meaning in the dominant culture to draw attention to the relationship between power and messages. A dérive is a practice that encourages exploration and wandering, allowing attention to follow emergent features (Debord 1956). When one undertakes this type of research, they attend to the experiences of their environment, looking to see unarticulated aspects of the environment. Dérives are intended to be conducted by small groups so that participants may compare their observations. They treat the practice as an essential research method that reveals psychogeography not found on maps that primarily denote political and property boundaries.

From tactical media, I borrow from détournement and dérive. I play with the formal language of medical devices; however, rather than providing a cure, my designs simulate illness. Within my workshop design, the device is used to create an imaginative space where participants can explore their breath and the simulated experience of asthma.

"Design practitioners are well-aware of and indeed exploit uncertainty as a means to facilitate design thinking, innovation, and creativity. As design intentions are explored through the use of designerly tools such as sketching, design activity remains divergent, iterative, and uncommitted. This ambiguous uncertainty facilitates design thinking and the exploration of often ill-defined design problems. In short, there exists a unique relationship between uncertainty and design activity. Because to design is to engage with an exploration of ideas towards the yet to be. Understanding this relationship is important if we are to develop our understanding of what it is to design."

— James Self (Self 2012)

5 A Social Design Process

Design is most commonly thought of as a process for solving problems, but it is also a process for defining what issues to address in the first place. In commercial design roles, designers are unlikely to be involved in setting the agendas for design activities. In *The Intergalactic Design Guide*, Cheryl Heller describes a social design process that charges designers with setting agendas and finding problems in collaboration with others (Heller 2018). Social design addresses the design of social outcomes. Within the social design process, the only thing needed to get started is the belief that change is necessary. A summary of Heller's process is:

1. Find a context for change
2. Synthesize research and frame a problem
3. Generate ideas for ways to address the problem
4. Share your ideas and get feedback
5. Evaluate your feedback and figure out what comes next

My approach to designing an intervention to address asthma and the environment was similar to Heller's social design process, with inspiration from critical design practices. I did not necessarily follow Heller's stages in sequence. What I learned from one stage often inspired me to return to a previous stage.

5.1 Finding a Context for Change

My search for a context where change seemed possible began with an interest in addressing an environmental health issue. Previously, I had designed an application called DetoxMe for the Silent Spring Institute to increase awareness of exposures to toxic chemicals from consumer products. My work with Silent Spring exposed me to the urgency and scale of environmental health risks.

I began by reflecting on threats that affect my community in Providence, Rhode Island, and decided to investigate air quality and asthma. Rhode Island asthma rates are the ninth highest in the nation, and Providence residents face ongoing threats that stem from urban development and gentrification. While working on this thesis, two relevant events came to light. First, *ecoRI News*, a local environmental news website, reported that there are 24 schools in Providence situated within 1,000 feet of busy roadways, subjecting children, a vulnerable population for respiratory illness, to traffic-related air pollution. And second, a coalition of neighborhood associations began action to oppose the construction of a waste transfer station on Providence's industrial waterfront. They believed this would increase air pollution and subject the surrounding lower-income and minority communities to greater exposure to pollutants. I considered the schools near high-traffic roadways and the waste transfer station as opportunities for a design intervention to contribute to ongoing efforts to mobilize communities and policymakers. I began working with these specific cases in mind.

5.2 Synthesizing Research and Framing a Problem

The first two chapters document my research into the existing work related to asthma and the variety of approaches to understanding health and the environment taken by health professionals, individuals, communities, designers, and artists.

Kim Fortun is an anthropologist who has studied asthma through the frame of cultural analysis. She advocates for addressing asthma with "explanatory pluralism," a concept she borrows from the physicist Evelyn Fox Keller (Fortun et al. 2014). Explanatory pluralism makes space for different explanations and epistemologies to exist simultaneously, as they do with asthma.

To frame a problem from my research to explore through design, I embraced explanatory pluralism of asthma. I chose to use space as a structure where the intersection of social, geographic, and environmental factors that contribute to asthma are bound together. The problem I address is disparities in the burden of asthma that stem from systemic disparities and that manifest in geography.

5.3 Generating Ideas for Ways to Address the Problem

Asthma is surrounded by uncertainty because its etiology is ambiguous, and the triggers vary for each individual. Fortunately, the practice of design is well suited for coping with uncertainty. Designers make sense of patterns and relationships that emerge from ambiguity. As Self mentions in the quote at the beginning of this chapter, designers deal with uncertainty by making things to give ambiguous ideas material form. Through the materialization, we can interact with the problem in different ways and learn new things by critiquing our work.

I began my exploration by prototyping a variety of approaches to communicating the complexity of asthma. The resulting images and objects led me to further research and refinement, and ultimately to a project that I felt was strong enough to share with others for feedback. The next chapter describes my design process in detail.

5.4 Sharing My Ideas and Getting Feedback

Designers learn through objects by sharing them and observing how others interact. Behavior, feedback, discussions are all outcomes of interaction with objects. This type of interaction informs feedback loops of further making and evaluation.

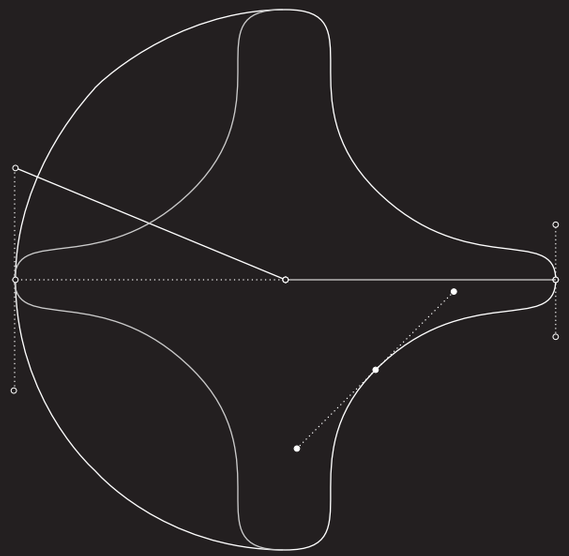
My initial experiments in data physicalization and using breath as an interface for communicating spatial data led to conversations with faculty and colleagues that informed additional prototype and feedback cycles.

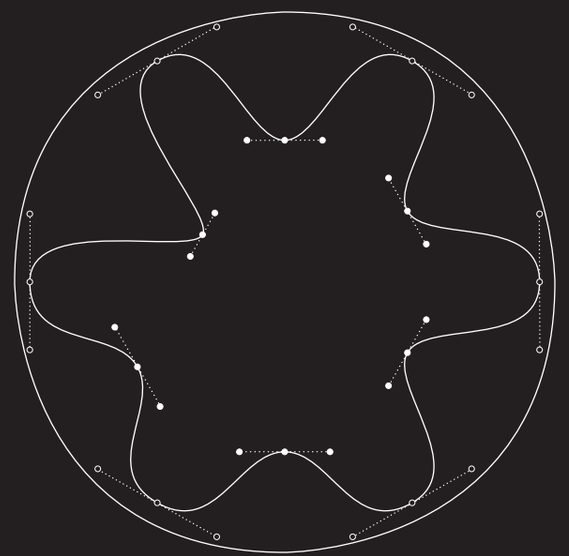
5.5 Evaluating Feedback

I decided to conduct two types of evaluation: an expert review and a participant survey. For my expert review, I solicited feedback from three people with expertise in fields related to my project: public health, environmental justice, community health education, and political and social design methods.

During my studies, an outbreak of a severe acute respiratory disease developed into a global pandemic. Called "coronavirus disease 2019" (COVID-19). The disease was highly contagious and had a mortality rate believed to be much higher than the flu. Emergency public health interventions were put in place to slow the rate of transmission and protect people with underlying medical conditions. As a result, I was unable to thoroughly test my workshop and complete a participant survey as planned. A draft of my survey can be found in Appendix B. Without being able to test the actual workshop, there are undoubtedly some shortcomings that could be addressed through successive iterations of the workshop design.

Once an idea has reached a level of stability, it's time to attend to the logistics of disseminating and deploying the design in the world. Dissemination involves creating an awareness of the design. Deployment can be a process with lengthy supply chains and manufacturing, or as simple as sharing at a different scale, with anonymous audiences. Stewardship of the design is also an essential consideration of dissemination and deployment. Stewardship includes considering the design's impact in a variety of areas: social, environmental, commercial, as well as planning for maintaining and evolving the design.

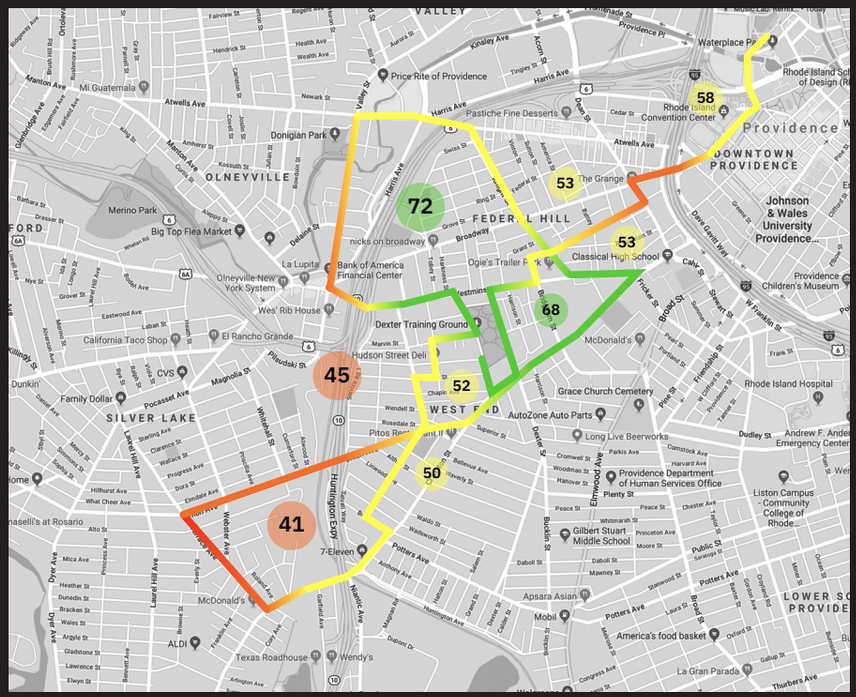


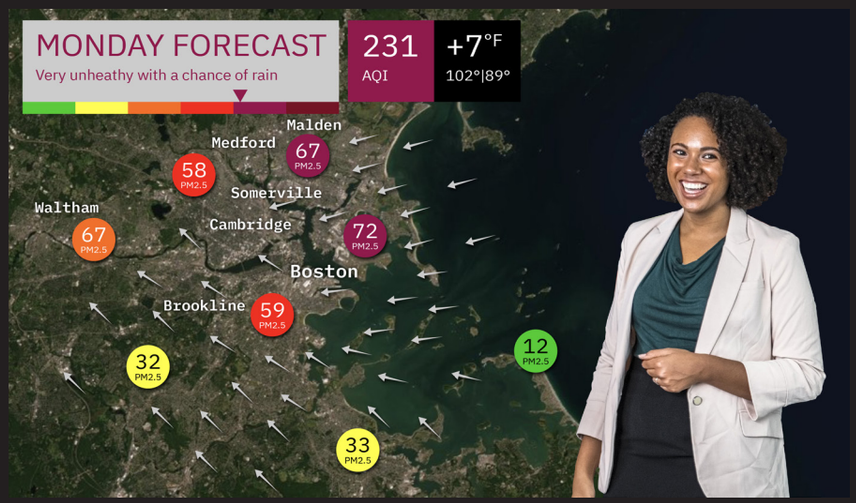


6 Preliminary Design Experiments

While conducting my preliminary design experiments, I regularly updated and refined my problem statement and my understanding of the context for this work. The first part of this chapter recounts my preliminary design experiments. The second part describes my focused design direction, prototyping and refinement process, and evaluation.

Following are a series of concepts, experiments, and prototypes that contributed to my understanding of a problem space where I could communicate the social complexities of asthma through design. Many of these concepts could have become my main focus, but I ultimately discarded them as my understanding of the use context of my design and audience evolved. Writing during the COVID-19 pandemic, it is clear that many of these designs, including the final one, would not adequately protect users against exposure to the extremely contagious coronavirus pathogen that has emerged since I conceived of them.





Personal Air Quality Map

Human-Made Weather Report

6.1 Personal Air Quality Map

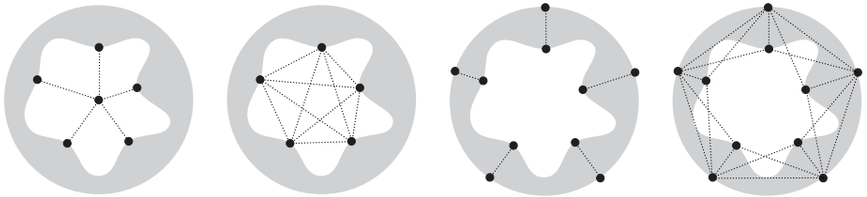
A problem many cities have with air quality monitoring is that there are few EPA monitoring sites, which means that there may be localized concentrations of pollutants that are not being monitored. Continuous air-quality data is modeled based on input from these sites, which are usually installed on low rooftops. The models are used to estimate population exposures to toxicants in the air; however, they don't reflect the actual exposures of individuals. Actual exposures differ as people travel between their homes, workplaces, and within their communities.

Personal air quality monitors can capture indoor and outdoor air quality data. I had been collecting personal air quality data using an Atmotube device since August 2019. Onboard sensors track concentrations of particulate (PM1, PM2.5, and PM10), VOCs, temperature, humidity, and atmospheric pressure. The device transfers the concentration data to a smartphone where it is combined with geospatial data from the phone's GPS. I investigated a method of mapping air-quality zones based on individual travel routes using consumer-grade air-quality sensors. Mapping over time could create a personal understanding of local air qualities.

I discarded this concept because its scope was too narrow—it fails to address a collective issue. I found that sensors were not responsive enough to reflect changes that occurred within time intervals less than ten minutes. Travel in busses and cars also distorted the spatial data because they are essentially indoor environments that move.

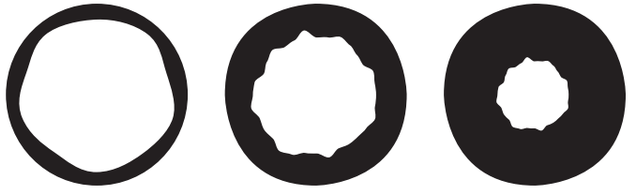
6.2 Human-Made Weather Report

The urgency of many environmental issues is lost when people hear about them infrequently. I presented air quality in a *Human-Made Weather Report* in an attempt to bring long-term impacts of climate change and pollution into our daily consciousness. The concept prioritizes human-made environmental impacts over natural weather, altering the assumptions of a daily weather report. Rather than checking if you need to take an umbrella, you check this report to see if you need to bring an inhaler. A forecast of "unhealthy with



Experiments mapping data to the *Constriction Diagram*

Refined *Constriction Diagram.* The inner opening represents asthma prevalence. Socioeconomic factors define the texture of the inner surface.



a chance of rain" also inserts information about the effects of pollution on human health. Temperature is reported relative to the previous extreme to emphasize climate change trends.

This concept was inspired by the US Air Quality Index system, which categorizes the health risks associated with various thresholds of pollutants. Since creating this, I found other reports that offer health advisories along with weather reports, such as the AccuWeather Asthma Index.

6.3 Constriction Diagram

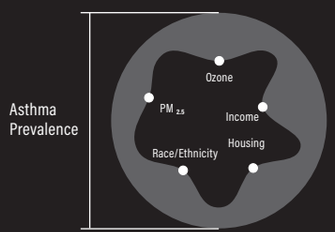
While searching for a more specific problem space, I explored asthma data using a typical visualization pipeline: collect, analyze, map the data to parameters of form, evaluate, and revise. Standard visualization forms, I found, were unable to convey the synthesis of a variety of factors, such as air quality, socioeconomic factors, and asthma prevalence. I began looking to physical forms, or metonyms, to express the data. I focused on airway constriction as a way to show how a combination of factors affects a community. My initial diagrams were inspired by scientific illustrations of healthy and asthmatic airways. In cross-section, normal airways were open whereas asthmatic airways were more constricted because the interior passageways become inflamed and filled with mucus.

The diagrams represent air quality, asthma prevalence, and environmental factors as an airway in various states of constriction. I explored several schemes for mapping data to the form. In the latest diagram, the diameter of the inner opening represents asthma prevalence for a geographic location. Socioeconomic factors contribute to the texture of the inner surface. I wanted to situate the data geographically so it would be possible to compare locations to illustrate disparity so I placed the diagrams on a map.

The asthma data I used came from the CDC's 500 Cities Study, a multi-year study of health factors in 500 US cities that includes data for people who are being treated for asthma. I combined this with modeled air quality data from the US EPA. I also added data describing socioeconomic factors from the US census 2010–2014, which included household income, housing age, health insurance, and other factors that develop a portrait of stress.

6.4 Data Straw

The *Constriction Diagram* seemed to have promise, so I conducted a second stage of design exploration. I animated Constriction Diagrams to show cycles of data over time. The animated diagrams appeared to "breathe" through cycles of seasonal variations in air quality. I realized that the animated diagrams hinted at the experience of asthma—invoking air hunger, or "dyspnea" in medical parlance, when they were constricted. Anyone who has held their breath is familiar with the sensation of air hunger. Often physicalization approaches entail being in space or engaging external senses. Breath is a sensation within the body. Perception of sensation within the body is called interoception.

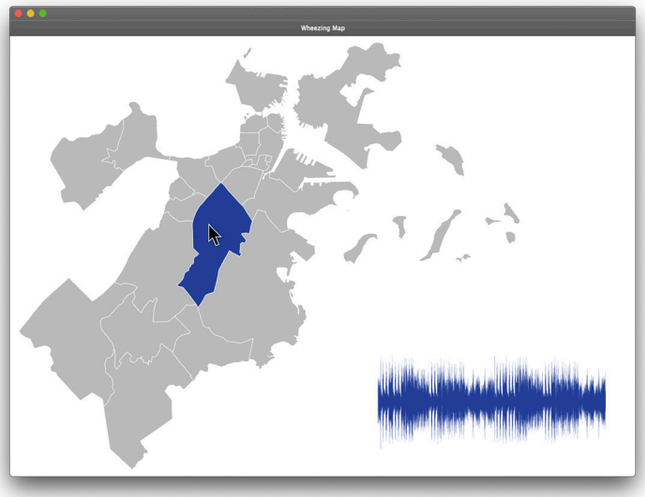


A concept for an interactive map of the asthma index using the constriction diagrams

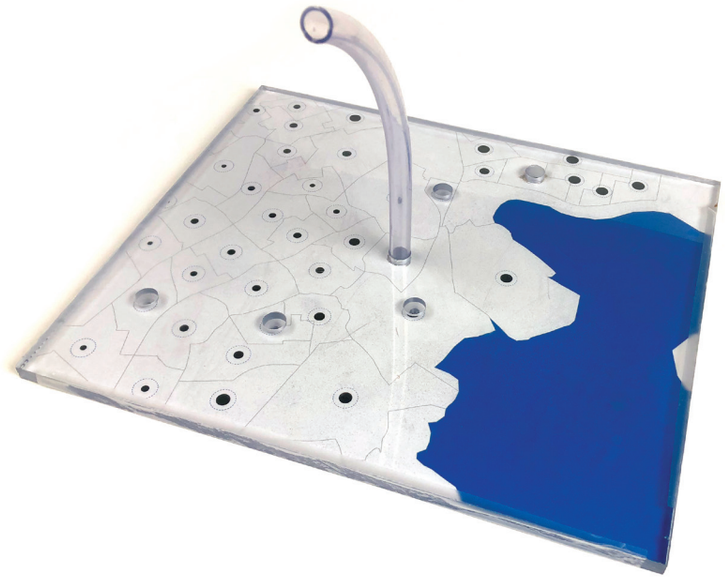
Constriction Diagram data mapping expereiments

Right: *Data Straw*

Wheezing Map



Breathing Map



It connects perception with the regulatory and predictive processes of the brain. It is an appropriate mechanism for expressing asthma because it is related to the symptoms of the disease and the regulatory processes that contribute to the hypersensitivity that characterizes asthma.

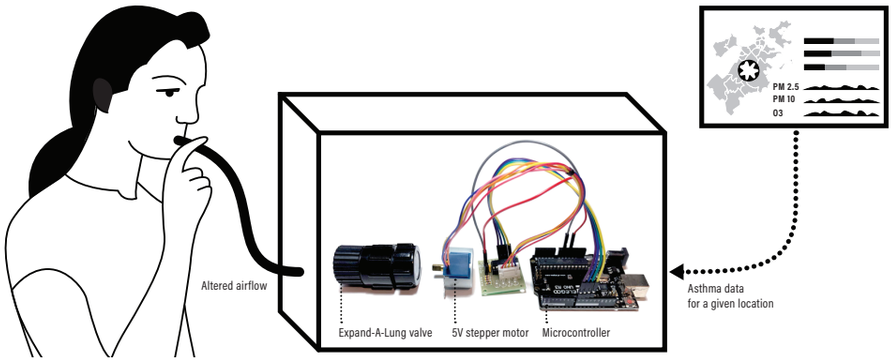
The *Data Straw* takes time-based slices of the data from the *Constriction Diagram* and layers them to form a tube, much like a drinking straw. I hoped that in slices where the data indicated a high prevalence of asthma, the constricted opening of the straw would emit a whistling sound like wheezing when a person attempted to breathe through it. This didn't work. Furthermore, the 3D resin used to print the tube off-gassed a chemical odor for several weeks after printing, making it a medium unsuitable for this application since the safety of breathing resin vapor into the lungs is uncertain, and the experience is unpleasant.

6.5 Wheezing Map

The *Wheezing Map* uses wheezing sounds that vary in severity to represent asthma prevalence. The sound conveys the urgency and anxiety of an asthma attack. Mapping sound to data became a limiting factor because I could not find enough recordings of people wheezing to represent the data. I considered finding a way to generate wheezing sounds, but I ultimately decided to abandon this direction. I gathered casual feedback on this design direction and most people agreed that the strongest wheezing sound conveyed discomfort and was unpleasant to listen to; however, it was difficult to discern differences in the data based on sound alone.

6.6 Breathing Map

Combining the *Data Straw* and *Wheezing Map*, I came to the *Breathing Map*. In this direction, asthma prevalence is encoded in holes of varying sizes drilled in an acrylic panel. To read the data, you breathe through a tube that connects to the holes. This format solves several problems the *Data Straw* had. The map would be presented in a gallery or museum context. Since users only put their mouths on an inexpensive segment of food-grade tubing, it's possible to provide access for many visitors to interact with the data while protecting them against health risks from sharing a single device such as the *Data Straw*. To calibrate the hole



The *Air Hunger Device* reduces airflow to induce the sensation of air hunger

size, I informally tested hole sizes with a few different people to establish a range. Then I set the limits of the scale of the holes based on the maximum and minimum values in the asthma prevalence data from the 500 Cities Study. For my prototype, I drilled holes in the acrylic panel. The variation in hole sizes were limited by the range of drill bit sizes. If I were to produce an actual map using this technique, I would fabricate it on a CNC mill to more accurately control the hole sizes.

6.7 Air Hunger Device

The *Breathing Map* direction has limitations that are common to data physicalization—it's a static snapshot of data, frozen in the object. Being a large, fixed display, customizing the map for different regions would be costly and complicated. The *Air Hunger Device* achieves a continuous physicalization of data by controlling airflow using a microcontroller, stepper motor, and valve.

The *Air Hunger Device* reduces airflow to induce the sensation of air hunger. I used a valve taken from a breath-training gadget used by athletes, the *Expand-A-Lung*. The device determines the aperture of a breathing tube based on data related to specific geographic locations. The geographies with the highest asthma risk should induce the sensation of air hunger. I prototyped only enough of this design to validate the concept. I was able to control a stepper that moved the valve attached to the breathing tube.

While this design did realize the flexibility to adapt to a variety of data, it begged the question of which context it might be used in. I discussed numerous possibilities with my advisors and colleagues. The device could be attached to a computer and used to "breathe data" for locations selected on a map. Another option would be to add location sensors and enable users to breathe data at various places in the physical world. It could be part of a gallery exhibition.

The most significant critique of the *Air Hunger Device* was the incongruency between revealing information using a device that was, in essence, a "black box" that obscures how it translates data into a physical experience. It lost the clarity that the *Breathing Map* had.

6.8 Learning from My Experiments

Through this process of rapid ideation, I explored a range of forms and interactions. These experiments enabled me to increase my knowledge of asthma and air quality, and develop a variety of techniques to express environmental health issues through data and objects. Each experiment also suggested different use cases. For example, the *Breathing Map* would likely exist in a museum or gallery and be used by audiences comfortable with those spaces. In contrast, the *Data Straw* is small and portable and could be used in settings such as in-home visits by community health educators.

The act of making is a way to engage in an issue and wonder about possibilities through interaction with objects. The embodiment of an issue through breathing was the idea that held the most appeal at the end of this stage. It is the most direct physical translation of asthma. The discomfort of dyspnea is a powerful experience that has the potential to create a lasting impression. For this reason, I chose to continue to work with the *Air Hunger Device* to express the spatialized inequities of asthma in a community workshop setting. By presenting this experience in a social space, I hope that participants can connect the environmental risks of asthma to their lives and conceive of collective action to address the disparities in the burden of asthma.

7 Case Study: Breathing Injustice

The *Breathing Injustice Workshop* contains curricula and resources to run a participatory asthma education workshop. The workshop is organized around the use of a breathing device, the *Asthmaker*, in a choreographed exercise to reveal how spatialized air quality threats affect people with asthma. It raises questions about the disparities in the prevalence of the illness and the location of the air quality threats. The workshop can be customized for different audiences by tailoring the discussion session to address local issues and conditions. Variations may explicitly address race and privilege or focus on a specific, urgent issue and calls for action.

The audience for this project is communities who face health threats from poor air quality. It can be used by community groups, schools, or health educators to inform the public about asthma, and raise awareness of the impact air quality has on respiratory health. It is intended to raise awareness of environmental monitoring practices and disparities in environmental exposures. The workshop provides opportunities for participants to critique data sources that reveal evidence of the prevalence and distribution of asthma by geography and sociodemographics by comparing them with their lived experiences. It can also be used to inform policymakers of the impact their decisions about environmental regulation have on the communities they serve.

The *Asthmaker* design and *Breathing Injustice Workshop* documents will be available online along with instructions for manufacturing the breathing device. All source files will be provided and licensed under a free/libre open-source license, which permits others to copy, modify, and distribute the materials provided that attribution is given to the original designer and that copies include share-alike copyright terms that allow further derivative works.

7.1 The Asthmaker Device

The *Asthmaker* is a discursive device that serves as the central piece of the Breathing Injustice Workshop. It is simple to operate; the user places the tube in their mouth and breathes normally through it. As the user turns the dial from zero to six, airflow is restricted, simulating airway constriction.

People with asthma tend to have numerous devices in their lives to measure the condition of their airways and deliver medication. In doctor's offices, clinicians test lung function using spirometers to measure airflow in and out of the lungs. At home, many asthma patients use a handheld peak flow meter to measure the maximum speed of their exhaled air and indicate if their lungs are constricted. Nebulizers and inhalers deliver medication directly to the lungs. The *Asthmaker* references the form of these devices while serving a function that is quite different: it restricts airflow instead of restoring it.

My materials gathering process included collecting parts of medical devices used in the treatment of respiratory illnesses. These devices have solved the human interface and hygiene issues that encumbered my earlier designs because they are single-use, disposable objects. I incorporated disposable cardboard spacer tubes, used with inhalers and spirometers, into the *Asthmaker* design.

I conducted informal tests with colleagues of a variety of shapes and sizes for the aperture, ultimately choosing a configuration that provides a logarithmic taper. Logarithmic taper controls are commonly used in audio engineering because they offer a more even perception of loudness. I hypothesized that this might be true of airflow. In my samples that used a linear taper, small movements at the large end of the dial were difficult to perceive.

I designed the final breathing device valve so it could be produced and assembled easily using low-cost 3D printers—the valve press-fits to the end of the spacer tube. The valve's outer dial snaps into the inner cap so that assembly doesn't require any tools or fasteners. The valve components can be printed using default printer profiles and don't need extra support structures or finishing processes. The typical total cost of materials for a single Asthmaker is 20—37¢: the cardboard spacers can be purchased in bulk from many medical suppliers for 10—25¢ each, and the 3D-printed valves use 6g (1.97m) of PLA filament, costing approximately 10—12¢ each.

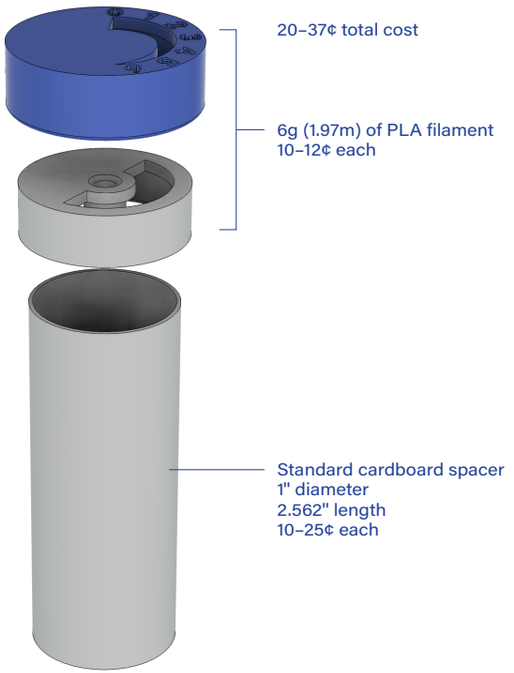
Considering the health impacts and lifecycle of the device is important. The design should be printed using Polylactic Acid (PLA) filament. PLA is "Generally Recognized as Safe" for food contact applications (Conn et al. 1995). Since the *Asthmaker* valve doesn't come in contact with the mouth, there is likely little need to be concerned about exposure-related health effects from the device. PLA is a carbon-neutral bioplastic made from corn starch. Given the right conditions, it is biodegradable and compostable through industrial processes. The cardboard tubes are low cost, can be purchased from medical suppliers, and are recyclable and biodegradable.

I entertained several aesthetic considerations in developing this device. I attempted to balance the formal reference to biomedical devices with a humble simplicity that is intended to make both the use and production unintimidating. I wanted to reference the devices people with asthma routinely use while creating an experience that enables others understand this condition. The *Asthmaker* breathing device uses blue and white—colors associated with the sterile cleanliness of medical products. The device then overturns this reference by simulating, instead of curing, symptoms of the illness.

While medical products must evoke trust in the consumer, the design of pharmaceutical packaging often lacks the refinement of other consumer products, relying on cliche and synthetic product names. Compressed typography fits these

Below: 3D-printed breathing device valve prototypes

Right: Cost of manufacturing the breathing device



hybrid names into constrained spaces: Asmanex Twisthaler, Pulmicort Turbuhaler, ProAir Digihaler, Flovent Rotadisk, Foradil Aerolizer. The active ingredients and dose are treated similarly—as challenging to read as they are to pronounce. Intentionally or not, these labels are aesthetically congruent with the technoscientific origins of these products.

My product naming and packaging references this formal language. The name, *Asthmaker*, is a portmanteau of "asthma" and "maker." The logo uses compressed typography and a vague symbol, taken from my earlier constriction diagrams. I chose to package the device in a heat-sealable mylar bag to communicate that the device is hygienic. From a distance, the *Asthmaker* appears to fit with the range of asthma medications. Upon closer inspection, it is different. Rather than using glib stock photography favored by the pharmaceutical industry, I created a racially ambiguous illustration. Up close, my breathing device is more approachable. The interface is easy to understand. By simply twisting the dial, the user can see the full range of its action. 3D printing is unpolished. The user can see through the components, giving the device a kind of transparency that actual inhalers lack.

A tester of an early breathing device prototype reported that she had never breathed air so dry. Indeed the experience of the breathing device is uncomfortable, but the discomfort should only be experienced voluntarily. The audio guide for the workshop has several cues to bring the user's awareness to the sensation of breathing through the device. The tone of the narration is intended to be calming, and paced to a slow and deliberate breathing cadence. The ambient music and audio cues are designed to immerse the listener in the experience and to amplify the emotional impact of restricted breathing. A low, labored, heavy tone tells the user when to take steps. The tones occur at an unnaturally slow rate to emphasize the anticipation of breath and communicate the difficulty of moving through the narrated environment.

7.2 Workshop Guide

The guide provides instructions for conducting a *Breathing Injustice Workshop* and manufacturing the *Asthmaker* device. The guide includes source files for all documents and suggestions for ways workshop facilitators can customize the information for their locations. A typical workshop should take 20–30 minutes, depending on the duration of the discussion. The minimum number of participants is three. Outside of the social context of the workshop, an individual may conduct a self-directed breathing exercise, but this use case is not a priority in the design. The space where the workshop takes place determines the maximum number of participants. The ideal space is at least 25 feet long and 12 feet wide. The workshop can be conducted indoors or outdoors.

There are two roles in the workshop: facilitators and participants. These roles are not rigidly defined—as long as the workshop is productive, the roles may be shared. People who do not wish to participate, or who have asthma or other respiratory conditions, should assume the facilitator role and assist participants by directing them to the appropriate locations for the breathing exercise and leading the discussion. The facilitators also manage the sequence of events.

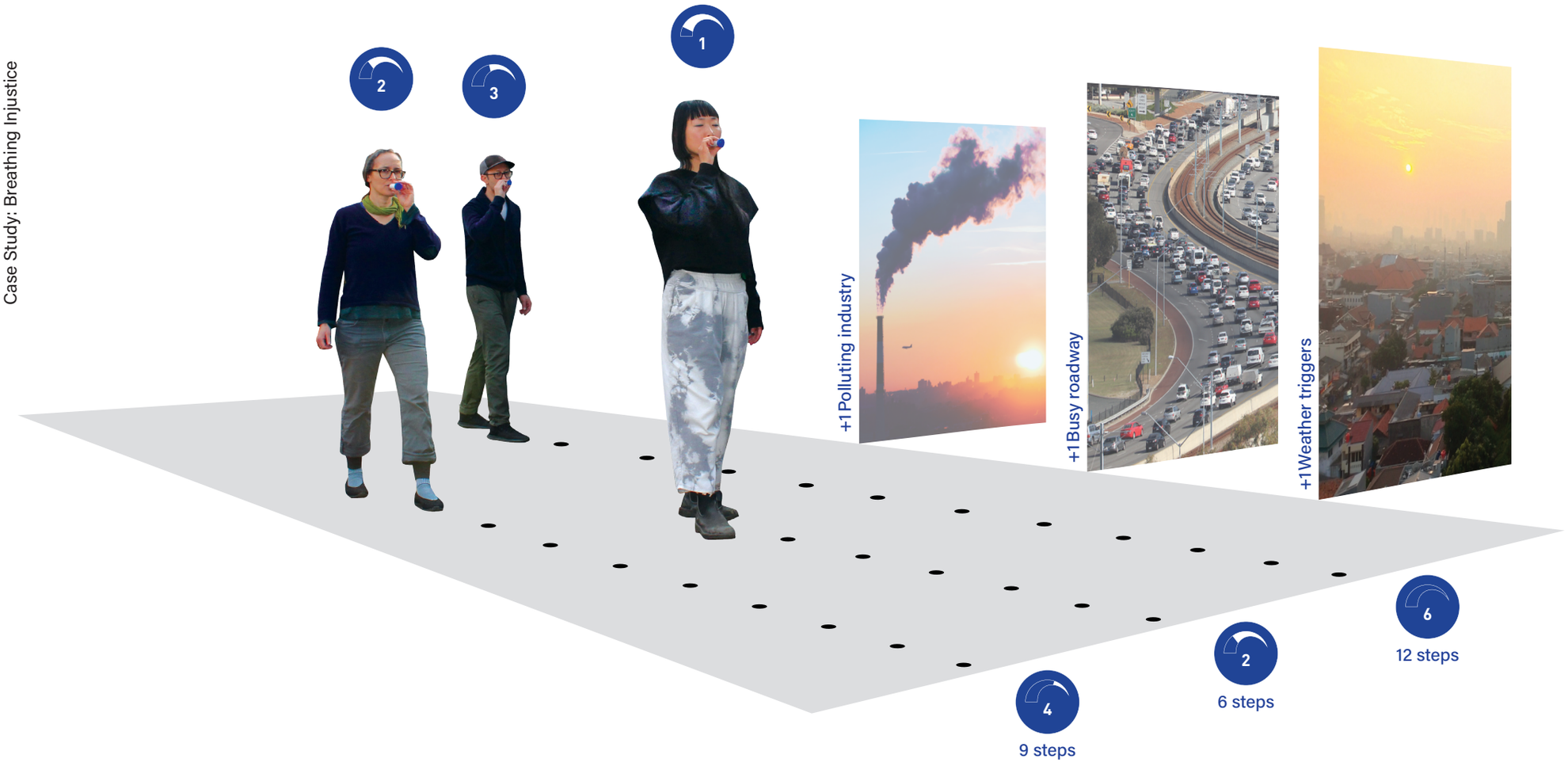
The guide also has discussion prompts and links to online air quality and asthma data, and a template for workshop planners to add local resources. The discussion is intended as a forum for the participants to share and compare their experiences with the breathing exercise to their lived experiences. The workshop should conclude with a review and analysis of air quality and asthma prevalence data, with links to local resources.

Breathing Exercise

Participants need an *Asthmaker* breathing device, a web-enabled smartphone, and headphones. Workshop facilitators should choose a location for the exercise in advance and designate a home position—a common starting point for all participants.

There are three choreographed routines in the workshop (see Appendix B). Participants are assigned routines randomly by the Breathing Injustice website. Each routine has an audio guide that directs the participants' movement though the space and indicates which settings on the breathing device the participants should use. The scenarios simulate a variety of factors including housing quality, geographic location, sociodemographic features, and proximity to sources of pollution. The routines each cover different distances

Case Study: Breathing Injustice



Below: Asthmaker breathing device packaging

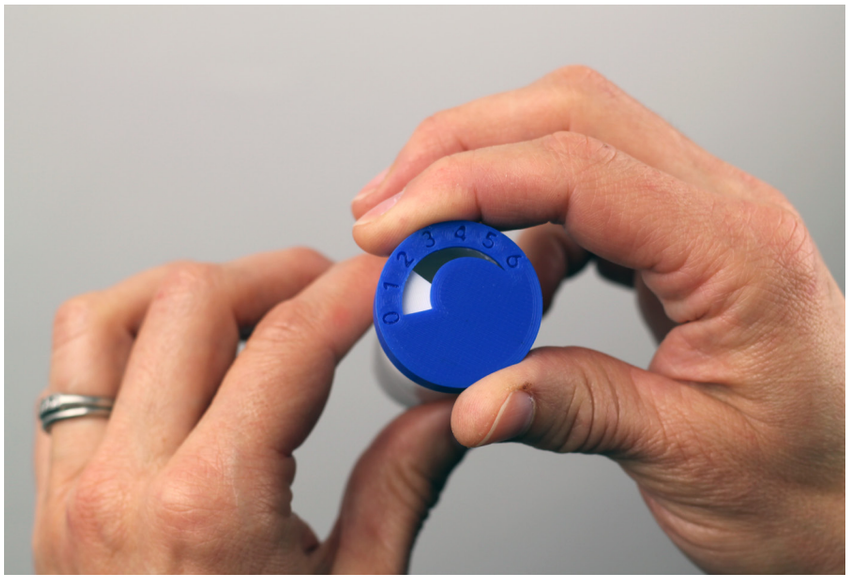
Upper right: Mobile interface for the workshop guide.

Lower right: final screens of the guide allow participants to easily identify discussion group

Mobile interface for the workshop guide

Upper right: Adjusting the breathing device

Lower right: Use of the breathing device and the audio guide

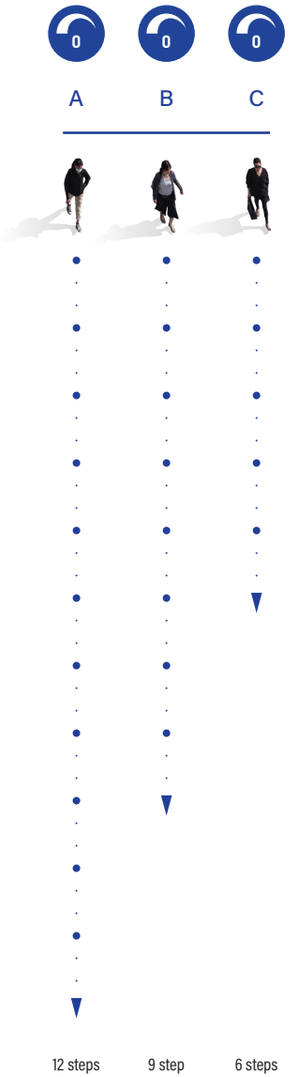


Stage 1

Start at home

Randomize routines

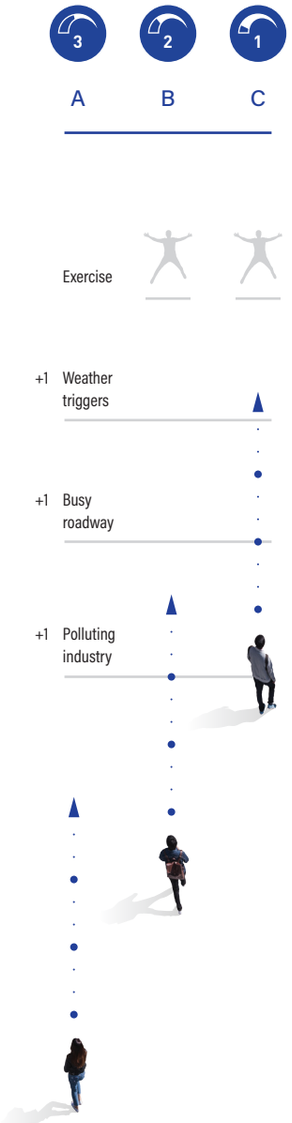
Follow audio guide to starting position



Stage 2

Face home

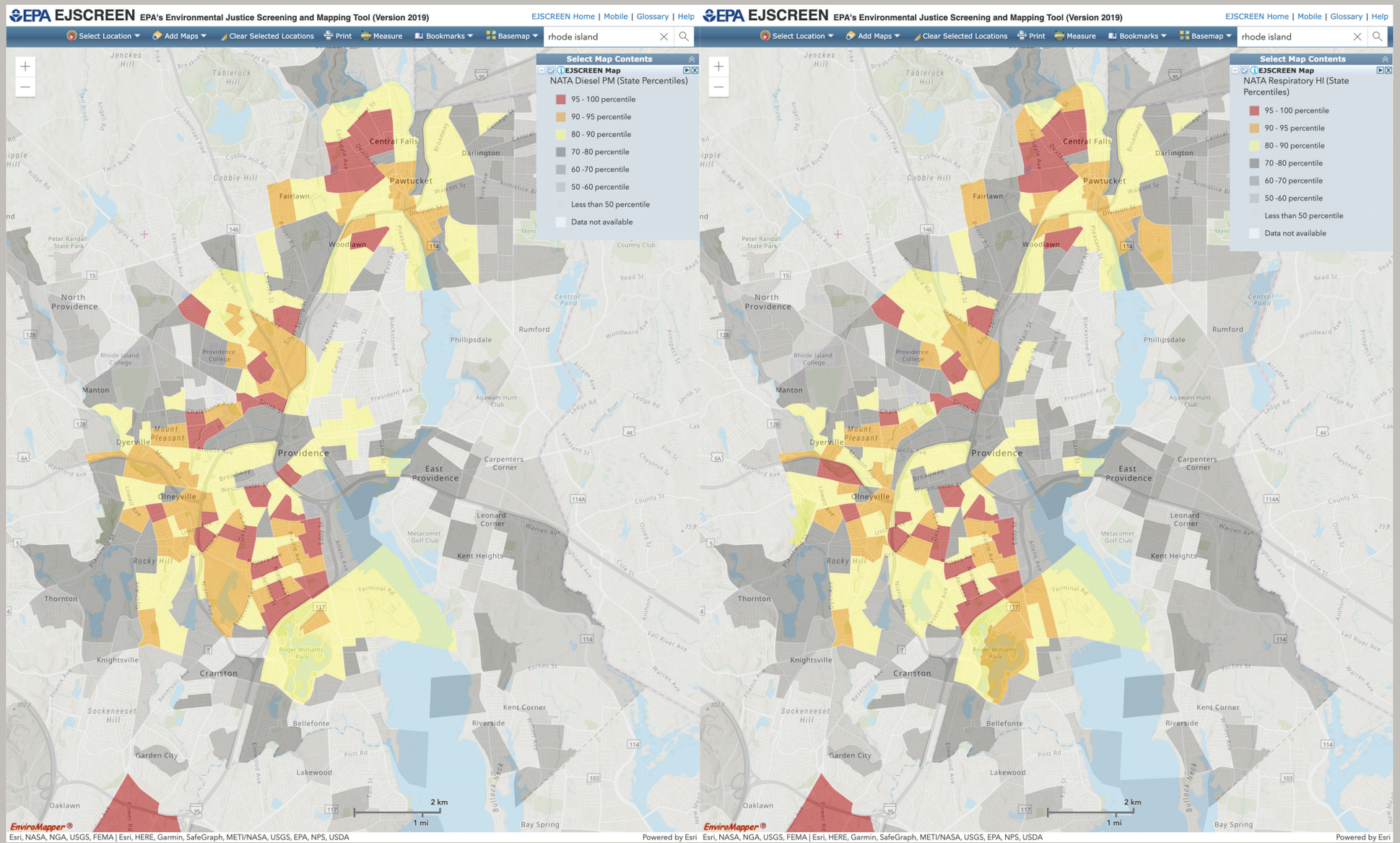
Follow audio cues indicating when to step and adjust breathing levels



Stage 3

Return home

Begin reflection



EPA Environmental Justice Screening and Mapping Tool (EJSCREEN) is used to focus the workshop discussion around local conditions.

Left: State percentiles of diesel particulate based on the National Air Toxics Assessment

Right: State percentiles of Respiratory Health Index based on the National Air Toxics Assessment

and vary in duration from four and a half to six minutes. Participants start from a common point, move away to their starting points, and then once again converge on the initial location. While the exercise is in progress participants will be peripherally aware of the location and activities of others, noting the differences in their activities. At the conclusion of the exercise, the web app will display a different color for the routing the participant completed serving as a signal to other participants. This can be used to form discussion groups after the exercise.

There are three stages to the breathing exercise. In stage one, participants connect to the Breathing Injustice website to receive a randomized routine audio file. They are directed to walk from the home position to their designated starting location. They are then instructed to set their initial level for the breathing device. Since it takes a moment for people to recognize the effects of altered airflow, the audio guide includes a timed calibration step to help the participants become aware of their breath, sensitizing them to the experience. In stage two, the audio guides the participants through a series of scenarios that have corresponding audio cues, breathing device adjustments, and movements. Finally, in stage three, participants are guided through a brief reflection before concluding the breathing exercise.

In the discussion portion of the workshop, participants compare experiences. First, they are prompted to discuss their experience among participants who were randomly assigned the same routine. Then they are encouraged to form groups where members represent each of the three routines to compare and interpret the scenarios. For many, this may be their first time consciously thinking about environmental factors in relationship to health. The discussion proceeds to a review of local data using the EPA's EJSCREEN interactive map tool to ground the experience in evidence used by public health officials and advocacy groups. EJSCREEN enables users to compare thematic maps side by side and provides a range of demographic, health, and spatial data. Prompts from the workshop facilitators encourage participants to locate the path of their routine on the maps and speculate on which breathing device settings might apply to the geography covered in their daily travels.

The discussion is intended to expose environmental monitoring practices and disparities in environmental exposures. It provides opportunities for participants to critique data sources that reveal evidence of the prevalence and distribution of asthma by geography and sociodemographics by comparing them with their lived experiences.

7.3 Expert Review

I evaluated my design direction by assembling an expert review panel that represented a range of perspectives on public health and social engagement. The panel included a Rhode Island Department of Health official who is also an environmental justice organizer, a community health educator, and a design researcher with expertise in socially-engaged design practices. I asked each reviewer to evaluate the appropriateness of the design approach, the factual accuracy of the information, and areas for improvement.

Public health official and environmental justice organizer

My first reviewer was Julian Drix, the Asthma Program Manager at the Rhode Island Department of Health (Drix 2020). Drix was formerly a co-director of the Environmental Justice League of Rhode Island (EJLRI), making for a unique combination of experience with environmental health and environmental justice perspectives on asthma and the environment. Drix was encouraging, clarified some critical points about childhood asthma, and brought up several useful ideas.

Our discussion covered some details about public health perspectives on asthma. Drix explained that asthma is now being conceived of as an umbrella of conditions that can be compared to the way we describe autism as a spectrum. Drix liked the numbers on the breathing device and believed that the connection to air quality was evident. He pointed out that air quality affects children differently. Children are more likely to experience damage to lung tissue because their bodies are still developing. They also receive a much higher exposure to toxicants in air pollution than adults because they tend to be outdoors more and engage in physical activity, which increases their respiratory rate.

While at EJLRI, Drix ran community workshops to communicate the connection between asthma and air quality. In these workshops, EJLRI borrowed a technique from June Tourangeau, a Providence, Rhode Island-based Licensed Practical Nurse (LPN) and a long-time asthma educator. During home visits to help parents understand their children's asthma, Tourangeau would ask people to breathe through a drinking straw, then a coffee stirrer, to convey the asthma experience. Drix suggested adding jumping jacks to the workshop choreography to demonstrate how asthma can make physical activity difficult.

We discussed the ways government and the public have different understandings about how social change happens. Within government, officials should work to understand better how communities share knowledge and form opinions. The public also needs to know more about how government decision-making works and how targets for policies are selected.

Drix offered several improvements to the workshop that would add clarity and make more concrete connections to the geography of asthma in people's neighborhoods. One suggestion was to make use of the EPA Air Quality Index color warning system to connect air quality to the choreographed breathing events in a concrete way. He also suggested adding photos of polluting industry and busy roadways to help participants make connections to local features in their communities. We also discussed the EPA Environmental Justice Screening and Mapping Tool (EJSCREEN) as a tool for exploring local sociodemographic, health, and environmental data. Drix suggested that mapping literacy be added to the curriculum. Based on his experience working in communities, he observed that people often had difficulty understanding spatial data on maps.

Community health educator

My second expert review was with Ty-Eisha Rivera, a Certified Asthma Educator who has been working with Hasbro Children's Hospital and the HARP program (Home Asthma Response Plan) in Providence, Rhode Island. She has conducted asthma education workshops in schools and homes. Rivera is also a parent of children with asthma.

When visiting families, Rivera pays close attention to the environment inside and outside the home. Before entering a home, she observes the number of trees in the area and the proximity to highways, noting that healthy housing is rarely close to highways and polluting industries. She recalled, "I had a family living near a busy street, and her walls were just black from the cars." She emphasized that where a person lives correlates with asthma prevalence. There are fewer emergency room visits for asthma where the air quality is better.

Rivera's role as a community health educator is to provide people with accurate information about their health, to teach healthy behaviors, and promote awareness of harmful practices and products. Her home visits for asthma include instructions on how and why her clients should use medications and where they might find asthma triggers in the home. As part of this, she talks about consumer products that have the potential to aggravate asthma or trigger asthma attacks, such as particular cleaning products, chemicals, and artificial scents. Corporations advertise consumer products by forming associations between certain scents with freshness and cleanliness. Rivera pointed out that such products release chemicals that cover up unpleasant odors rather than eliminating the cause. In her home visits, she presents healthy alternatives to cleaning with chemicals that may exacerbate asthma.

We discussed the communication tactics used by home health educators and contrasted them with my approach. During home visits, Rivera goes over an informative booklet, then examines the home, always aware of presenting information in a nonjudgmental manner that is respectful of the clients. I asked how often this information was new to them. Rivera told me that for many people, especially parents, their knowledge of asthma was based on their own experiences. It is common for a parent of a child with asthma to think that their child's triggers will be similar to their own. Like Drix, Rivera emphasized that everyone's asthma experience is different—individual bodies react uniquely to medications and environmental triggers. The scientific understanding of asthma has changed over time, and cultural perceptions of the condition vary.

While Rivera's visits focus on individuals and actions, they can take to manage their condition, my workshop addresses the role of communities and policymakers—forming a bridge between individuals and communities.

Rivera suggested that presenting asthma through a simulated experience would be more engaging for audiences who do not have respiratory illness than the traditional presentation methods used by public health professionals. She noted an annual asthma advocacy event where my workshop would be useful. Allergy and Asthma Day Capitol Hill is an opportunity for community members and advocates to bring concerns directly to state legislators, such as lowering the cost of medication and improving air quality. It is organized by the Allergy & Asthma Network, a national asthma advocacy nonprofit. "A lot of the time, people making the laws don't understand the impact on the people they are working for," Rivera said. This event occurs each year in May; however, it was canceled this year due to the COVID-19 pandemic.

Rivera was encouraging and noted that it is vital to help others understand respiratory illness. She recommended that I integrate into my curricula conditions inside the home and intrinsic factors such as income and education. Rivera thought that incorporating physical exercise as a factor that can exacerbate asthma was necessary, just as Drix also advised. When she first saw images of the breathing device, she was unsure what it did, suggesting that I should present it in the context of its intended use.

Researcher of socially-engaged design practices

My third expert review was with Carl DiSalvo, a design researcher and associate professor at the Georgia Institute of Technology. He has studied and written about socially-engaged design practices and civic media.

My conversation with DiSalvo focused on the participant experience and my desired outcomes of the workshop. DiSalvo agreed that presenting information about asthma through a physical experience could be a powerful way to engage people and shift the ways they think about asthma. He also believed that building on the work of health social movements to cast asthma as a common condition was an excellent approach to bring awareness to the politics of air quality.

DiSalvo had some important critiques of the workshop as I presented it to him. In essence, he questioned whether the choreography of the breathing device would be a moving experience, and he wondered how I might do more to help the participants imagine the environmental conditions that impact asthma.

To address the choreography, we talked through the possibility of having the participants follow a written narrative while they experienced variations in airflow from using the breathing device. The narrative would include descriptions and sensory details about the spatialized threats, such as polluting industry and busy roadways. We discussed using visual cues but decided it might distract from the sensory experience. Sound could also be a medium for providing sensory cues. The sound programs could be delivered through a phone-based system or a mobile website accessed by participants through their smartphones.

At the time of the review, my workshop design was such that each participant would go through all three routines. DiSalvo and I concluded that this might not be necessary and that the workshop discussion could be a space for participants to examine the differences between the three routines.

DiSalvo liked that the workshop and breathing device could be distributed online as a way to expand the reach of my work and make it accessible to others I may not have direct contact with. For the long term, DiSalvo questioned whether the workshop experience would maintain a level of attachment that would contribute to the political change around air quality that I intend. He acknowledged this is a struggle designers are facing, especially when working in a social design context. DiSalvo offered advice on how to approach long-term engagement and how designers should address the evaluation and accountability of projects like mine.

When contributing to an ongoing political agenda, change takes time. In a commercial design context, product cycles and market feedback come quickly in contrast to the work of government, nonprofits, and social movements. Accountability has to be addressed at the same time scale as the desired outcome. For this reason, designers must find a way to stay with the work and give ourselves time to evaluate and react to how the work is used. Partnerships with established organizations are important because organizations

have dedicated their programs to long-term change. DiSalvo suggested that for my workshop to be successful over the long term, it would require adoption by such an organization.

7.4 Reflection on Expert Evaluations

The three experts' evaluations each contributed a unique and informed perspective that led me to revise my workshop design. I considered their feedback to improve the content, user experience, and to clarify my operational goals.

Drix's evaluation led me to consider local applications for my workshop and expanded my consideration of vulnerable populations to include children. To accommodate this, I added mentions to children in my script. I integrated the EPA's EJSCREEN interactive map in my workshop discussion so that participants could review local data to situate the breathing exercise within their communities.

Rivera inspired me to consider a broader range of triggers and take into account conditions within homes. I updated my scripts for the breathing workshop so that participants would start with descriptions of home environments. Each scenario has unique details describing factors inspired by Rivera's account of the types of things she looks for on home visits, such as scented candles, cleaning products, and pets. Rivera also inspired me to add physical activity to the breathing exercise scripts.

To address DiSalvo's recommendations, I prototyped and informally tested the ergonomics of using a written script to coordinate the choreography of the breathing device. My test consisted of myself and a volunteer attempting to follow a written script while using the breathing device in the same space. We found it challenging to manage. It was awkward to interrupt the text with cues telling the participant to move through space. My test subject also felt that the written text didn't convey the spatial conditions effectively. She also reported that it was difficult to read and walk at the same time.

I had better results interpreting the script as an audio narration, in which I used sound cues to provide sensory details of the environmental conditions. Following DiSalvo's recommendation, I also created a mobile website for participants to access a randomized routine audio program.

7.5 Evaluation Plan

I intend to perform a qualitative evaluation of the workshop once the COVID-19 pandemic has passed. To do this, I will run a prototype workshop with 5–6 participants and conduct a survey to evaluate the mechanics of the workshop and the effectiveness of the communication (see Appendix B).

I acknowledge that being a thesis project, there are limitations to the time and scope of this work. Long term, my hope is that this work can become part of the programming of advocacy organizations that have the experience and capacity to use, monitor, and evaluate the workshop over time. This workshop ultimately belongs as part of a larger endeavor to achieve greater health and environmental equity with regard to air quality, a task that is beyond the capabilities of an individual. To achieve this, I intend to present this work to organizations in hopes that it can be used to realize change.

8 Conclusion

I began by questioning how design could help communities facing an increased burden of asthma from environmental factors form a collective understanding that they can use to advocate for change. New design practices that differ from commercial practices can communicate the complexity and urgency of threats and create boundary objects that bring together communities, public health officials, and researchers. As design evolves, design researchers are theorizing ways the field can facilitate participation in democracy. This project puts some of those theories into practice.

In my attempt to address the ways race, geography, illness, and the environment come together in asthma, I have encountered a complexity that could not be treated with commercial design practices. Yet my design-based approach has a few advantages. Like the action research methods I discuss in *Chapter 2*, design is a process that facilitates learning by taking action in the face of incomplete or uncertain information. Like health social movements, my design focuses on the external political aspects of illness, rather than the medicalized experiences of individuals. Like community-based participatory research, my workshop attempts to put community members in charge of setting agendas for action.

This thesis represents a beginning rather than a conclusion. In practice, design is a social and collaborative process. Future work in this area will inevitably involve deepe interdisciplinary collaborations and knowledge situated in

communities where advocacy and activism are likely to be underway. To further develop the curriculum and workshop choreography, partnerships with public health agencies and community groups would ensure the workshop fits with local agendas. Publishing the workshop and breathing device as open-source designs also means that others can create variations to meet their specific needs.

Through the design process, I became better acquainted with local knowledge and activities already underway to reduce the burden of asthma in Providence, Rhode Island. My workshop and breathing device could play a role in communicating the impact of poor air quality in Rhode Island's urban areas and could be incorporated into complementary public meetings. Several people I met on the way expressed interest in my workshop and thought that it might be used in their education or advocacy work.

I hope that this thesis is an example of socially-engaged design work that inspires for others to address complex issues of environmental health and justice through design. Outside of the commercial context, design processes must make room for new collaborations that enable participation and support dignity. Through these processes, designers release the ideas of complete control over outcomes that are common in transactional commercial design practices. Instead, accountability entails maintaining connections to the work, collaborators, and constituents.

Through this work, I have drawn on nontraditional precedents that come from activists, artists, and social scientists working within design, environmental health, and environmental justice. What I have learned has opened possibilities of addressing a different set of concerns in my work.

This thesis has also helped me situate my perspective as a designer, allowing me to acknowledge better the complexity of the contexts in which I work. It has opened the possibility to participate in the substance of issues in areas traditionally reserved for domain experts.

The making and evaluation of artifacts can expose issues in tangible form. Objects can create shared experiences that facilitate dialogue. Through designed experiences, people can explore alternative perspectives. Hopefully, bit by bit, this opening can foster a community consciousness that leads to real improvements in our shared environment and collective wellbeing.

Appendix A:
Audio Guide Scripts

These are the scripts used for the audio files that guide workshop participants through the choreographed routines. You can hear the audio version of these at http://www.breathinginjustice.info/go/list.html.

Narration and sound design by Todd Linkner.

Ambient and environmental sounds were downloaded from freesound.org and are released under Creative Commons licenses.

bsumusictech. “leaves_air conditioner startup.”
WAV file, created 4 Nov, 2008.

Erokia. “Ambient Wave Compilation by Erokia.”
WAV file, created 28 May, 2019.

klankbeeld. “CityPark redesigned 130307_00.”
FLAC file, created 12 Mar, 2013.

moonfisher. “Birds_Park.”
WAV file, created 24 Apr, 2013.

Robinhood76. “ 5884 heavy truck departure.”
WAV file, created 11 Jun, 2015.

SamuelGremaud. “HIGHWAY.”
WAV file, created 7 Feb, 2019.

Viertelnachvier. “factory1.”
WAV file, created 22 Sep, 2014.

Routine A: 6m 0s

You are about to begin a simulation of the experience of asthma. If you have a respiratory illness such as asthma or COPD, do not use the breathing device. Instead, please assist others in this workshop. If you do choose to participate in this exercise, feel free to stop at any time.

First, you should move to the home position indicated by your workshop facilitators. Now take twelve steps away from the home position. Turn around to face the home position. From this point on, when you hear this sound (step sound cue), take one step toward the home position.

Let's begin by turning the dial of your breathing device to level three, place the cardboard tube in your mouth, and begin breathing normally. Try and follow each breath in and out. How does it feel? Bring your awareness to your chest. Feel it expand and contract.

Imagine you are now at your home. You can smell the scent of cleaning products. You just used them to remove the black soot that accumulates on your windowsill every few days. You can hear the sound of the city bus stopping near your building (bus brake and idling sound). It comes every twenty minutes, disrupting your thoughts. You decide to take a walk (step 1 sound cue).

Turn your breathing device dial to level four (step 2 sound cue). As you head down your street (step 3 sound cue), you can see a factory in the distance (factory sound). Today as the wind blows, you can smell the sharp, sweet chemical odor. Some people in your neighborhood don't notice this, but you often do. Sometimes the air makes your eyes water (step 4 sound cue). You continue your walk. You wave to a neighbor. A few blocks later (step 5 sound cue), you cross the highway. Traffic hums below the bridge you are walking on (step 6 sound cue).

Turn your breathing device dial to level five. Rush hour traffic fills the lanes twice a day (highway traffic sound). On weekends, the traffic going to the city continues into the evening. The air has a gritty texture, and you can smell the automobile exhaust. This is the route you take every day to go to work (step 7 sound cue). Your children must also cross the bridge to get to their school on the other side of the highway (step 8 sound cue) (step 9 sound cue).

Once you have passed the highway, you feel relief. The sun is shining brightly today. You notice that it is warmer than expected. The horizon is hazy (singing birds). You remember watching the weather report today. The commentator recommended that older people and those with heart and lung conditions stay inside today. The Air Quality Index is 160 (urban sounds).

Turn your breathing device dial to level six (step 10 sound cue). The sun is now immediately above you (step 11 sound cue). The day is hot and uncomfortable (leaf blower sound) (step 12 sound cue). Once again, bring your attention to your breath. How does your chest feel? What is going on around you?

You can now remove your breathing device and breathe normally. In your mind, go over your experience. What do you remember about the sensations? Were you uncomfortable? How might you feel if the simulation were to continue? Did you experience relief when you stopped using your breathing device?

Routine B: 5m 0s

You are about to begin a simulation of the experience of asthma. If you have a respiratory illness such as asthma or COPD, do not use the breathing device. Instead, please assist others in this workshop. If you do choose to participate in this exercise, feel free to stop at any time.

First, you should move to the home position indicated by your workshop facilitators. Now take nine steps away from the home position. Turn around to face the home position. From this point on, when you hear this sound (step sound cue), take one step toward the home position.

Let's begin by turning the dial of your breathing device to level two, place the cardboard tube in your mouth, and begin breathing normally. Try and follow each breath in and out. How does it feel? Bring your awareness to your chest. Feel it expand and contract.

You are now at your home. You can hear the hum of your window-mounted air conditioner (air conditioner blower). Your cat brushes up against your legs and greets you. You decide to go to the park (step 1 sound cue) (step 2 sound cue) (step 3 sound cue).

Turn your breathing device dial to level three. You continue your walk. You wave to a neighbor. In the distance, you can hear the highway (highway sound). Rush hour traffic hums twice a day. On weekends, the traffic going to the city continues into the evening. The air has a gritty texture, and you can smell the automobile exhaust (step 4 sound cue) (step 6 sound cue) (step 6 sound cue).

You came to the park for your daily exercise. Now do six jumping jacks. One. Two. Three. Four. Five. Six. The sun is shining brightly today (birds singing). You notice that it is warmer than expected. The horizon is hazy. You remember watching the weather report this morning (urban sounds). The commentator recommended that older people and those with heart and lung conditions stay inside today. The Air Quality Index is 160 (leaf blower sounds). Turn your breathing device dial to level four (step 7 sound cue) (step 8 sound cue) (step 9 sound cue).

You can now remove your breathing device and breathe normally. In your mind, go over your experience. What do you remember about the sensations? Were you uncomfortable? How might you feel if the simulation were to continue? Did you experience relief when you stopped using your breathing device?

Routine C: 4m 30s

You are about to begin a simulation of the experience of asthma. If you have a respiratory illness such as asthma or COPD, do not use the breathing device. Instead, please assist others in this workshop. If you do choose to participate in this exercise, feel free to stop at any time.

First, you should move to the home position indicated by your workshop facilitators. Now take six steps away from the home position. Turn around to face the home position. From this point on, when you hear this sound (step sound cue), take one step toward the home position.

Let's begin by turning the dial of your breathing device to level one, place the cardboard tube in your mouth, and begin breathing normally. Try and follow each breath in and out. How does it feel? Bring your awareness to your chest. Feel it expand and contract.

You are now at your home. You can smell the new carpet that was delivered a few days ago. Last night you had trouble sleeping and woke up several times. You have a slight headache, so you decide to go for a walk to the park (step 1 sound cue) (step 2 sound cue) (step 3 sound cue).

You came to the park for your daily exercise, thinking that might make you feel better (birds singing). Now do ten jumping jacks. One. Two. Three. Four. Five. Six. Seven. Eight. Nine. Ten (urban sounds).

The park is a popular place today. You'd like to sit down, but all the seats in the shade are taken. You remember watching the weather report today. The reporter recommended that older people and those with heart and lung conditions stay inside today. The Air Quality Index is 160.

Turn your breathing device dial to level two. The sun is now immediately above you (leaf blower sounds). The day is hot and uncomfortable.

You can now remove your breathing device and breathe normally. In your mind, go over your experience. What do you remember about the sensations? Were you uncomfortable? How might you feel if the simulation were to continue? Did you experience relief when you stopped using your breathing device?

Appendix B: Workshop Evaluation Questionnaire

The following is a study protocol and survey to evaluate the Breathing Injustice Workshop. I will administer the survey to 5–6 participants. I will begin by explaining informed consent and collecting a signed release. I will then facilitate the complete workshop and discussion session, which will take approximately 30 minutes, after which I will administer the survey. Participants will be compensated for their participation with a $20 gift card.

Appendix B

Breathing Injustice
Workshop Evaluation Questionnaire

1 Overall understanding

1.1 How would you describe this workshop to a friend?

1.2 What did you learn?

1.3 What was your favorite part of the workshop?

1.4 Was there anything that didn't make sense to you?

1.5 How likely are you to take some form of action to advocate for better air quality in your community?

◯ very unlikely ◯ unlikely ◯ undecided ◯ likely ◯ very likely

2 Breathing Exercise

2.1 Did you participate in the breathing exercise?

◯ yes ◯ no

2.2 If so, which routine were you assigned?

◯ Routine A ◯ Routine B ◯ Routine C ◯ I don't know

2.3 How comfortable were you using the breathing device?

◯ very uncomfortable ◯ somewhat uncomfortable ◯ undecided ◯ comfortable ◯ very comfortable

2.4 Did you find it difficult to breathe?

◯ very difficult ◯ somewhat difficult ◯ undecided ◯ easy ◯ very easy

2.5 Is there anything else you'd like to ahare about your experience with the breathing device?

3 Workshop Discussion

3.1 Which topics did your discussion group address?

◯ asthma
◯ air quality
◯ racism
◯ poverty
◯ health care
◯ other: _____

3.2 Were the scenarios in the audio program relatable?

3.2 What reasons for the differences in scenarios did you come up with?

3.3 The discussion was informative

◯ strongly disagree ◯ disagree ◯ undecided ◯ agree ◯ strongly agree

3.4 I feel that I was treated respectfully:

◯ strongly disagree ◯ disagree ◯ undecided ◯ agree ◯ strongly agree

3.5 What local environmental health resources did you learn about for the first time?

3.6 Were there local resources or organizations that should have been mentioned but weren't?

3.7 Do you have any questions about the study or the workshop?

Thank you for your participation.

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