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## **Population Health:** The Translation of Research to Policy



#### **Case Studies and Commentary**

#### Robert Wood Johnson Foundation Health & Society Scholars

The Robert Wood Johnson Foundation Health & Society Scholars (HSS) program was designed to build the nation's capacity for research, leadership, and policy change, while addressing the multiple determinants of population health. One of its goals was to produce a cadre of scientific leaders who could contribute to this research and spearhead action to improve overall population health and eliminate health inequities.

This report, edited by Robert A. Hiatt, MD, PhD, University of California, San Francisco, takes a case study approach, using six diverse examples of science to policy translation generated by Scholars in the HSS program from 2003 to 2016. Because the HSS program was discontinued in 2017, the Milbank Memorial Fund published these case studies in 2018 in hopes that many audiences, including students, would use them to learn about the connections between research, decision making, and policy.

### Case Study 6

# Exposure to Heat Waves: Making Film and Policy

Raising awareness about the health effects of heat waves and climate change by producing a film

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#### Synopsis

This essay is both a professional and personal accounting of a topic that I began to study as a Robert Wood Johnson Foundation Health & Society Scholar (HSS) at the University of Pennsylvania. The health effects of heat waves and climate change began as a piece of research, became more central to my work in policy, and then became a story in a television series. Heat drives the most critical health impact of climate change. In the United States, exposure to heat waves kills more people than all natural disasters combined. However, identifying deaths caused by heat waves is a difficult and controversial issue. These estimations have policy ramifications at the federal level because the Environmental Protection Agency (EPA) uses them as the central indicator for human health impacts of climate change. Paradoxically, health effects of heat exposure are largely ignored, even within the most vulnerable populations. Therefore, public education and education of policymakers is critical. I produced a story for a Showtime television series on the effects of climate change, *Years of Living Dangerously*, with heat as the central story line and Matt Damon as the celebrity correspondent.

#### Learning Objectives

- Understand the risk of heat exposure for health.
- Identify the controversies regarding calculating death from heat exposure.
- Understand how research can be of service to policy.
- Become familiar with film as a tool for translating research.

#### Introduction

I was trained as a sociologist at Brown University and, while there, took film classes at the Rhode Island School of Design. I focused on environmental health and chemical toxins in my academic work and made my first two short documentary films as a student, one in Brazil and the other in the United States, both on environmental causes of breast cancer.

As a Robert Wood Johnson Foundation Health & Society Scholar, I developed a new area of expertise in climate change and health. I was particularly interested in the social dimensions of this subject—how we even identify what illnesses are caused by climate change, how people perceive these risks, and how health could be used to talk to people who couldn't care less about climate change. I focused on three topics: heat-related exposures, West Nile virus, and chemical toxins. The research I conducted at the University of Pennsylvania shifted my academic focus to climate change and changed the trajectory of my career. At the time, I was, and possibly still am, the only scientist working on this environmental health issue.

My first area of research in climate change was exposure to heat waves. As a Scholar, I began working with an HSS alum, Marie O'Neill, an epidemiologist trained at Harvard University. Dr. O'Neill had been conducting research on the effects of air quality and heat in Latin American cities but was left with questions regarding how preparedness could be executed. We made a complementary interdisciplinary team with the quantitative and qualitative approaches we took to the question of heat exposure. We received funding from the U.S. Centers for Disease Control and Prevention (CDC) to study how U.S. cities were responding to heat wave exposures, the weather-related disaster that causes the largest number of deaths. As part of our proposal, we committed to reporting our findings to each of the cities where research was conducted: Phoenix, New York, Philadelphia, and Detroit. We found that cities were largely inexperienced in heat preparedness and that high-risk individuals neither perceived themselves to be at risk nor took advantage of city-provided resources during extreme heat events. I continued this research on heat and examined a number of facets of heat exposure.

In the initial phases of my investigation of the history of heat death controversy, it became apparent that, in Philadelphia and other cities, medical examiners and coroners felt hamstrung: The methodology to identify heat-related deaths was uncertain, resulting in a possible underestimation of risk from heat. Over time, I discovered the policy relevance of this issue. I began a two-year position at the Global Change Research Program at the EPA, the primary office responsible for providing research regarding climate change impacts to the federal government. Concurrently, I served as the only social scientist on the Adaptation Science Task Force for the Council on Environmental Quality and Office of Science and Technology Policy, as well as a member of its Climate Change Communication Task Force, and other interagency committees. As a part of the first task force, we completed the first federal climate adaptation plan. While at the EPA, I came to understand that the estimation of deaths from heat had real policy ramifications. Heat mortality was one of the few human health indicators being used by the agency to estimate the impact of greenhouse gases. Working in an administration that was intent on addressing climate change, I understood that better estimation of heat death could improve regulation of greenhouse gases, therefore protecting the public's health from climate change.

After I left the EPA, I returned to academia as an associate professor in the Milken Institute School of Public Health at George Washington University. There, I began investigating how to improve estimation of heat death. I also began work translating my research findings to the broader public.

Climate change has happened slowly, although sudden changes are now being recorded as a pattern of recent weather events. As I began to study heat, I realized it was the most pressing health-related impact of climate change.<sup>1,2</sup> Global temperature averages have climbed by 1 to 2°F in the last century and are projected to increase 2 to 11°F by 2100.<sup>3</sup> Epidemiologists have

found a consistent relationship between extreme heat and heightened mortality.<sup>4</sup> In the years 1979 to 2002, cumulative mortality due to heat was higher than floods, tornados, hurricanes, lightning, and earthquakes combined.<sup>5</sup> Heat waves lead to poor health via two main pathways: 1) extreme temperature rise leads to heatstroke, and 2) cardiopulmonary problems and respiratory illnesses are often linked to shifts in air pollution concentrations caused by increasing temperatures.<sup>6</sup> Cities are particularly vulnerable to heat waves due to dense environments that lack green space.<sup>7</sup> Urban heat islands<sup>8</sup> occur in cities where temperatures spike eight to 10 degrees above average.<sup>9</sup> Heat waves have been thought to disproportionally affect older adults and people of low socioeconomic status, which may partially explain why little public pressure has developed to address their impacts.<sup>10</sup>

Heat waves are expected to increase in frequency and severity with climate change.<sup>11</sup> They have resulted in a rising number of crises and mass mortality events domestically and internationally, including in Philadelphia, where 118 people died in 1993; in Chicago in 1995, where approximately 800 people died within a few weeks; and in Western Europe, in 2003, where an estimated 70,000 people died."<sup>12,13</sup> In 2009, thousands of people died in Western India when a heat wave and drought occurred simultaneously.<sup>14</sup> In 2010, an unprecedented heat wave combined with an outbreak in forest fires sparked a public health crisis in Moscow that resulted in thousands of deaths.<sup>15</sup> Most recently, 2017 was the third-hottest year ever recorded on Earth.<sup>16</sup> These increasing temperatures heighten the chance that such extreme weather events will occur.

There is confusion as to what constitutes a heat-related death, raising concerns about potential underestimation.<sup>17-19</sup> Social contention about what constitutes a heat-related death has driven debates among policymakers, medical examiners and coroners, and academics since the 1970s, resulting in shifting approaches to estimating deaths. A recent analysis published by the CDC almost doubled the estimates previously reported for the United States, yet this estimate is still far from that in comparable countries like the United Kingdom. In the 1993 Philadelphia heat wave, the medical examiner found that many deaths clearly caused by the heat wave were not calculated as heat related because of the narrow definition for heat-related deaths. He expanded the definition beyond the traditional criteria of a body temperature measured at greater than 105°F to include a body being found in an enclosed environment with heightened ambient temperature and the person being seen alive before the heat wave.<sup>20</sup> The medical examiner also used a similarly broadened definition in the 1995 Chicago heat wave when approximately 800 heat-related deaths were calculated. However, in that case, the mayor denied the validity of the medical examiner's death calculations, claiming they were an overestimation, even when the examiner claimed they were an underestimation.<sup>12</sup> Death estimations then became a subject of contestation that involved a politically charged conversation between Chicago's medical examiner, the mayor, other city institutions, and the CDC.

The medical examiners in Milwaukee, Chicago, and Philadelphia called for a standardized definition of heat-related deaths as a part of the National Association of Medical Examiners Ad Hoc Committee on the Definition of Heat-Related Fatalities.<sup>21</sup> They recommended a broad definition in which exposure to high ambient temperature either caused the death or significantly contributed to the death. A year later, the same group conducted an analysis of heat-related deaths in the Chicago heat wave to test their expanded definition and found that it still did not capture the total number of deaths.<sup>22</sup>

Currently, there remains no widely accepted criterion to classify heat-related deaths.<sup>23</sup> Death certificates are the most commonly used source in many studies to investigate the impact of heat waves on mortality.<sup>24-26</sup> Epidemiologic studies examine increases in different types of mortality comparing periods in which heat waves did and did not occur.<sup>15,18,27,28</sup> They used general mortality, non-accidental mortality, or more specifically cardiopulmonary, cardiovascular, or respiratory mortality<sup>24-28</sup> to assess the impact of exposure to extreme heat. Nonetheless, this approach does not clarify how many excess deaths are specifically attributable to heat.

#### Study Design and Execution

To better understand how many people are dying of heat and what drives potential underestimation, I designed a study of the process of diagnosing a heat-related death. The central research questions were:

- a. What are the diverse social constructions of heat-related death and how do they affect its calculation?
- b. What proportion of deaths can be described as diagnosed heat death, possible heat death, probable heat death, and non-heat death as compared to official estimates?

The study was qualitative and based on two types of evidence: 1) semi-structured interviews investigating how multiple social actors involved in identifying heat-related deaths describe their logic, rationale, and process for collecting and submitting evidence; and 2) an in-depth investigation of possible heat-related death records in New York City from 2009 to 2013 to identify how deaths were or were not being identified as resultant from heat exposure.

Approximately 25 interviews were conducted in New York, Los Angeles, and Philadelphia with medical examiners, coroners, physicians, and epidemiologists who work at the federal level on this issue. We also constructed a novel database of 1,500 records of heat deaths using deaths reported by the New York City Office of the Chief Medical Examiner as an official heat death or possible heat death based on International Classification of Diseases (ICD), 10th revision,

codes on the death certificates. The CDC defines deaths coded as exposure to excessive natural heat (X30) and attributed to effects of heat and light (T67) as official heat deaths. We included deaths identified with ICD codes considered by epidemiologists as heat-related deaths in their analyses. We examined death records of these kinds during heat-wave periods from 2009 through 2013. Our findings suggested several reasons that heat-related deaths may be underestimated and, in particular, why in New York City there may be fairly substantial underestimation.

#### Translating Research to Policy

Accurate science is the basis for regulatory policy at the EPA, among other agencies. Therefore, when seeking to develop science that affects policy, it's important to think first about which regulatory tools the science might advance or support. For example, the Clean Air Act is used to regulate airborne pollutants, so evidence is needed to make the Clean Air Act appropriately strict or targeted toward protecting vulnerable populations. Evidence that offers such details can be used directly in policy. In addition to regulatory policy, there is programmatic policy for which other kinds of research are necessary. To support the advancement of particular kinds of programmatic policy, it's important that scholars identify which kind of programs they seek to influence and define projects that can help articulate how those programs can best be developed or administered. If you need to, ask someone working with that policy or at least in the agency you think you may be able to affect.

#### Successes and Challenges

A central impediment to action on climate change was the lack of public concern about and awareness of the health implications of climate change. I became a producer on *Years of Living Dangerously*, a nine-part Showtime series about climate change that won the Emmy for Best Documentary Series in 2014. The series illustrates the impacts of and solutions to climate change around the world. Each episode features a celebrity correspondent who takes the viewer on a journey to understand one particular topic. The correspondent acts as a proxy for the audience, asking questions to find out people's opinions and elucidate the scientific evidence.

I produced a story starring Matt Damon on the issue of heat death underestimation. We took Matt on an excursion through his home city of Los Angeles to reveal how heat affects human health and to investigate how many people might actually be dying of heath-related deaths. In the story, he meets the Los Angeles medical examiner who says there has only been one official heat death that year. He also meets an EPA scientist who says that her estimates show hundreds of deaths. Along the way, we meet a father who lost his son in a heat wave on the foot-

ball field and the CDC experts who are trying to prevent heat deaths.

This episode and the issue of estimating heat deaths was difficult to portray on film because heat is an invisible threat, and the issue of underestimation is both highly scientific and abstract. My intention was to show that heat affects many more people than previously understood and to make clear to policymakers that climate change will kill more people than current projections demonstrate. My intention was to demonstrate that heat deaths were going unexamined, resulting in a lower level of awareness about the health impacts of climate change. Since the EPA uses heat death as a basic measurement for the health implications of climate change and the basis for regulatory policy, the implication of the story is that measurement of heat death and related regulatory policy must be improved.

I was asked to present this episode on Capitol Hill and was a member of a panel speaking to the many members of Congress who came to the screening. While it is difficult to estimate the impact of this work, I believe that I realized my goal to educate the public about health impacts of heat and of climate change and to affect congressional perception of these issues.

#### Lessons Learned

A critical lesson I learned while working in the policy arena was that policymakers, and especially elected representatives, are most interested in conducting activities requested by their constituents, often powerful constituents. Power can be wielded by financial interests as well as by drivers of influence on the public discourse. Elites, such as academics and experts, can influence public discourse, but I observed that our efforts are sometimes hampered by a lack of awareness on the part of both the general public and niche interest groups that might be able to leverage our evidence-based scientific research to advance policy.

The first and, by far, the most important lesson is the absolute necessity of commitment to my own ideas and taking risks. The change each one of us makes comes from committing to a vision of what we believe is the truth and working to achieve it every day. The vast majority of my ideas are absolutely terrible. It is only through trying the best ones that I come to realize which are viable.

This overall lesson is certainly true when working in a government context. The most effective people are those who pay little attention to the rules or bigger agendas and instead simply stick to their bullheaded ideas of what must be accomplished. Ask for forgiveness, not permission.

The second lesson is the incredible importance of mentors and collaborators. None of the work I have described would have happened without the long list of incredible mentors who supported me, to whom I could turn in moments of need, and most of whom have become good friends. These mentors helped me identify opportunities to engage in my profession in new ways, supported my ideas even when they seemed unattainable, and introduced me to people who would also believe in me. Taking the time to find mentors, to cultivate them, and to enjoy being their friend is as important as doing the work itself. And, that means giving back to them what they give you. Mentors often end up or start out being collaborators. When you build a cadre of people around you who can support you, your work will grow faster and have a much bigger impact, especially if you pick the best people you can possibly find to work with.

#### Conclusions

There are many routes to affect policy as an expert, academic, or scientist. Working at the local level is almost always the quickest way to effect policy change, and that change can filter up to federal policy. If you choose not to work inside the government, learning how to make research policy-relevant will forge a different and creative path to structural change. As a result of this research, policy work, and filmmaking, I appreciate more of the challenges inherent in being an expert attempting to affect policy at multiple levels and at scale.

#### **Discussion Questions**

- 1. How does heat affect human health?
- 2. How should research in the field of climate change and health be designed to promote mitigation and adaptation?
- 3. Why are film and public education important to policymaking?
- 4. What are some principles for working as a researcher to affect policy?

#### Assignment

This assignment has two parts. First, identify a policy that your research could affect. Articulate the pathway through which findings from your research might affect that policy. Make sure to identify what scale policy you aim to affect. Second, conceptualize a documentary or narrative film story line that could portray your findings to a specific audience. Write a paragraph that describes how this story would be told, how you would present the stakes of the issue, the specific messages contained therein, the main story line, and the expected responses on the part of the viewers.

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