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### Casebook in Public Health Ethics: An Open Educational Resource

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#### Introduction: An OER Casebook for Public Health Ethics

A basic internet search for "bioethics casebook" returns double-digit results in a wide variety of domains relevant to bioethics. There are casebooks that embrace a generalist approach (Veatch, Haddad, & English 2014; Pierce & Randels 2010; Mappes & DeGrazia 2006). There are casebooks that apply to specific areas within bioethics such as pediatric ethics (Antommaria 2022), international health research (Cash et al., 2009), nursing (Benjamin & Curtis 2010), and inpatient hospital ethics (Kuczewski, Pinkus, & Wasson 2018). And there are a number of different casebooks on law & bioethics (Furrow et al. 2013; Griffin & Krause, 2016; Dolgin & Shepherd 2018), most of which are intended for use in legal education.

In contrast to this relatively rich supply of casebooks for bioethics in general, there are two casebooks in public health ethics. One of those focuses heavily on ethics in public health research, was most recently updated in 2009, and presents case studies rather than teaching cases per se (Coughlin 2009). The general absence of a sufficient casebook for the growing subfield led the Public Health Ethics Unit at the U.S. Centers for Disease Control ("CDC") to commission and develop the second of these casebooks. This second casebook, an open educational resource entitled "Public Health Ethics: Cases Spanning the Globe," was published in a single edition by Springer Press in 2016. Essentially, then, the entire field of public health ethics is served by one relatively recent casebook. While this single casebook is excellent in quality, it cannot nor does it purport to cover the breadth of problems and controversies relevant to public health practice and policy. Moreover, while the choice to adopt a global health lens is laudable, there are inevitable translation problems that attend individual efforts to apply cases from one national or global context to another. Finally, cases suitable for teaching in applied health ethics contexts are distinguishable from "case studies" in a variety of ways. Thus, even excellent case studies in public and population health may be insufficient for teaching public health and population-level ethics<sup>1</sup> without significant development and adaptation.

There is thus an urgent need for additional casebooks in public health ethics. The present Casebook attempts to help fill the gap, tracking the superb 2016 CDC casebook in a commitment to open science. The present Casebook is focused on a U.S. context. Such focus does not reflect the all-too-common USian exceptionalism, at least not in any approving sense. As to public health, there is little question that unfortunately the U.S. is indeed exceptional. Its public health system barely merits the label as it was neither centrally planned as a system nor does it often function in systematic ways. Especially relative to health care services, public health in the US is shockingly

<sup>&</sup>lt;sup>1</sup> Although there may be relevant theoretical distinctions between, "public health ethics" and "population-level ethics" this Casebook will use the terms interchangeably.





underfunded on local, state, and federal levels. These and many other structural and political problems converged during the ongoing COVID-19 pandemic to result in what can only be termed an abysmal performance in managing, controlling, and responding to the pandemic and shielding the most vulnerable communities. The peculiarities, paradoxes, and punctures of the US public health system justify the presence of at least one Casebook that focuses on the US, as the present effort does.

In addition, the Casebook functions primarily as a casebook. While it offers a short framing Commentary and discussion questions for each of the six categories of cases included, it does not attempt to analyze the cases in detail nor provide significant background or context in the wider public health ethics literature. Within that literature, there is ample research and scholarship on every case and ethical problem covered in this text. Therefore, outside of a short list of Suggested Readings, the reader is invited to integrate additional texts and learning resources to supplement the teaching cases in this book. The Casebook is intended as an instrument to assist teachers and scholars in public health ethics develop the field through the application of teaching cases.

Finally, in service of that aim, the Casebook offers a general Public Health Ethics Case Analysis Template. A variety of excellent frameworks for analyzing cases in public health ethics exists; the Template is intended only as a supplement and is in no way necessary for achieving important learning objectives via the cases themselves.

Public health ethics is a thriving, growing field. The COVID-19 pandemic has cast the field's significance in sharp relief. There is a desperate need to grow capacity among public health workers, leaders, and policymakers in skills of ethical reasoning and procedural justice that can be integrated into everyday practice and policy. Ideally, this Casebook can help advance that objective.

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### Case Category #1: Structural Violence & Public Health

Oppression is a fundamental cause of population health inequalities. There is overwhelming evidence in the social epidemiologic evidence base for this conclusion. While most people with foundational training in public health understand that the social determinants of health are primary factors in shaping the distribution of health in populations, it is critical to perceive the "causes of the causes" (Rose 1985; Rose 1992; Goldberg 2017). Different communities enjoy unequal access to resources that largely determine the conditions in which people live, work, and play. Accumulations of power and capital are the primary factors in conditioning such access; oppression and discrimination are creatures of social, economic, and political power and therefore act as primary drivers in determining access to critical social drivers of health.

Thus, in public health law scholar Ruqaiijah Yearby's Revised SDOH Model, the root cause of downstream health outcomes is structural discrimination. Such discrimination operates through a variety of "tools" and "systems" to determine the health of entire communities.

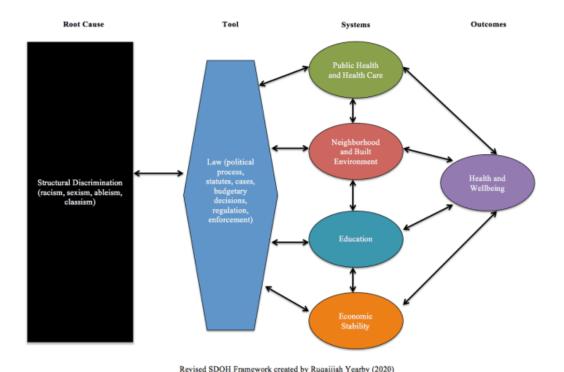


Figure 1 (used with permission)

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Although there are many ways to synthesize the extensive evidence base establishing these claims, arguably one of the most useful in teaching public health ethics is the concept of "structural violence." Originating from Latin American liberation theologians in the 1960s and then by mathematician Johan Galtung, structural violence "describes ... social structures that stop individuals, groups, and societies from reaching their full potential" "The arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people (typically, not those responsible for perpetuating such inequalities)" (Farmer et al., 2016).

As a concept, structural violence is helpful in teaching contexts for three reasons. First, it rests upon a solid evidence base, as noted above. Second, thanks at least in part to the work of Paul Farmer and colleagues, the concept of structural violence is familiar in health professional and population health contexts. This makes it especially useful in teaching the connections between historical patterns of domination, oppression, and subordination and contemporary public health problems. Third, structural violence is helpful because it can accommodate many different forms of oppression. Racism, ableism, sexism, ageism, and other forms of domination and subordination can be categorized within the notion of structural violence even as each manifestation of violence and oppression of course are independently significant. (That is, the utility of structural violence as a teaching tool that can illuminate intersections between different forms of oppression is not an excuse for failing to consider the problem of structural racism as a social and public health problem in its own right).

Accordingly, the cases in this category all center problems of structural violence and its role as the fundamental cause of population health inequalities.

#### Case #1

#### Deaf Culture, Eugenics, & Public Health

Dr. Jones is an otolaryngologist called in to consult on the case of a 16-month-old-child named Michelle newly diagnosed as deaf. Michelle's parents, John and Mary, are also deaf, and self-identify as participants in Deaf Culture.\* Michelle is a candidate for a cochlear implant, and Dr. Jones and Michelle's pediatrician, Dr. Shaw, strongly recommends the procedure to Michelle's parents. To their surprise, John and Mary erupt in anger at the suggestion, and accuse Dr. Jones and Dr. Shaw of trying to practice eugenics by eliminating Deaf Culture. They say that being Deaf is not a pathology, and is rather exactly like being a stranger in a country where almost no one speaks your language.





John and Mary say that they are excited to raise Michelle within Deaf Culture, and that only someone who is Deaf can be a core member and an insider in Deaf communities.

Taken aback, Dr. Jones and Dr. Shaw thank John and Mary for their explanation, and seek a consultation with Risk Management and Bioethics. Dr. Jones said that his primary concern is whether the administration of a cochlear implant is so obviously in the best interests of the child that the parental refusal to consent may be overridden. Dr. Shaw added that, although she understands that parents have wide latitude to make health care decisions for their children, parents are not generally permitted to make "martyrs" of their children. Dr. Jones and Dr. Shaw are concerned that this might be such a case and ask the bioethicist what to do.

What should Dr. Jones and Dr. Shaw do? Why?

\*The National Deaf Center on Postsecondary Outcomes <u>explains</u> Deaf Culture this way: "It often comes as a surprise that many deaf people refer to themselves as being members of the Deaf community and ascribe to Deaf culture. These people view themselves as a unique cultural and linguistic minority who use sign language as their primary language. The characteristics of Deaf culture are formed out of many shared life experiences rooted in a visual world designed for communication ease."

#### **Discussion Questions:**

- 1. To what extent do John and Mary's perspectives reflect a social model of disability? To what extent does the care team's perspectives reflect a medical model of disability? Can these be reconciled? If so, how? If not, why not?
- 2. How do the long histories of eugenicist thought and practice in the health professions inform the conversation between John and Mary and the care team?
- 3. There is substantial debate over the extent to which efforts to "correct" human functionings and capabilities deemed pathological *express* eugenicist perspectives, whether intended or not. Does the care team's preference for the intervention express a belief that the world would be better if there were less Deaf people? Is it fair for John and Mary to believe as such? Why or why not?
- 4. Do the concerns about ableist expressivism noted in DQ3 apply to other health conditions? For example, Fat Activists and Fat Radicals often argue the public health efforts to reduce fatness express a belief that the world would be better without persons in larger bodies. Do you agree with this claim?
- 5. Bioethics as a field generally does not enjoy good relations with disability rights and disability advocacy communities. Bioethicists are typically not regarded as trustworthy actors by

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communities of disabled people. How does this context affect the decision in the case above? What should bioethicists do to become more trustworthy to disabled people?

#### Case #2

#### Experimental Vaccines, Racism, & Trustworthiness

In your capacity as a physician, you have been invited to a meeting of regional public health leaders addressing the current state of an avian influenza pandemic. About 45 officials are present, and they reflect the variety of the public health workforce (nurses and nurse-scientists, lawyers, policy analysts, physicians, pharmacists, program managers etc.). At issue is a recent directive from the Centers for Disease Control instructing state and local health officials to prepare for early administration of a vaccine.

The mood is tense, and one reason rapidly becomes clear: A substantial portion of the participants are decidedly uncomfortable with the prospect of rolling out a vaccine that has been rushed through development at literally unprecedented speed. Not a single member of the meeting is vaccine-skeptical or vaccine-hesitant in anyway. To the contrary, the Zoomful of public health leaders is staunchly pro-vaccine as a public health intervention. There is nevertheless great trepidation about administering a vaccine now, which would be a year at most after the zoonotic disease began actively spreading in humans.

Moreover, one official, George McWilliams, notes that the triage protocols likely to govern distribution of the vaccine will likely prioritize those most at risk from severe outcomes, which would include African-American, Indigenous, and Latinx communities in the U.S. The first two of these historically oppressed groups in particular have documented mistrust for medical and public health officials. Early surveys report significant hesitancy and unwillingness within these communities to receive an early vaccine. Molly Freeman cues up her digital hand and says, "George's point is so important. They are right. Public health officials are not trustworthy, and we should not be trusted because we haven't earned it."

T.S. Rodriguez then speaks next and says "And tracking George and Molly's point, I remember from my history of public health course that during the 1900 bubonic plague outbreak in San Francisco, the US Public Health Service was prepared to forcibly inoculate 8000 residents in Chinatown with the prophylactic Haffkine vaccine, which, even by the standards of the time, was unquestionably experimental. I mean, a substantial gathering of officials and assistants gathered with syringes and vials on the border of Chinatown on the morning of May 19, 1900. It could easily have

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resulted in violence. And when that didn't work, the next plan was to forcibly remove the entire population of Chinatown to Mission Island. Do we want to repeat this terrible, racist history?"

Mx. Rodriguez then turns to you and says, "What do you think, especially as an outside observer? What should we do? What should our next steps be?"

#### **Discussion Questions**:

- 1. Bioethicists have emphasized that trust is distinguishable from trustworthiness and that, when it comes to historically oppressed groups, it is trustworthiness that is most important. Why might this be so?
- 2. Vaccine hesitancy and skepticism are literally as old as vaccines. Although Jenner is credited with introducing vaccination to the West at the end of the eighteenth century, there is no question that inoculation practices are significantly older across Africa, the Middle East, and China. To what extent should this colonial history of vaccination shape contemporary problems of mistrust among historically oppressed groups? Can this awareness be leveraged by "untrustworthy" actors to build trustworthiness? Why or why not?
- 3. Despite the concerns voiced in the prompt, during the rollout of vaccines in the COVID-19 pandemic, Black and Brown communities showed high vaccine uptake. By the summer of 2021, for example, the Navajo Nation was among the most <a href="https://disable.communities.or.or.">highly-vaccinated</a> sovereign communities on the planet. What does this tell us about the connection between trustworthiness and public health?
- 4. To some extent, the issues raised in the Case reflect ethical problems related to implementation. How can ethicists be of service to people charged with implementation responsibilities, both in and out of public health emergencies?

#### Case #3

#### Racial Bias in Clinical Algorithms

Upstate Regional Health System has convened a meeting of one of its three Quality Improvement Committees. There are 11 members of the Committee, with representation from clinical care including two senior physicians, two nurse practitioners, and a pharmacist. Two non-clinical health system administrators are present, as well as a risk management professional and a community representative. The QI Committee typically includes a resident or trainee, and today you are serving in this role.

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The subject of the meeting is to consider a proposal to officially change Upstate policy to recommend against using clinical practice guidelines ("CPGs") that specifically recommend race correction in clinical algorithms. A review committee has gone through CPGs that Upstate uses or recommends to its staff and clinical teams and has found that a number of them in a variety of services do utilize race corrections. Such CPGs can be found in

- Cardiology;
- Cardiac surgery;
- Nephrology;
- Obstetrics;
- Urology;
- Oncology; and
- Family Medicine.

The review committee warned that its search methodology was imperfect and rushed, and that therefore there are likely other CPGs in use at Upstate that also include race corrections in clinical algorithms. At the outset of the meeting, one of the health system administrators, Mx. Tsui, laid out the case for advising care teams against using such CPGs:

"Descriptive epidemiology is one thing, but the data on which these algorithms are based is often absurdly flawed in design or in its basic conception of race. Using them risks reifying biological essentialism, which is bad in its own way since it is one of the conceptual bases for structural and medical racism. Perpetuating biological essentialism also can obfuscate the ways in which it is racism and structural violence that are the primary causes of racial health inequities. It's racism, not race. In addition, these race corrections can push us away from services and interventions for our BIPOC and Black patients in particular. This can make existing health and health care inequities worse. Basically, there's many decent reasons to use race-based categories in epidemiologic research if they're intended to reveal the effects of structural racism on health outcomes. But moving to use that research into prescriptive CPGs without extreme caution and anti-racist effort is a bad idea, and none of these CPGs have integrated that needed caution and work."

One of the nurse-practitioners, Nurse Locklear, speaks up and says, "That's a great summary of the arguments in favor of changing the policy. But they haven't convinced me yet. While the concerns are legitimate, we're also increasingly operating in a climate in which overutilization is a serious concern for both outcomes and finances. Sure, we don't want to exacerbate racial health inequities, but we also need more information to understand where a tendency to under-utilize actually produces worse health rather than simply less unnecessary care. In addition, it's not as simple as just

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changing CPGs ad hoc. Upstate CPGs are connected to malpractice coverage. Advising that our care teams avoid using CPGs thus raises liability and risk management concerns, as our risk management expert Ms. McWilliams can tell us. Similarly, our increasing moves to value-based reimbursement also include components that measure adherence to CPGs."

Nurse Locklear pauses and then inclines her head to Dr. Rodriguez, the senior physician in attendance. Dr. Rodriguez smiles and says, "Look, I've been using these CPGs or others like them for years now. I strongly believe race corrections are an important tool for clinical care and that they are needed to address health inequalities. I am proud to teach my trainees and staff the careful use of these algorithms, and I think it would be a big mistake for Upstate to dictate in its policies how clinicians and care teams should practice."

After several more rounds of conversation, the Committee decides to take a preliminary vote. After 10 members have voted, the count is evenly split, 5-5. Your LC is the deciding vote, at least for this preliminary vote.

How will the LC vote? And what is the justification for your choice?

#### **Discussion Questions:**

- 1. Racial bias in clinical algorithms is a particularly good example of structural violence inasmuch as the care team can maintain deep anti-racist and anti-oppression commitments and yet unintentionally perpetuate structural violence through the application of these algorithms. Is it fair to task the care team itself with responsibility for fixing racially biased CPGs and algorithms? If not, why not? Whose responsibility is it?
- 2. Can clinicians be charged with the task of examining CPGs they are applying for evidence of racial bias? If not, why not?
- 3. Are racial corrections in the health professions ever appropriate? (Hint: Most definitions of justice imply that prioritizing the least well-off is ethically mandatory).
- 4. Do the problems noted in the Case suggest that health professionals ought to apply a "color-blind" approach to health care? Do you think patients explicitly want such an approach? Why or why not?

Case #4

#### Hospitals and the Social Determinants of Health

Upstate Health System convenes regular meetings with its Community Advisory Board. At the most recent meeting, an administrator named George Williams delivers a presentation on a pilot project Upstate is running entitled "Pathways to Housing." They describe the project this way:

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"Upstate partners with the National Fair Housing Alliance ("NFHA") for the Local County Pathways to Housing program. The program supports medically vulnerable homeless patients by providing permanent housing rental assistance, long-term comprehensive case management, with medical and supportive services in scattered site apartments within Local County. Eligible patients are high utilizers of local emergency rooms who are experiencing homelessness, medical and behavioral health challenges. Care Connections for the Homeless team provides outreach based medical care and medical case management. This medical team works in collaboration with NFHA case managers to identify and engage program participants. Medicagroup, as the largest provider of Medicaid services in the Local County area, also serves as a partner in the project to augment behavioral health supportive services and care coordination for clients."

After Mx. Williams's presentation, there is an opportunity for Q&A and Discussion, and one of the participants, a Woman of Color named Andrea Wilson, speaks up and say the following:

"I appreciate what Upstate is trying to do but I have some concerns. Academic health systems do not have a good record of attending to racism and structural violence or on leading collective action on structural determinants of health. Most of the anti-oppression work in our communities has been done through self-help and mutual aid *by* our communities, on the grassroots level and rooted in community-based organizations ("CBOs"). We have no problem partnering with Upstate but we do not support Upstate commandeering these efforts. Won't that just result in more resources and funds going to the already affluent health system and Upstate hospitals? Why not direct these funds and resources directly to the communities and CBOs and let us lead on program design & implementation?"

#### **Discussion Questions**

- 1. Some policy scholars have voiced concern over the "medicalization" of health policy. What might this mean? Why could it be of concern?
- 2. If health systems have traditionally fallen short in advancing action on social determinants of health, isn't that a reason for them taking the initiative to do better? And with more resources comes more responsibility why shouldn't health systems take on leadership roles in policy work addressing racism and structural violence?
- 3. Commentators and community-based advocates argue that "humility is a key component of justice and equity work. Why do you think this might be important? How does it apply here?

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### Case Category #2: Surveillance & Public Health

Surveillance is a core activity for public health. In fact, it fairly characterizes the first two of the <u>Ten</u> Essential Public Health Services:

- 1. Assess and monitor population health status, factors that influence health, and community needs and assets
- 2. Investigate, diagnose, and address health problems and hazards affecting the population

Without accurate estimates of the patterns of disease and injury (often referred to as "descriptive epidemiology"), it is difficult to gauge priorities for intervention and allocate resources accordingly. Surveillance raises profound ethical questions, and commitments to justice can transgress for reasons of both over- and under- inclusivity. That is, the history of public health surveillance shows that some marginalized and oppressed communities are made the object of perpetual surveillance in the name of public health in ways that fuel and sustain structural violence. Indeed, the sustained surveillance is both an effect and a cause of such structural violence because in many cases the justification for the perpetual surveillance are racist and oppressive beliefs about the relevant community.

For example, preceding the 1900 bubonic plague outbreak in San Francisco's Chinatown, widespread anti-Chinese and anti-Asian beliefs deemed Chinese people living in the U.S. as both biologically and epidemiologically inferior (Trauner 1978). Chinese people were deemed to be inherently more susceptible to disease and/or more liable to spread communicable disease due to their living conditions (for which they were deemed responsible). These beliefs justified more intensive surveillance practices which only deepened once a man named Wong Chut King died of plague in March of 1900. The San Francisco Board of Health, in partnership with the U.S. Public Health Service, increased its surveillance of Chinatown that led both to a discriminatory and ultimately unconstitutional sanitary cordon of barbed wire being enforced around Chinatown. The Board of Health also discussed plans to forcibly inoculate the entire community with an experimental plague vaccine, and, failing that, to forcibly remove the community to an island in San Francisco Bay (Risse 2012; Shah 2001).

Moreover, the early 20<sup>th</sup> c. association of tuberculosis with various racial and ethnic minorities led to the designation of "lung blocks" in eastern cities like New York and Baltimore, which prompted intensive scrutiny and surveillance from local, county, and state officials (Roberts 2009).

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Yet, as noted above, the total absence of public health surveillance itself for vulnerable and/or minoritized groups is not always morally laudable. For example, data disaggregation problems have led entire communities to be subsumed under the general U.S. Census category of "Asian-American /Pacific Islander" (AAPI). Scholar Kevin Nguyen recently explained:

"Even though AAPI people are a diverse group consisting of more 50 ethnicities and 100-plus languages, their health data are often aggregated as one race and treated as a monolith. This grouping masks wide variation in access to care, health status, and health outcomes for different subgroups (such as Native Hawaiian Samoan)."

It is precisely <u>because</u> "AAPI health disparities matter" that public health surveillance is ethically mandatory; "AAPI data disaggregation, or the collection and reporting of AAPI subgroups, is a critical first step for identifying and addressing [these disparities]."

The three cases in this category all center these ethical problems in context of disease and injury surveillance.

Case #5

#### Pain, Doubt, & Population Health

While Jane Kasper's application for Social Security disability benefits is under consideration, her pain worsens. For the last eight weeks, Ms. Kasper's life has been mostly a torment, what she describes as a "hell, a well of pain" from which she cannot seem to escape. Aside from her family, the only coping mechanisms that tend to help in the midst of these severe pain spells are some of the light yoga exercises Ms. Kasper is able to do, and her use of an oral combination treatment of morphine and a non-narcotic medication named memantine that is currently approved for use in persons with Alzheimer's Diseases. The evidence for the long-term safety and efficacy of opioid analgesics for chronic non-cancer pain is generally quite weak. One randomized-controlled trial suggests that the combination pharmaceutical regimen Ms. Kasper is on might be efficacious (Gustin et al., 2010; see also Goebel 2012), but that trial had an extremely small sample size (n=20) and has not been replicated in any larger studies.

By about six weeks ago, Ms. Kasper's pain has been so intense that she has been forced to "double-up" on her medications, taking almost three times the daily prescribed amount. Three days ago, on a Friday afternoon, Ms. Kasper presented to the Chronic Pain Outpatient Center ("Center") without an appointment, disheveled, unwashed, with swollen red-rimmed eyes, and wearing a bathrobe and

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slippers over her sweatpants. When the office manager inquires as to how Ms. Kasper arrived at the Center, she mumbles that she took the bus.

Ms. Kasper is uninsured and has never been seen as a patient at the Center before. At the time of her arrival, the Center does not have access to any of her medical records. Ms. Kasper sits morosely in the waiting room for 45 minutes, stares at the ground, and says nothing other than to ask for a tissue to dry her eyes.

Ms. Kasper gets called in to see the provider, a family nurse practitioner named Rhonda Johnson, and requests a refill of her regimen, or, in the alternative, a new prescription for morphine. Nurse Johnson completes her examination of Ms. Kasper, leaves, and returns with a physician named Bill Jones. Dr. Jones sits down and discusses with Ms. Kasper her symptoms and condition, and asks Ms. Kasper from whom she had obtained her previous prescription. Ms. Kasper indicates that she saw a physician while visiting her husband's family, and filled the prescription at a free clinic there.

Dr. Jones first recommends that Ms. Kasper receive a magnetic resonance imaging scan, and Ms. Kasper raises her eyebrows and inclines her head, but says nothing. Dr. Jones then indicates that he is willing to write a 30-day prescription for the combination regimen, but only if Ms. Kasper agrees to sign a so-called "medication adherence contract," and submit to both random and scheduled drug testing over the course of their treatment relationship. He further states that if Ms. Kasper misses any scheduled follow-up appointments, he will immediately terminate her as a patient. He concludes by telling Ms. Kasper that the Center pharmacy, which is the only pharmacy likely to fill a prescription for opioids in the absence of a prior treatment relationship, is closed for the weekend, but recommends she take prescription-strength ibuprofen until she can get the prescription filled.

Ms. Kasper's eyes open wide with shock, and she begins to scream obscenities at Dr. Jones and Nurse Johnson, accusing them of "character assassination" and gender discrimination. She is crying, stating over and over again that she is a professional, a wife, and a mother, and that every day feels like torture. She then gets up and runs out of the examination room, and out the front door of the clinic. No one at the Center hears from Ms. Kasper again.

The Center is officially owned by Perrin Health Care Corporation, which also owns and operates the Perrin Medical Center ("PMC") in town (of which the Center is a part). One week ago, the general counsel for PMC, a man named George White, is served with notice of a lawsuit for negligence in the care and treatment of Ms. Kasper's pain condition. Some quick research reveals that there is in fact some precedent for such cases.

Mr. White meets with several PMC administrators and urges them to convene a meeting of the PMC Ethics Committee, of which you are a member. The purpose of the meeting is to discuss whether the care and treatment offered to Ms. Kasper was ethically appropriate.





Do you think it was? Why or why not? What larger concerns of justice and equity does this case raise?

#### **Discussion Questions**

- 1. If the care teams at PMC treat all pain patients the same as they treated Ms. Kasper here, can that care be discriminatory? Why or why not?
- 2. There is little doubt that, as a population, people in pain are subjected to much more medical and public health surveillance than people presenting with non-pain-related illnesses. Is this enhanced surveillance ethically justifiable? Why or why not?
- 3. To what extent does the stigma of people in pain affect the ethical calculus of the case? To what extent does the stigma of people who take opioids affect the ethical calculus of the case? (Note that these are related but not identical stigmas, since there is evidence that we stigmatize people in pain who do not want or take opioids).
- 4. What population health problem are we trying to solve by subjecting people in pain to increased surveillance? Who is intended to benefit from this surveillance? And do those benefits outweigh the harms done to the population being surveilled?
- 5. Although the case prompt specifically mentions gender discrimination as a possible factor, can you think of any other stigmas related to social status that could be relevant in justifying increased surveillance of pain patients?

Case #6

#### HIV Surveillance & Law Enforcement

A county Department of Public Health has engaged in an innovative program with the county District Attorney's Office. When individuals are arrested for consensual behaviors that are high risk for HIV infection, they are given an opportunity to be tested for HIV. In return for consent to be tested they are offered a plea bargain and a reduced sentence. Officials believe that this program will increase testing, counseling and treatment for high-risk individuals that are frequently missed. Is this program ethically appropriate? Why or why not?

(case attributed to Kenneth J. DeVille, used with permission)

#### Discussion Questions:

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- 1. Public health ethicists frequently talk of the conflict between utilitarianism ("the greatest good for the greatest number" and justice (as fairness or equity). Why might this value conflict be relevant here?
- 2. There are obvious concerns of coercion here. To what extent do they render the program unethical?
- 3. Can you think of any background reasons why communities at heightened risk of HIV infection might be wary of state surveillance? How does the existence of those reasons bear on the legitimacy of the program?
- 4. To what extent should local health departments be partnering with local prosecutors in advancing public health ends? Are such partnerships inherently problematic? Why or why not?

Case #7

#### Screening Ethics & Population Health

Linda Huang is the Chief Operating Officer for the Franconia Health System, a mid-sized regional health system operating in the U.S. A dispute has arisen among Franconia's Quality Improvement Committee, which has spilled over to the Health System Ethics Committee as well. The issue concerns the appropriate clinical protocol for the use of diagnostic mammograms for women aged 40-49. For several decades, Franconia had followed the consensus guidelines promulgated by leading oncology associations (such as the American Cancer Society and the American Society of Clinical Oncology) that recommended annual mammograms for all women in this cohort.

However, four members of the QI Committee have recently suggested that the Health System should officially endorse a policy in line with the changed recommendations of the US Preventive Services Task Force (USPSTF). In 2009, the USPSTF issued a grade of "C" for the use of annual mammograms for women aged 40-49, concluding that

"The decision to start screening mammography in women prior to age 50 years should be an individual one. Women who place a higher value on the potential benefit than the potential harms may choose to begin biennial screening between the ages of 40 and 49 years."

This marked a change from the USPSTF's prior recommendation of 2002, which recommended such annual mammograms for all women in this age cohort. Members of the QI Committee argue that the number-needed-to-screen for annual mammograms for all women in this age cohort is unacceptable -- roughly 1900 to 1 (i.e., measured over an 11-year-period, 1900 women must have mammograms to save the life of 1 woman from breast cancer). There are significant risks of false positives in this age cohort (roughly 2000 for the cohort), which means that the psychosocial and

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financial costs of such annual mammograms (roughly 20,000) are significant. The proponents of the change also argue that the standardization of mammography protocols across the Health System is crucial to improving system outcomes, population health metrics, and to controlling hyperinflationary costs that are frequently passed onto patients and their families. Finally, they point out that there is nothing in the suggested protocol that precludes individual providers from ordering mammograms for patients in this age cohort if they deem it appropriate. Rather, the objective is simply to standardize the idea that such screening should not be the default for all Franconia patients in the cohort.

Opponents of the change are enraged. They accuse the proponents of attempting to force providers to practice "cookbook health care." They note that many professional organizations do not agree with the USPSTF; the American College of Radiology, for example, expressly called the guidelines "untrustworthy" in 2015. They argue that the need for personalized health care contradicts the very idea of issuing a blanket policy against annual mammograms for women aged 40-49. Because, they reason, even the USPSTF concedes that the question of whether a women in this cohort should have annual mammograms should be the result of shared-decision-making between the patient and the care team, it is ethically unacceptable to endorse the proposed protocol as Franconia policy.

Ms. Huang consults the Health System Ethics Committee for guidance, but they are also divided on the issue. The chair of the committee does note the perspective of two commentators in a 2009 article on the subject:

"... [S]cientific evidence can only help us describe the continuum of benefit versus harm. The assessment of whether the benefit is great enough to warrant the risk of harm — i.e., the decision of where the threshold for intervention should lie — is necessarily a value judgment."

The QI Committee is composed of 9 members, including Ms. Huang. The Committee is currently split 4-4 on whether to endorse officially the USPSTF recommendation. As COO, Ms. Huang has the responsibility of casting the deciding vote. How should she vote?

#### Case #8

#### Screening Ethics, Racism, & Population Health

While the mammography controversy has raged since 2009, system-level screening guidelines often respond very slowly in considering changes. Just as the Health System Ethics Committee is preparing to meet, the USPSTF changed its guidelines yet again. In its most recent review (2023), the USPSTF for the first time explicitly included evidence that stratified risk based on racial and ethnic identity. This evidence showed a considerably elevated risk for Black women aged 40-45. On

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the strength of this evidence, the USPSTF <u>upgraded</u> its recommendation for women in the 40-49 category, assigning a grade of "B" for "biennial screening mammography for women ages 40-74."

Mx. Huang decided to convene an additional meeting of the Health System Ethics Committee to discuss the most recent USPSTF recommendations. At the meeting, one of the members notes that the strongest benefit-to-harm ratio is found in specific subgroups such as Black women, but that the benefit-to-harm ratio for the overall cohort of women aged 40-49 remains sufficiently close to warrant the ethical determination a difficult one. Mehra Golsan, a breast cancer surgeon, criticized the USPSTF in an op-ed in the *New York Times* for "fail[ing]to issue more individualized recommendations for these groups, instead calling only for more research."

Further, Dr. Golsan reasoned that

[i]t would be helpful if cancer screening recommendations became more unified for people at average risk and more individualized for groups at higher risk. We should have more open conversations about how mammograms, ultrasounds, M.R.I.s and doctors' breast exams are imperfect. They sometimes identify abnormalities that are benign, and the anxiety created by a false positive imaging or biopsy is significant.

The USPSTF's Draft Report explaining the change <u>noted</u> that while all four screening strategies assessed "estimated higher values for Black female persons as compared with female persons overall," all four models also found the lowest values for recommending *annual* mammograms for women aged 40-74.

What guidance should the Ethics Committee offer? Should they endorse the 2009 guidelines or the 2023 changes? Why?

#### **Discussion Questions**

- 1. In its 2023 Draft Report, the USPSTF explicitly states that the "modeling analysis regards race as a social construct and aimed to provide evidence regarding the tradeoffs of mammography screening strategies for female persons that self-identify as Black as an approach to mitigate health effects of racism." Why do you think the USPSTF deems it important to regard race as a social construct? What is at stake in doing so?
- 2. Do you agree with Dr. Golsan's critique that the USPTSF recommendations ought to be stratified by subgroup instead of issuing only recommendations for *all* women in the age cohort of 40-74?
- 3. What do you think about the metric of "number-needed-to-screen?" How can we weigh the value of a single life saved against the considerable harms of overdiagnosis?
- 4. Can we use a trolley problem for framing the question in #3? Do you think it might be helpful for the Ethics Committee? Why or why not?

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### Case Category #3: Priority-Setting & Public Health

As I remarked in a 2017 text, there is an argument to be made that the foundational questions of public health ethics fundamentally turn on issues of priority-setting. This is because there is often no inherently forced choice in a set of interventions available to public health actors. For example, as to tobacco control, there is no reason why policymakers could not simultaneously implement interventions related to taxation, health promotion targeted at prevention, tobacco cessation programs, and enhanced warning labels. The so-called false choice fallacy must be avoided given the lack of ethical justifications suggesting that all of these interventions, and many others besides, cannot be pursued at once.

While there may not be inherent ethical constraints on recommending multiple simultaneous public health interventions, there are important practical constraints. Specifically, while public health actors can endorse a wide range of interventions at the same time, they cannot pursue all such interventions with the same energy and investment of resources. The practical reality of scarce resources and virtually unlimited public health needs requires actors to make difficult decisions about which interventions to prioritize in different circumstances for different intended beneficiaries. These priority-setting questions are so important that some public health ethicists have centered them in the theoretical frameworks they offer. For example, in their highly influential 2006 book on social justice as the foundation of public health and health policy, Madison Powers and Ruth Faden set out to answer the question of "Which inequalities matter most?" Even if, as a field public and population health actors make the advancement of equity an ethical lodestone, that priority alone does not help us discern which inequalities matter most. We still require tools and frameworks that help us reason systematically through competing health claims and needs to determine which interventions are most important in redressing particular health inequalities.

Many of the cases in this book touch on difficult questions of priority-setting in public health ethics. Because of this, this section features only a single case that frames a difficult budgeting exercise in terms of priority-setting. Feel free to locate the others in the book that implicate priority-setting concerns as a way of conceptually mapping issue-spotting skills in ethical analysis.

Case #9

Budgets, Ethics, and Priority-Setting

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Your employer, East County Health Department, is going through its annual budgeting process. Despite a surplus, the state has slashed social services budgets across the board and demanded significant reversions. The total budget for East County Health Department has been reduced to about **US\$43 million**. Your supervisor has assembled a team to decide how to allocate the needed cuts, which have to add up to **US\$12 million**.

You've been given a list of proposed program cuts, the cost savings, and a short description for each. Your supervisor tells you that not only do you have to produce a draft allocation scheme, but the scheme must *rank* your preferred programs in order from "most important" to "least important." You know that you also need to develop some ethical justifications for your allocation scheme.

### Partial List of Divisions for East County Health Department & Proposed Cuts

#### General Environmental Health

East County offers a variety of services under this program, including but not limited to all safety inspections (i.e., food, swimming pools, child care facilities, tattoo establishments, hotels, etc.). Lead screening programs also fall under this division.

Total Budget: US\$8 million Proposed Cut: US\$3 million

#### School Health Education

This Division offers services and resources for school health education, including some resources to suicide and crisis interventions. The Division has also been discussing implementing naloxone training, although this is unlikely to be approved by local school boards anytime soon.

Total Budget: US\$1 million Proposed Cut: US\$500,000

#### Women, Infants & Children

This Division is one of the largest in the East County Health Department. It supports prenatal care, nutrition support (both promotion and state supplemental assistance), breastfeeding classes and support, and well-child checkups.

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Total Budget: US\$7.5 million

Proposed Cut: US\$3 million

#### STI Control

This Division offers confidential testing, treatment, and partner notification for a variety of sexually-transmitted infections ("STIs").

Total Budget: US\$3 million

Proposed Cut: US1.5 million

#### **Immunizations**

This Division provides all CDC-recommended childhood vaccines as well as a variety of adult vaccines.

Total Budget: US\$4 million

Proposed Cut: \$US3 million

#### <u>Laboratory Services</u>

This Division is responsible for the complete public health laboratory for East County Health Department. In addition to being responsible for all testing needed to support the other Division's missions, it also contracts with a variety of local organizations to offer testing in support of safety programs and to prepare for inspections. The Division therefore generates a significant revenue stream for the East County Health Department.

Total Budget: US\$1.5 million (this Division helps to support itself via its revenue stream)

Proposed Cut: US\$1 million

#### **Discussion Questions**

1. To some extent, this case asks you to exercise your imagination in terms of what proposed cuts might mean for specific programs and resources. While increased efficiencies are often possible, as the saying goes, 'Sometimes you cannot do more with less. Sometimes you can

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- only do less with less.' Assuming this case is one of those times, which programs are less significant? Why?
- 2. Commitments to justice often require prioritization of the needs of the least well-off. Is this relevant to your chosen allocation scheme? If so, how? If not, why not?
- 3. Can you think of any reasons why the East County Health Department might propose a 75% cut in spending for its immunization division? How do political considerations shape budget allocations? And what does ethical commitments require of public health actors affected by such considerations?
- 4. "Budgets are ethics exercises." Explain.
- 5. Given generally declining state support for local health departments in the US, such departments have often had to prioritize programs and services that generate revenue streams for the departments. These revenue-generating programs are then used to subsidize important but generally underfunded programs and services. Cutting revenue-generating programs therefore may have downstream implications for other programs. How does this affect priority-setting for the revenue-generating programs? How should public health actors weigh a program that generates revenue but is less important for health outcomes than a program which does not generate revenue but is more important for health outcomes? And what if the latter set of programs disproportionately support some of the least well-off communities?

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### Case Category #4: The Commercial Determinants of Health

The World Health Organization ("WHO") defines commercial determinants of health ("CDOH") as "private sector activities that affect people's health, directly or indirectly, positively or negatively. The private sector influences the social, physical and cultural environments through business actions and societal engagements; for example, supply chains, labour conditions, product design and packaging, research funding, lobbying, preference shaping and others." These commercial and private activities have a significant effect on the distribution of health in population, which means in turn that the relationships public health organizations and officials form with commercial actors are independent and powerful determinants of health (Goldberg 2016).

WHO observes that while commercial determinants can shape any community's health outcomes, "young people are especially at risk, and unhealthy commodities worsen pre-existing economic, social and racial inequities. Certain countries and regions, such as Small Island Developing States and low- and middle-income countries, face greater pressure from transnational actors." The pathways through which sophisticated commercial actors shape health outcomes are many and varied, sometimes even by setting the parameters for what counts as health to begin with (Gabriel and Goldberg 2014). Sometimes CDOH operate through relationships between public and private entities, often referred to as conflicts of interest ("COIs"). COIs too are therefore determinants of health and they are themselves best thought of a form of motivated bias.

Essentially, the relationships we form motivate us to be biased in all sorts of ways. So, for example, virtually every health profession warns members from providing care to close family members. The reason is because the nature of the relationship motivates the professional to act in biased ways. Note that the bias can cut in different directions; health professionals caring for loved ones may sometimes withhold care they would provide to others out of an aversion against causing pain or suffering to a loved one. Alternatively, health professionals may recommend screenings and interventions for loved ones that they would be unlikely to administer to other patients with whom they are not in such relation. Finally, note also that while financial exchange can be a powerful motivator of bias, relationships can motivate bias even in the absence of the specter of pecuniary gain, as in this example (the reasons why health professionals are advised against treating close family has little to do with the prospect of pecuniary gain).

In terms of interventions for minimizing the impact commercial determinants have on health, it is worth noting that one of the most popular tools, disclosure, is likely of little to no effect (Goldberg 2019). Disclosure may actually have perverse effects and in fact the only remedy shown to be effective in precluding "behavior of partiality" flowing from COIs is sequestration, or the separation of the parties in relation. Because sequestration is neither always possible nor even advisable in every





case, the ethical and practical difficulties involved in intervening on CDOH are fraught. The cases in this section explore these difficulties.

Case #10

#### Schools of Public Health, Unrestricted Gifts, and Motivated Bias

Smith & Jones University was founded in 1895 in St. Louis, MO. It was fortunate to enjoy the support of many influential St. Louisans virtually from its inception. In the late 1880s-early 1890s, several powerful local brewery magnates were enthusiastically involved with the fundraising and political efforts needed to endow and create the university. Two of them sat on the original Board of Trustees, and only rarely since its founding has the Board not featured a trustee affiliated in some way with the alcoholic beverage industry.

Buoyed by the strong support from leaders in the private sector, politicians and public officials blessed the enterprise as well, and Smith & Jones flourished from an early date in its history. It expanded quickly, adding a law school in 1905, a medical school in 1912, and a school of divinity in 1923. Schools of social work and public health were established in 1948 and 1951, respectively.

Although Smith & Jones is both well-established and well-respected locally and regionally, it is not immune to many of the pressures facing private, free-standing educational institutions in the 21st century. Its high tuition is something of a competitive disadvantage to students with options to attend significantly less expensive public schools. While the university has supported research and researchers, it has been overshadowed in these fields by other universities in the field who had invested more in the infrastructure and support networks needed to build world-class research programs (by contrast, Smith & Jones had always positioned itself as more of a community-driven and community-focused institution, serving a need the larger research universities were mostly unwilling to satisfy). The complexity of higher education, and the layers of rules and regulations with which any modern university must comply have significantly added to the expenses of administration and instruction.

Accordingly, donor development and advancement have risen in importance at Smith & Jones, with more resources and personnel devoted to these activities. Several years ago, the university created an Office of Innovation & Technical Transfer to increase the connections between its small but rigorous research programs and potential commercialization and monetization.

On a recent Monday afternoon, the university's communications director, Joan Crawford, requests an urgent meeting with several top Smith & Jones administrators (vice-provost/vice- chancellor and

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above). At the meeting, Ms. Crawford says she is in possession of a leaked draft of an article set to run in a major daily newspaper in the city. The article describes the relationship between the university and a private nonprofit organization named The Goldflower Foundation. In the last fiscal year, The Goldflower Foundation has donated \$2.9 million designated as gifts intended for university advancement. The article also notes that The Goldflower Foundation is the sponsor of an accepted \$1.5 million unrestricted educational grant to a research team composed entirely of faculty and staff employed by the school of public health at Smith & Jones. (The \$2.9 million gifts are routed through the office of university of advancement, while the \$1.5 million educational grant was routed through the office of grants and contracts, as per Smith & Jones policy).

Somehow, the author of the article obtained a copy of the grant itself, and it is described in the article. The grant is apparently intended to support the development of educational programming and resources targeted around the idea of "responsible drinking," a concept promulgated most notably by entities associated with the International Alliance for Responsible Drinking "(IARD"). The IARD is almost entirely sponsored by global conglomerates connected to the alcoholic beverage industry. The article notes that there are multiple studies in the public health literature devoted to evaluating the idea of "responsible drinking," suggesting that the approach is a legitimate albeit controversial one within public health practice. However, the article also notes that many of the published articles are quite skeptical of the concept and view it more as a marketing tool for the alcoholic beverage industry than as a significant framework for intervention on the risks of alcohol consumption.

Ms. Crawford then informs the audience that The Goldflower Foundation is a private, nonprofit organization drawing 100% of its funding from many of the same global conglomerates that fund IARD. She pauses and looks around the table.

A vice-provost named Michael Turner takes the opportunity to ask, "I'm not sure I understand what the problem is here. So we have a potential conflict of interest between a donor who also happens to fund researchers on this campus, and the researchers. This is not a new situation; we have policies and procedures in place for managing these kinds of situations."

Looking at the faces around the table, Ms. Crawford takes a deep breath and notes, "Well, it may be even worse than we think, which is partly why I've asked risk management to weigh in. We also have a content expert here on conflicts of interest and how they operate, and I've asked him to explain some ideas and concepts that might be important for the group here to synthesize and incorporate into its decision calculus. Dr. Williams, care to jump in?"

Dr. Williams, an ethicist and a trained attorney, states the following:

"Hello, everyone. I'm here just to explain a few basic things about the evidence regarding COIs. There's actually a lot of good research on what is more properly termed 'motivated bias,' and I hope

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understanding some of the basics will inform your decision-making. So, first of all, we want to dispense with the language of 'potential' vs. 'actual' COIs. That framework actually doesn't make much sense, according to the cognitive science."

"Essentially, motivated bias refers to the tendency of all humans to make biased decisions that arise from particular motivations. Such motivations come from a variety of sources. And what's really important is that motivated bias tends to flow from the relationships we form with other people."

"The evidence is also very good that the deeper the entanglements between the parties – the more antecedent acts and more contact exists between the parties – the more likely it is that behavior of partiality will occur."

Dr. Williams finishes his presentation and a representative of the chancellor's office asks a question: "Wait . . . we already have a host of COI policies and procedures through which we identify and manage COIs like the ones we're discussing here. What's the problem with just following these protocols?"

Dr. Williams responds, "There may not be – that's for you all to decide! However, note that the primary approach to dealing with COIs in institutional settings is by disclosure and management. But all that does is disclose the existence of the relationship itself. It doesn't eliminate or even minimize it in any way. Thus, you would predict that disclosure and management is not an effective means of preventing biased behavior. And in fact this is exactly what the evidence shows" (Goldberg 2019).

"Don't get me wrong – I'm in favor of transparency, but it is an ethical floor, not a ceiling. And there's little evidence it is an effective remedy for whatever problems we think attend COIs. Look, you didn't ask, but I'll tell you my perspective, for whatever it is worth. There is ample room for reasonable people of good conscience to disagree on what, if anything, should be done about the problems posed by COIs. This is a complex ethical problem, and it's not easy to figure out the right path. However, there is much, much less room for disagreement on whether the kinds of relationships we're discussing have an impact on our behavior. They do. This has been proven over and over again – the evidence is overwhelming, and views to the contrary are simply not credible."

At that point, Ms. Crawford steps in and thanks Dr. Williams for his insight. Dr. Williams acknowledges the gratitude, and departs the meeting.

Ms. Crawford takes a deep breath, looks around the room, and says, "Actually, there's more to the story. It gets worse, unfortunately." First, Ms. Crawford explains that all of the university's COI protocols and committees are attached to its research mission and arm. Gifts and donations coming in via university advancement are generally not subject to the COI procedures, perhaps because cultivating the kinds of relationships Dr. Williams warned about is literally the raison d'etre of university advancement. Mr. O'Brien, the advancement officer present at the meeting, nods and

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remarks, "I doubt even Dr. Williams would contest that relationships with important partners in public, non-profit, and yes, the private sector are absolutely critical to sustaining the university and advancing its community-oriented mission. I know of no reputable university that would deny this." Nevertheless, Ms. Crawford notes, because of the absence of COI protocols and processes connected to these relationships and the office of advancement, it is unclear what resources exist for the university to address any potential problems arising from the donations made by The Goldflower Foundation to Smith & Jones.

Second, the actual accepted grant agreement itself, which has been executed and approved both by the PI and by the office of grants and contracts at Smith & Jones, has some problematic language. Specifically, the grant agreement posits that all educational materials produced by the research team under the auspices of the grant constitute intellectual property owned by The Goldflower Foundation and may not be distributed without the express permission of the Foundation. An additional clause notes that all such educational materials also qualify as trade secrets of The Goldflower Foundation.

Ms. Crawford indicates that she has briefly conferred with legal counsel at Smith & Jones, and there is no question that these provisions violate university policy, which expressly states that all intellectual property arising from work performed by Smith & Jones employees in the course of their employment belong to Smith & Jones itself (such provisions being standard at most research institutions). In addition, while trade secret status does not in and of itself transfer ownership, and therefore does not necessarily violate the intellectual property requirements of Smith & Jones, a number of scandals at universities in the 1990s demonstrated that legal prohibitions on disclosure connected to research can actually violate ethical standards. For example, Ms. Crawford noted, at times human participants research can result in dangers to the participants themselves. But there are cases where private sponsors sought to prevent researchers from disclosing study results to participants, arguing that such disclosures violated trade secret provisions that bound the researchers. Such provisions are now either frowned upon or expressly prohibited by most universities. Smith & Jones is one institution that does prohibit such trade secret and confidentiality provisions in grants to which its researchers are a party.

Ms. Crawford stopped speaking and was greeted by mostly astonished faces. A man named Dr. Reed, who is an associate dean in the school of public health, spoke first. "I am somewhat embarrassed to admit I'm not familiar with this grant, although we certainly have enough grantfunded research in the school of public health to make such familiarity difficult. But I want to be sure I understand what you're saying. Namely, we currently have a research team in the school working on a grant that was approved and executed by the office of grants and contracts that almost certainly violates university policy."

Ms. Crawford grimaces and nods.

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Dr. Reed replies, "Well, how is that even possible? How did that get past grants and contracts?"

Ms. Crawford shrugs her shoulders and says "We're honestly not sure. But we know this doesn't look good. Essentially, we are a university that has maintained close ties with representatives of the alcoholic beverage industry for over a century. These relationships endure to the present, and they are important to our place in the community, as well as in sustaining the mission of the university. The newspaper article lays out how a private nonprofit foundation wholly organized and funded by the industry is not only donating relatively large sums of money as a gift, but is also funding a research team within the school of public health. The grant project itself is supposedly "unrestricted," but actually contains restrictions that violate the university's own policies and raise ethics problems to boot. Finally, the actual substance of the grant – promulgation of educational materials related to 'responsible drinking' – is questionable to the point where critics may with some justification argue it is not legitimate science and is rather more akin to marketing on behalf of the industry in question."

"This does not look good for us."

She is met by silence around the table, which is eventually broken by Dr. Reed clearing his throat and saying, "I hate to add any fuel to this very large fire, but there is one more point we'll need to consider. The school of public health partners with a number of local health departments ("LHDs") in and around the St. Louis area. We have teams within the school that also work with these LHDs to develop educational materials and interventions designed to promote behavioral change connected to consumption of alcoholic beverages. I can say for a fact that The Goldflower Foundation has a relationship with several of these LHDs, as their logo has appeared on documents and materials produced by the LHDs. I have no idea if there is any funding or sponsorship by The Goldflower Foundation, but the relationships definitely exist."

"Needless to say, our partnerships with these LHDs are absolutely crucial to our work and our mission in the school of public health. We have to be very careful and very sensitive here."

#### **Discussion Questions**

- 1. One of the most basic problems involved in working through problems around the CDOH the general lack of understanding of the science that informs it. Do you believe that the COIs in this case present actual moral dilemmas? Why or why not?
- 2. Who are the key actors here? What might be some of their professional values?
- 3. Is there a value conflict here? If so, what values are in conflict?
- 4. This case presents multiple, interlocking COIs. Most discussion of COIs in law,ethics,and policy discourse focuses on what might be termed "individual COIs," which tend to occur where individuals have relationships that give rise to concerns of behavior of partiality. This





case does feature such a COI – can you identify it? However, this case also illustrates at least two different "institutional COIs." Can you identify these? The tools available to actors for dealing with the latter are very different from those available for addressing the former. Why do you think this might be the case? What, if anything, should be done about it?

- 5. Why do you think the Office of Grants and Contracts at Smith & Jones might have approved a grant agreement that so obviously contravenes university policy?
- 7. How should the committee proceed? Should the grant be terminated? Should the university seek to amend the grant agreement to remove some of the provisions that contravene university policy and apparent ethical standards? Or should the university simply allow the grant to proceed but create procedures designed to prevent this from happening again?
- 8. How should the Office of University Advancement handle this situation? Should they end their relationship with The Goldflower Foundation? Are separate COI protocols needed for gifts and donations? Why or why not?

#### Case #11

#### Public Health Agencies, Revolving Doors, & Regulated Industry

In your job at Upstate County Health Department, you are hard at work on budgeting for an important health promotion program. A colleague knocks on the door and you invite them in. It is Mx. Rodriguez, who is one of your team leads. This team is currently hiring for a key policy position and the applications have been rolling in.

They sit down and say "Ok, we just received a new application for our policy position. Here's the thing: It's from John Smith."

You lean back in your chair to consider the impact of Mx. Rodriguez's information. John Smith is a former Upstate Health Policy Director, which means that Mr. Smith essentially ran health policy for the entire state. After an election six years ago, Mr. Smith resigned as state policy director and took a position working for Expert Pharma Consulting, a trade association and lobbying group for the pharmaceutical industry.

In the most recent election, control of the state government flipped to the party that was previously in the minority. In his cover letter, Mr. Smith indicates that this change in governance means that several policy windows are now open for the first time in years. He writes that he would be excited to participate in policy initiatives that seek to take advantage of these windows and is especially excited to work in county government.

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After thinking for a few moments, you lean forward and say to Mx. Rodriguez, "Obviously Mr. Smith's background and expertise are stellar. Moreover, he knows how to get things done in Upstate government and his networks and contacts are unparalleled. If he really wants to work at the county level, we can't imagine a stronger candidate on paper. What do you think?"

Mx. Rodriguez nods but then frowns. They reply, "I agree on all of those points. But I have some concerns. We know that the revolving door between commercial industry and public health agencies has a long history. It's absolutely a technique that many regulated industries have used to manufacture doubt and create a regulatory vacuum, the best example of which is of course Big Tobacco. Someone needs to take a stand against this behavior. If Mr. Smith wants to go off and join the pharmaceutical industry, that's his business. But pharma is an industry we are charged with governing, not a client. If we continue to hire people directly from that industry, aren't we just contributing to the problem of regulatory capture?"

You are the hiring authority for this position, so the decision is yours. What should you do?

#### **Discussion Questions:**

- 1. How does the "revolving door" problem affect population health? Be specific.
- 2. Some people would argue that the decision you face here is what is known as a "commons" problem. Commons problems occur where what is best for the group requires a sacrifice at the individual level. Since most individuals will choose what is best for their own interests, the group as a whole will continue to experience worse outcomes. In this case, refusing to hire Mr. Smith might damage Upstate County's own policy interests, even if it benefits public health as a whole to limit the revolving door problem. Do you think this is a commons problem? What can be done to resolve the problem? Is it the LHD's responsibility to resolve commons problems? Why or why not?
- 3. Should LHDs and other public health agencies explicitly prefer applicants for open positions who lack experience working for commercial industries? Or should the opposite be true that applicants who have such experience are explicitly preferred? What ethical arguments can you identify in favor of each position?
- 4. What does it mean for a regulated industry to "manufacture doubt?" (You might have to do a quick internet search to guide your response!) Why does the historical context matter for the ethical question here?

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### Case Category #5: Climate, Environment, & Public Health

Climate crisis is a public health emergency with devastating intergenerational complications. It is difficult to overstate the enormous impact climate crisis is already having on population health and health inequalities. The adverse impact is only expected to grow in the coming decades. While the ethical, legal, and social implications of climate crisis are wide and varied, climate crisis does frame a particularly interesting category of problem in public health ethics <a href="known">known</a> as the "identified vs. statistical victims" quandary.

This problem arises in context of climate crisis because from both consequentialist and justice-oriented approaches, public health actors need to identify which populations will benefit and which populations will be harmed by a particular intervention. Moreover, the distribution of benefits and harms within larger populations also raises concerns of justice and equity. The 'identified vs. statistical victims' problem generally arises because in many cases, epidemiology suggests that transferring resources from caring for identified victims to unidentified or "statistical" victims may result in many more lives being saved. For example, there is little doubt, based on the evidence, that if the U.S. transferred some of the enormous resources it expends on emergency care into upstream action on structural determinants of health, more lives would be saved in the long run. However, doing so might result in trauma victims being denied life-saving care. Even if doing so would save more lives in the long run, there is a strong moral argument to be made that persons who require immediate aid that we are capable of offering have a greater claim on social resources.

Climate crisis triggers the "identified vs. statistical victims" problem with regard to *future* publics. While currently existing beings and life forms may of course benefit from meaningful interventions to combat climate crisis, there is no question that a disproportionate share of the benefits will be captured by future generations. That is, interventions that successfully reduce carbon footprints and delay or prevent warming will disproportionately benefit people and beings that do not exist yet and may not exist for decades or centuries. Are we morally obligated to transfer resources from people and communities currently in need to climate crisis interventions because the latter might well save more lives in the long run? What claims do non-existing, unidentified, statistical victims exert on us?

The cases in this Category can do little more than touch on some central ethical issues raised by climate crisis but can serve as a point-of-departure for deeper discussions on one of the paramount health crises of the Anthropocene.

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Case #12

#### Collective Goods, Property Interests, and Public Health

In a semi-rural community, concern arose over groundwater contamination by an agricultural pesticide that was known to be extremely toxic. Groundwater was the principal source of drinking water for the community. Community residents with contaminated wells were urged not to drink the water.

A well-sampling program was instituted by the local health department with aid from the state department of environmental protection to determine the extent of the contamination. Residents whose wells were sampled were offered access to their own test results. Test results of individual wells were not made public because local officials felt obligated to protect individual rights to confidentiality. As a result of the lack of specific information about test result from neighborhood wells, it was difficult for non-tested residents to determine the likelihood that their own well would become contaminated. This uncertainty was compounded further when skepticism arose in the community about the local health department's ability to analyze the data and risks adequately.

Is the well-sampling program morally justifiable? Why or why not?

(case sourced from Kenneth DeVille, used with permission)

#### Discussion Questions

- 1. This case reflects the common situation in public health which complex ethical determinations must be made with significant uncertainty and with highly imperfect information. Can the information deficiency be resolved before a decision must be made here? If not, how can public health actors manage these deficiencies in the process of ethical decision-making? What steps should be taken?
- 2. Can you identify any interests that might justify making the test results public? Who are the beneficiaries of such interests? What are the likely consequences of making the test results public?
- 3. In terms of specific consequences, what might making the test public do to the value of real property owned by people in the relevant area? Who is responsible for the diminution of value? Should public health agencies be required to compensate property owners for the loss? If not, who should owe compensation? And what if a single person or entity cannot be identified? Is the loss simply an non-compensable injury?

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4. Given the lack of trust in the public health agency's well-sampling program, individual property owners may elect to commission their own testing. Why might this situation raise justice concerns?

Case #13

#### Urban Heat Islands, Heat Waves, & Public Health

In your job at Central City Public Health, you lead the Climate Crisis Team. It is now June and your team is planning and preparing for the upcoming summer. Central City is located in a desert climate in which the average temperature range for July and August hovers between about 82-104 degrees Fahrenheit.

An increasing portion of your team's workload every year involves planning for these hottest months of the year. Over your career, you've noticed that the challenges have intensified, as one of the consequences of climate emergency is increased probability of intense heat waves. The risks of such heat waves are often magnified in urban settings in which concentrations of heat-absorbent concrete structures, lack of trees, and fragile power grids converge. The team's work is critical because excessive heat is a significant risk factor, arguably being surpassed only by air pollution in its effects on health outcomes. Like most other population-level risk factors, the risks of excessive heat are distributed highly unequally not only in geography, but among communities. In particular, and in the U.S., older adults are at elevated risk, as they are more likely to experience social isolation and more likely to reside in older dwellings that are not air-conditioned.

The team assembles in a conference room. You lower your mask to sip some water, reposition it correctly, and begin,

"Ok, you've hopefully prepped for the meeting as I asked, by reviewing the results of a recent modeling study showing what could happen during a 5-day heat wave in which the electrical grid failed for a 48-hr period during that wave. We have a similar summer climate to Phoenix, which was one of the modeled cities. The study suggested that as many as 800,000 people could visit emergency departments under the modeled scenario – well over 50% of the urban population."

You pause for questions but no one utters a word.

"So, we have some obvious questions and problems here. We have a limited budget and too many interventions. As you noted, the investigators in the study identify a number of priorities:

- Back-up power generation at regional cooling centers;
- Provision of drinking water;
- Evacuation and temporary housing assistance;

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- Enhancement of street tree canopy (i.e., planting more trees);
- Installation of 'cool-roofing' products."

"These are all strategies Central City Public Health wants to pursue, but we can't do all of this in the next month and some of the benefits for these interventions might have delayed benefits (i.e., in future summers as opposed to the current summer). We have to balance some of these mitigation strategies against the emergency needs the modeling study identifies.

It's our job to decide the priority for these interventions. Which should we prioritize and why?"

#### **Discussion Questions:**

- 1. As the saying goes, "all models are wrong but some are useful." Better modeling informs the ethical analysis but cannot by itself dictate which prioritization strategy maximizes justice and equity. Why might this be so? Why can't epidemiologic data by itself provide the answers to ethical problems?
- 2. This case presents a classic dilemma in public health ethics: the so-called "identified vs. statistical victims problem." In public health, often times the primary beneficiaries for interventions will be future publics, sometimes people who aren't even born yet. This is obviously the case with regards to climate emergency interventions, which are likely to benefit future generations more than currently existing people. Yet some have argued that we owe greater moral obligations to currently existing people who are in extremis we cannot turn them away, even if in so doing we might be able to save more lives in the long run. What do you think about these points? What ethical principles or values are at stake? (Hint: think "justice" vs. "utilitarianism").
- 3. Can a trolley problem help make sense of the dilemma noted in DQ#2? Why or why not?
- 4. Commitments to justice are often thought to require prioritization of the needs of the least well-off. Sometimes such prioritization may result in less lives being saved overall. Can you foresee such a trade-off in this case? If so, how would you resolve it?

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### Case Category #6: Communicable Disease & Public Health

It feels strange to frame a case category for which problems relating to a once-in-a-century pandemic remain extant. Ethical problems relating to communicable disease are foundational to public health ethics as a field. The recognition that communicable disease, epidemic, and pandemic ethics constitute a distinct set of applied ethical problems for which traditional canons of Western medical and health care ethics were poorly equipped was a *raison d'etre* for the field. In their 2008 editorial launching the new journal *Public Health Ethics*, founding editors Angus Dawson and Marcel Verweij specifically mention infectious diseases control and pandemic preparedness as key issues to be assayed in the new journal. To be sure, the editors name a number of other issues and topics as well; arguing that communicable disease ethics played a formative role in the foundation of the field of public health ethics is not a claim that other topics are less important or were insignificant to the formation of the field.

Nevertheless, there is no question that a multiplicity of ethical problems attend communicable disease in general, let alone outbreak scenarios of epidemic and pandemic disease. The cases in this section merely scratch the surface, as very obviously entire books need to be written on public health ethics and COVID-19 alone.

(see also Case #2)

Case #14

#### Ventilator Triage, Disability, & Pandemic Ethics

You work as an Ethics Advisor for the Uplandia National Public Health Agency. You are excited because today marks the initiation of a new ad hoc committee working to address problems of 'Triage Ethics in Public Health Emergencies.'

You enter the conference room and welcome the participants.

"Hello everyone! Thanks so much for joining us. I'd like to begin with some background context as a way of framing our work on this committee. We'll address a specific problem first and then move out from there.

"As we all know, in the early stages of the COVID-19 pandemic, there were reasonable fears that the need for mechanical ventilators would vastly outstrip the available supply. The U.S. Centers for

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Disease Control ("CDC") anticipated this problem in pandemic planning at least as far back as 2011, when it released an advisory report from an ethics committee convened to address the problem.

During the early crisis of the COVID-19 pandemic, officials charged with triaging the supply of mechanical ventilators experienced a serious ethical dilemma. Most health systems devised an allocation matrix that assigned points to different variables as a way of prioritizing access. These matrices tended to reject "non-clinical" allocation criteria such as age and sex even where the evidence in April 2020 suggested those factors had a significant impact on COVID-19 mortality. The concern was that including such criteria would result in impermissible forms of discrimination such as age and sex discrimination."

You pause for questions. Seeing none, you continue.

"In contrast, clinical allocation criteria, such as living with conditions or illnesses that lowered survivability from COVID-19, were often deemed relevant and included in these allocation matrices. Many people objected to this on the basis that, as one bioethicist <u>explained</u>, '[c]linical guidelines that emphasize "objective" criteria like preexisting and chronic health conditions will reinforce existing structural injustice and discrimination that disadvantages and burdens the poor, the disabled, and people of color.'

Disability rights advocated in particular were outraged by these matrices, arguing that they would dramatically reduce disabled people's access to life-saving ventilators."

At this point, one of the participants in the meeting, Ms. Singh, raises her hand and states, "I can see the point. The history of public health with regards to disability justice is generally not good. We actively fueled the eugenics movement for decades and participated in involuntary sterilization of disabled woman all over the world, to cite just two examples. Understandably a lot of disability advocates currently do not regard public health officials and agencies as <u>trustworthy</u> actors."

Another participant, Mr. Waerea, shakes his head and replies, "I totally understand all of that context and it's legitimate. But there's a good argument to be made that neither overall outcomes nor justice is served by abandoning clinical allocation criteria in these kinds of triage determinations. We know that if we don't include criteria that's relevant to survivability, some people who could have been saved will end up dying. Moreover, most disabilities don't even affect survivability. As another ethicist noted, '[t]his means that patients with disabilities are more likely to receive scarce treatments under evidence-based triage, which allocates scarce treatments to save more lives, than under random selection.' So we should absolutely include these kinds of clinical allocation criteria in our triage matrices moving forward."

You let this conversation sink in for a moment and then ask the group, "Ok, this is our first policy question. Do we want to endorse allocation matrices that specifically include clinical criteria relevant to survivability or not?"

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How should the committee respond?

#### **Discussion Questions**

- 1. Bioethicists sometimes discuss the significance of the distinction between trust and trustworthiness. Why might it matter here?
- 2. Does the historical context regarding public health actors and disabled people inform the ethical debate in this case? If so, how? If not, why not?
- 3. Here again we see tension between values of justice and utilitarianism. Can you describe the value tension? However, Mr. Waerea's point implies that there actually isn't a real value conflict here, and that there is a choice that maximizes both values. Do you agree with him? Why or why not?
- 4. The concern that including clinical criteria related to survivability in allocation matrices violates justice does not just implicate disabled people, as Syd Johnson notes above. People of Color too are much more likely to be disfavored by such criteria. Why might this be the case? How do these background conditions of structural violence shape the ethical decision of the committee?
- 5. Generate a discussion question of your own that highlights some important aspect of the ethical problem in this case. Be prepared to report out!

#### Case #15

#### Outbreaks, Social Policy, & Priority Setting

You work as a paid intern for a nonprofit public interest policy and advocacy organization. The organization focuses its work on the non-medical determinants of health, advocating for social policies beyond health care services. In your second week, you are invited into a team meeting to address messaging and advocacy strategies related to enacting state-level "paid-sick-leave" laws.

The team lead, Mx. Williams, calls the meeting to order and frames the discussion:

"Look, one of the lessons we are learning in the ongoing pandemic is the ways in which social policy vacuums are worsening overall health outcomes and disproportionately harming some of our most marginalized groups. Part of my training included work in the history of public health and I know that pandemics expertly highlight and even intensify existing social inequalities. This is true not just for societies experiencing pandemics, but for infectious diseases in general, which are highly

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sensitive to social determinants of health. The evidence is plain that PSL laws are among our most important social policies, since they give sick people the chance to stay home and recuperate, which is both good for sick people, their families, and their communities and for the rest of us since it can slow transmission during pandemic waves."

Another team member, Mr. Kovalenko, shakes his head and says, "Look, we've had a terrible time developing an effective messaging strategy for this that harnesses our current pandemic moment and the pandemic relief funds that are available. Obviously, we want to push and support PSL laws but the truth is that the benefits of PSL laws are really not even mostly about pandemics and communicable disease. We know that laws are major social determinants of health and the pathways through which laws impact health outcomes are many and varied. Policymakers have trouble seeing how PSL laws are specifically forms of pandemic relief and ask us to come back when they are less focused on pandemic policy."

Mx. Williams nods. They reply, "Yes, this is often referred to as the 'boundary problem' in public health. If everything impacts public health outcomes, then there's almost no limit to the scope of public health activity. All policy work becomes public health policy work. We've tried to explain to policymakers that this is a 'feature, not a bug' but we haven't landed on a good messaging strategy for this. We keep being dismissed and told to come back on 'public health day,' whatever that is ... We need some better strategies for dealing with this problem."

Mx. Williams then designates a few members of the team to work specifically on this problem, including you.

#### **Discussion Questions**

- 1. This final case departs from the "forced choice" format adopted for virtually all other cases in the Casebook. Forced choice problems are excellent tools for teaching and skill-building in ethical reasoning but ethics is broader than what has been referred to as "quandary ethics." This final case shifts the lens to public health policy. Do you think that skills in ethical reasoning are at all useful in addressing practical policy problems? Why or why not?
- 2. Public health interventions are often lauded when they deliver "co-benefits," or benefits for other social problems other than that made the subject of the intervention. In this case, however, Mr. Kovalenko thinks that is a weakness rather than a strength. Explain why this might be the case.
- 3. Can you identify a strategy or strategies for addressing the boundary problem? Does it matter ethically? Why or why not?
- 4. What do you think about the idea that "laws are social determinants of health?" Explain.

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