

# Does a Public Health Crisis Justify More Research with Incarcerated People?

by KERAMET REITER

Covid-19 is differently dangerous inside prisons, jails, and immigration detention facilities. The virus spreads faster inside locked institutions: prisons and jails represent 39 of the 50 largest Covid-19 outbreaks in the United States.<sup>1</sup> And the virus kills more inside locked institutions: incarcerated people have an overall Covid-19 death rate three times higher than for nonincarcerated people (and an infection rate five and a half times higher).<sup>2</sup> The danger is not contained within institutional walls, however. Jails and prisons have been associated with increasing Covid-19 case and hospitalization rates in surrounding cities and states. For instance, in a study tracing viral spread in the city of Chicago and state of Illinois, Reinhart and Chen documented Cook County Jail as a pandemic epicenter: higher rates of arrest and release from Cook County jail, by zip code, predicted higher rates of Covid-19 infection in those zip codes.<sup>3</sup> In Chicago, as across the United States, Covid-19 case and mortality rates reflect Black-White disparities in U.S. incarceration rates and associated health disparities.<sup>4</sup> America's prisons, jails, and detention facilities—more than citizens' resistance to staying home, wearing masks, and participating in contact tracing—may actually be our nation's most significant liability in our attempts to contain Covid-19, let alone mitigate its racially disparate impacts.

Some researchers, however, see not a public health liability, but a medical opportunity in our pandemic-ravaged prisons. In August of 2020, the *Journal of the American Medical Association* published a Viewpoint

commentary laying out recommendations for the ethical inclusion of incarcerated individuals in early Covid-19 vaccine trials.<sup>5</sup> In the commentary, Emily Wang and colleagues attribute the exclusion of prisoners from vaccine trials to the “unintended consequences” of strict federal regulations governing research on human subjects, established in 1978 and traditionally presumed to preclude prisoner participation in drug and vaccine trials. The commentary argues, instead, for a more expansive interpretation of these regulations, especially the permitted category of “research on conditions particularly affecting prisoners as a class.”<sup>6</sup> Because Covid-19 is particularly affecting prisoners, a Covid-19 vaccine trial in prison might be justified, the authors argue. Three months later, Camila Strassle and colleagues, writing in the *New England Journal of Medicine*, more clearly delineated three reasons prisoners might justifiably be enrolled in Covid-19 vaccine trials: to get early access to treatment, to have the same choices about and access to treatment as nonincarcerated people, and to speed up the process of establishing vaccine efficacy. Unlike the *JAMA* authors, however, the *NEJM* authors conclude that a proliferation of “currently unmet ethical conditions” should continue to preclude the participation of incarcerated people in vaccine trials, at least during the Covid-19 pandemic.<sup>7</sup> In fact, the current public health crisis has only exacerbated the very conditions that have made U.S. prisoner participation in vaccine trials untenable—since (and since before) the 1970s implementation of federal regulations limiting the participation of vulnerable human subjects in research.

Though the *JAMA* and *NEJM* pieces reach opposing conclusions about the immediate question of whether prisoners might ethically participate in Covid-19 vac-

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cine trials, they at least implicitly agree about a fundamental premise: the public health crisis in our prisons demands new forms of engagement from medical professionals and researchers alike. But what might that engagement look like? We need new frameworks of analysis—frameworks that, first, refocus on structural, rather than individual, risk assessments and, second, acknowledge the *unnaturalness* of the “experiment” of incarceration.

### **Unmitigable Risk**

The *JAMA* authors’ recommendations for ethical inclusion of incarcerated people in phase III vaccine trials exemplify the frequent focus in conversations about prisoner participation in research on mitigating individual risk. Their recommendations (like the applicable federal regulations) focus on ensuring informed consent, avoiding coercion, and minimizing harm by obtaining input from vulnerable populations, providing ongoing efficacious care, and convening an oversight board to monitor vaccine trials in correctional settings.<sup>8</sup> But conditions in American prisons—from overcrowding to inadequate provision of basic needs, like food, soap, and health care, to rampant physical and emotional abuses of prisoner—are too pervasively horrific to permit either free and knowing consent to or noncoerced participation in vaccine trials.<sup>9</sup> These exact conditions, especially the persistent unavailability of ongoing efficacious care, facilitated Covid-19’s lethal spread through locked institutions. And these deprivation conditions are all the more salient now that the virus is an active threat across America’s more than seven thousand prisons, jails, and immigration detention facilities.<sup>10</sup> These structural risks, inherent to U.S. incarceration, seem likely to overwhelm any attempts to mitigate the individual risks of knowingly, freely, and safely participating in a randomized controlled vaccine or drug trial.

While the *JAMA* authors suggest that ethical vaccine trials could be implemented in prison with adequate oversight mechanisms in place, the *NEJM* authors suggest that adequate ethical oversight would require modifying underlying “correctional facility operations.” Indeed, implementing adequate oversight of “correctional facility operations,” as recommended in both commentaries, seems as aspirational as mitigating individual risk. As a report inventorying correctional oversight mechanisms in the United States notes: “[F]ormal and comprehensive external oversight—in the form of inspections and routine monitoring of conditions

that affect the rights of prisoners—is truly rare in this country.”<sup>11</sup> Recent attention to police killings has revealed just how hard criminal justice system abuses are to identify and constrain in the United States, even with the combined oversight mechanisms of public witnesses, cell phone footage, and body cameras—all notably absent in prisons and other locked facilities. If locked facilities were inaccessible to formal and informal oversight (by public witnesses, whether journalists, researchers, or compassionate medical providers) before the pandemic, they are all the more so now: visitors of all kinds are currently prohibited from entering prisons across the United States, in an attempt to control viral spread.<sup>12</sup> Under the worsening conditions of the pandemic in prison, and absent any existing infrastructure for adequate independent oversight, prisoner participation in vaccine trials should seemingly be curtailed, not expanded.

### **Unnatural Experiments**

Still, prisoners living under these worsening conditions are getting sicker and dying faster. To date, 2,459 U.S. prisoners have died, and 386,765 have been infected with Covid-19 in prisons alone; the number either dead or infected in jails and immigration detention facilities is unknown.<sup>13</sup> As a scholar of prisons, I, too, want to do something, anything, to slow this deadly contagion, mitigate suffering, and save lives. Maybe the sheer scale of this crisis justifies prisoner participation in Covid-19 vaccine trials, even knowing all the unmitigable risks. In fact, both the *JAMA* and the *NEJM* commentaries highlight the availability, in prisons, of large populations with “high exposure risk” and concentrated “transmission rates . . . higher . . . than elsewhere.”<sup>14</sup> In other words, “concentrating rigorous experimental interventions on an acutely impacted sample” might lead to identifying more effective interventions faster—a seemingly desirable outcome for researchers, prisoners, and nonprisoners alike.<sup>15</sup>

But David Rothman, the archetypal scholar of the asylum, warned in this journal almost forty years ago, “[T]here is an essential difference between taking advantage of *social*, as opposed to biological, conditions.”<sup>16</sup> While biological conditions might justify conducting a “natural” experiment to observe (or intervene in) the course of a disease with no known treatment, social deprivations provide no such justification. Rothman identified both the U.S. Public Health Services Syphilis Study’s observations of the course of untreated syphilis in Black men in Tuskegee, Alabama, and Sal

Krugman's observations of children with disabilities, whom he deliberately infected with hepatitis at the Willowbrook State School, as unnatural (and unethical) experiments, dependent on social conditions of deprivation, rather than on biological conditions of inevitability. Likewise, in the United States in 2020, social deprivations define incarceration.

In spite of Rothman's warnings, though, Tuskegee and Willowbrook are more often remembered as examples of research studies where consent was lacking, participation was coerced, and harms unmitigated, rather than as studies of (and dependent on) deprivation conditions. Hence, in recent calls for more widespread recruitment of minorities into Covid-19 vaccine trials, ethicists point to Tuskegee as a reason to recruit Black Americans into modern, ethical vaccine trials in order to rebuild the trust that Tuskegee eroded and also to ensure that vaccines do not have differently dangerous effects on Black bodies.<sup>17</sup>

The *JAMA* commentary made a variation of this argument in its call for prisoner participation in Covid-19 vaccine trials: it recommended making "racial equity a guiding lens" in prisoner recruitment and participation, arguing that this would "improve participation of racial and ethnic minorities, thereby improving external validity of Covid-19 vaccine trials."<sup>18</sup> These arguments ignore the unnaturally deprived conditions, especially salient in prison, that make racial and ethnic minorities seem biologically different. As Rana Hogarth recently explained, the conflation of deprivation conditions with biological difference is all-too pervasive in medicine: "we run the risk of framing health disparities in such a way that draws our attention to the bodies of those suffering under the disparities rather than drawing our attention to why the disparities exist in the first place."<sup>19</sup> In the context of prison, conflating deprivation conditions with biological differences then becomes a justification for asking incarcerated minorities to bear the burden of participating in a vaccine trial that will disproportionately benefit non-incarcerated (and likely nonminority) people.<sup>20</sup> Predictably, neither minorities nor prisoners ranked on the prioritization lists of who should get the first Covid-19 vaccines as they became available.<sup>21</sup>

### Unjustifiable Typologies of Ethical Research

I am a prison researcher, albeit one trained as a social scientist (and also as a lawyer), rather than as a doctor. In writing about the ethics of prison research, I have historically distinguished my (ethical) social science research from (unethical) biomedical research, because my research is observational rather than experimental and involves neither withholding nor administering treatment.<sup>22</sup> I have long argued that such social science research in prison serves as a key mechanism of knowledge generation and transparency—both central to developing more fair, effective, and humane policies around incarceration.<sup>23</sup> But my outrage at the proposed inclusion of prisoners in Covid-19 vaccine trials has led me to question my earlier, neat categorizations of

social science research with prisoners as ethical and biomedical research with prisoners as unethical. While the physical risks of social science research participation are less than those of biomedical research participation, the deprivation conditions of incarceration might compromise informed consent and the possibility of noncoerced participation for any research participant, regardless of the nature of the research. And, as in the Tuskegee and Willowbrook studies, the deprivation conditions of incarceration often constitute both the justification for and the subject of social science research on prisons and prisoners. While in the case of social science research, documenting deprivation conditions and their effects might be critical to transparency and reform, the documentation process often depends on and, even inadvertently, reinforces those deprivation conditions. In fact, social science studies, just like biomedical studies, too often accept the social deprivations of incarceration as immutable (if not actually biological) conditions. Two examples illustrate this.

First, Paul Christopher and colleagues conducted a study interviewing seventy prisoners about their experiences participating in "six different clinical studies" and concluded that prisoners "do not view their involvement in clinical research as inappropriately exploitative."<sup>24</sup> But, reading beyond the abstract, Christopher and colleagues report that "[t]hirty-seven (52.9%) participants agreed that joining the study was the only way to get the treatment they needed, while 24 (24.3%) agreed that they only joined the study because they couldn't get the treatment they needed in prison."<sup>25</sup> As I have noted elsewhere, the conclusion that prisoners were not exploited, when more than half of them reported joining studies because it was the "only way to get the treatment they needed," is simply inaccurate.<sup>26</sup> Nonetheless, the study continues to be cited without acknowledgement of how the need for care seemingly compelled clinical trial participation. The *JAMA* authors, in fact, cite this study for the assertion that prisoners' "perception of benefits and risks [of clinical trial participation] are no different than [that of] nonincarcerated participants, with the exception of the perceived benefit of accessing better health care through trial participation."<sup>27</sup> Adequate health care is a right, not a benefit.<sup>28</sup> And "choosing" to participate in a study because it is the only way to get health care fundamentally undermines any claim that incarcerated participants perceive (or are subject to) risks "no different from nonincarcerated participants." The fundamental problem with the Christopher study is that the social deprivations of incarceration (among which is the lack of access to health care) are accepted as immutable, and, in fact, become the justificatory basis for ongoing participation in social and biomedical research.

Second, David Pyrooz and colleagues conducted a study, in April and May of 2020, interviewing a random sample of thirty-one prisoners in high-security segregation settings about their perceptions of the risks of Covid-19 for prisoners. Pyrooz and colleagues concluded that "prisoners were not highly worried about contracting the disease."<sup>29</sup>

As of early March 2021, no other systematic studies have evaluated prisoners' fears of Covid-19. But first-person accounts and news reports suggest this initial study, although made up of a random sample of participants, is far from representative of incarcerated peoples' experiences of the pandemic.<sup>30</sup> As with the Christopher study, the disconnect between what the Pyrooz study participants described and how the researchers interpreted those descriptions resulted from accepting (rather than confronting) the immutability of the deprivation conditions framing prisoners' responses. In fact, the Pyrooz study participants were in segregation settings within prison: subject to extreme limitations on any human contact, with people in or out of prison. This additional layer of deprivation conditions likely restricted the amount of access research participants had to information about Covid-19 and also likely led to underreporting of any fear they were actually experiencing.<sup>31</sup>

Both the Christopher and the Pyrooz studies involved robust samples and yielded a high prevalence of statements (about not feeling exploited in one case and not being scared in the other) upon which the authors relied to conclude that prisoners were, in fact, not being exploited and were, in fact, not scared. In neither case, however, does a representative sample providing a consistent response necessarily produce an accurate reflection of reality. In the first case, prisoners did not feel exploited because they received health care, which they desperately wanted and needed, in exchange for participation in a clinical trial they perceived to be very low risk. Under these circumstances, each prisoner participant likely made a highly rational and personally beneficial decision to participate in the clinical trial, even though, structurally, the choice they were actually making was not to participate in a clinical trial but to receive health care. In the second case, prisoners likely did not report feeling scared because they did not have adequate information about what they would be scared of, early in the pandemic with limited access to news. Moreover, they were in situations (high-security prison settings) where fear is a potentially lethal liability and therefore often repressed. Although each prisoner participant likely accurately reported their individual experience of fear, their individual experiences fail to accurately capture the structural harms threatening prisoners locked in institutions of deprivation. Accepting deprivation conditions at face value, without challenging what role they are playing in either motivating the research or conditioning responses, raises ethical concerns about research participation in the social science, as well as the biomedical, contexts.

### Attending to Social Deprivation

In analyzing the ethics of incarceration research, researchers need a framework that supplements individualized assessments about informed consent, noncoerced participation, and the risk a given participant will be harmed by the research. Indeed, the *JAMA* authors, along with the *NEJM* authors, convincingly argue that existing federal rules gov-

erning informed consent, noncoerced participation, and individual risk mitigation likely would permit incarcerated people to participate in at least some vaccine trials. An adequate ethical framework, though, would protect potential research participants from both the structural harms of participating in vaccine research out of a desperate attempt to receive care researchers might not even be able to provide and the distributional injustice of concentrating risk among the most vulnerable for the benefit of the less vulnerable. An adequate ethical framework might even protect social science research participants from having their deprivation-conditioned responses (such as "I am not being exploited" and "I am not worried about contracting Covid-19") misconstrued. In sum, we need a framework that engages explicitly with structural risks, and especially the unnatural deprivation conditions of incarceration.

A first step in developing such a framework is identifying and analyzing the structural, rather than individual, factors that frequently contribute to the deprivation conditions of incarceration. Acknowledging three of these factors—scarcity, representational distortions, and institutional agency—at least opens the door to addressing or mitigating them. First, neither scarcity of subjects nor resources should be justifications for recruiting and incorporating prisoner participants into research. Incarcerated people, as a literally captive population, can readily become a convenient resource for researchers in need of subjects. As Albert Kligman, who tested and refined the lucrative acne drug Retin-A almost exclusively on incarcerated research participants, famously said the first time he entered a prison, "All I saw before me were acres of skin. It was like a farmer seeing a fertile field for the first time."<sup>32</sup> More than thirty years later, Kligman expressed regret that such prison studies had been shut down: "I still don't see there having been anything wrong with what we were doing."<sup>33</sup> While Kligman's explicit characterization of prisoners as "acres of skin" available for dermatological experimentation is condemnable by twenty-first-century ethical standards, researchers like *JAMA* authors are still comfortable arguing that prisons might provide a more robust source of the "racial and ethnic minorities" needed to improve the representativeness of Covid-19 vaccine trials. The very existence of this "fertile field" of available research subjects, however, risks creating further inappropriate research incentives—to concentrate risks among vulnerable populations and to maintain subjects in the conditions of deprivation that facilitate ongoing research, in prison, or without access to newly available treatments (as in the Tuskegee Syphilis Study).

Likewise, researchers who provide resources to incarcerated people, whether in the form of physical health care or simply empathetic human contact, can readily become a convenient resource for incarcerated research subjects, whose basic human needs are not otherwise being met. For instance, if a given incarcerated population is lacking a resource, like adequate health care, as were the people in the Christopher study, predicated provision of that resource

on research participation distorts the incentive structure not only for individuals deciding to participate in the research<sup>34</sup> but for institutions resisting engaging in reform. Specifically, the provision of some health care resources for some incarcerated people potentially distracts from the continued deprivations experienced by all the other incarcerated people not participating in the research. At the same time, requiring adequate provision of structurally scarce resources (whether health care, clean air, nutrition, or simply human contact) as a prerequisite to research participation would seemingly preclude social science, as well as biomedical, research involving many, if not all, incarcerated people. Establishing adequate provision of these resources need not necessarily be a prerequisite for conducting or participating in research, but inadequate provision of these resources should not be a *justification* for conducting or participating in research. Scarcity justifications create unethical incentives for researchers to recruit prisoners (to get more readily available subjects, especially of the vulnerable variety) and for prisoners to participate in research (to get more resources, especially of the health care variety).

Second, representational distortions should not justify recruiting and incorporating prisoner participants into research. Specifically, the fact that prisoners are more likely to be minorities, more likely to have health problems, or more likely to die from Covid-19 should not constitute a justification for research participation. Relying on such claims of overrepresentation in prison creates the distributional injustice problem previously highlighted: although the concentrated harms prisoners experience (like Covid-19 infection and fatality rates) make them an especially efficient population in which to study effects of and treatments for those harms, recruiting prisoners into such studies both compounds the deprivations that made them vulnerable in the first place and concentrates the risks of study participation on vulnerable people, usually for the benefit of less vulnerable people. If recruiting research participants from an unhealthy, marginalized population concentrates risk unfairly, the inverse is also true: focusing on the individual experiences of an unhealthy, marginalized population distracts from the structural harms that population faces beyond the narrow risks or benefits they describe as research participants (like Christopher's subjects choosing research participation over no health care and Pyrooz's subjects reporting limited fear in a dangerous situation).

Finally, prison researchers must acknowledge and engage with the agency of carceral institutions as intensively as with the agency of potential individual research participants. Researchers like the *JAMA* authors focus on protecting the agency of individuals to both participate in and oversee research—involving currently and formerly incarcerated people in research design and establishing a federal oversight board and follow-up procedures, for instance.<sup>35</sup> But they ignore the power of the broader institutional context in which the effectiveness of these protective measures might well be mitigated, undermined, or even, negated. In particular, the

*JAMA* authors and others treat Covid-19 outbreaks as things that “have occurred” or as “another threat” facing prisons.<sup>36</sup> Language about things that “happen” or external “threats” imply that an institution has the ability only to react to, but not necessarily to preempt or avoid, the situation. But the threat of Covid-19 to prisons in particular was a threat foreseen and forewarned: public health experts knew any closed institution—hospital, nursing home, prison, or jail—would be vulnerable to the virus and advised on specific steps to mitigate vulnerability—decreasing institutional populations, using protective equipment, testing and isolating, and limiting contact with the outside world.<sup>37</sup>

Prison, jail, and immigration detention systems across the United States implemented these recommendations tepidly at best. At San Quentin State Prison, in California, the site of one of the single worst outbreaks anywhere in the United States, with more than two thousand Covid-19 cases and twenty-eight deaths in a population of just over three thousand, researchers offered prison officials free coronavirus tests and prevention guidelines around safe releases and quarantine; instead, prison officials continued moving infected prisoners not just within San Quentin but between prisons across the state.<sup>38</sup> Prison officials do not just “face” threats: they choose to ignore, engage, or resist these threats. As the case of San Quentin officials' active exacerbation of the Covid-19 pandemic pointedly establishes, these choices are outside the control of external experts and researchers, even though these choices affect the everyday health and well-being of any potential incarcerated participant in research. Any assessment of an individual research participant's agency must also account for the powerful role of institutional agency in incarcerated people's lives. In sum, not only the unnatural deprivation conditions of incarceration but also institutional agency in imposing these conditions must be central concerns of any prison researcher or any evaluation of the ethics of prison research.

Where, then, does this structural analysis, skeptical of claims of scarcity, avoiding representational distortions, attending to institutional agency, and, above all, focused on unnatural deprivations, leave the medical doctor or prison researcher who is horrified by the toll Covid-19 is taking in our locked institutions and seeking to engage in some ameliorative way with these populations? If we integrate structural perspectives into our existing overly individualistic frameworks for assessing the ethics of prison research and attend especially to the unnatural deprivations of incarceration, we can design more ethical research projects involving people who are incarcerated. Indeed, research that documents and analyzes the unnaturalness of the social deprivations of incarceration has been critical to reforming and mitigating incarceration's harms. But if the carceral institution itself imposes extreme social deprivations, research participation among those incarcerated might never be ethical. The only truly ethical answer might be to take the potential research subjects out of the prison entirely; in fact, decarceration is the primary intervention public health and legal

advocates alike (including Wang, one of the *JAMA* authors) have suggested to mitigate the spread of Covid-19 in overcrowded prison facilities.<sup>39</sup>

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26. *Ibid.*, 10; Reiter, "Coercion and Access to Health Care."

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29. D. C. Pyrooz et al., "Views on COVID-19 from Inside Prison: Perspectives of High-Security Prisoners," *Justice Evaluation Journal* 3, no. 2 (2020): doi:10.1080/24751979.2020.1777578. The authors acknowledge that their findings may not be generalizable and also call for identifying and implementing strategies to mitigate the risks of Covid-19 in prisons, but I am focused here on the empirical interview data they collected and their analysis of that data, rather than on their slightly disconnected policy recommendations.

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# In This Together: *Navigating Ethical Challenges Posed by Family Clustering during the Covid-19 Pandemic*

by NICOLE R. VAN BUREN, ELIJAH WEBER, MARK J. BLITON, and THOMAS V. CUNNINGHAM

As the Covid-19 pandemic shifts to a “new normal” in hospitals and clinics, health care professionals—especially in clinical ethics, critical care, and palliative care—are observing new impediments to shared decision-making, family-centered care, and quality end-of-life care.<sup>1</sup> One such impediment is a phenomenon we refer to as “family clustering,” which is our term to describe the situation when multiple members of a household or extended family unit contract Covid-19 concurrently, such that the infections occur in a cluster, or grouping, at roughly the same time and location.<sup>2</sup> Family clustering can be distinguished from a cluster of infections in a congregate living facility, like a nursing home, or in a group of employees, for example, in an emergency department or meat processing plant. Working in Southern California hospitals hit hard by the pandemic, we have seen this phenomenon up close and believe it deserves attention because of the way family clustering can affect ethical health care.

Family clustering creates at least three important ethical problems. Surrogate decision-making can become exceedingly challenging for patients with severe, life-threatening

Covid-19 in the context of family clustering. Unique presentations of increased guilt and denial for family members of stricken, hospitalized loved ones can emerge from family clustering, inhibiting shared decision-making and increasing suffering. Family clustering also exacerbates existing health inequities that disproportionately affect and burden people of color, and many of the current strategies for addressing the practical and ethical challenges associated with Covid-19 are insufficient to deal with these moral and social problems. We conclude by offering five strategies to address the effects of family clustering during the pandemic.

## **A Lack of Available Surrogates**

Family clustering is a confirmed phenomenon associated with Covid-19,<sup>3</sup> and harrowing stories of this disease ravaging families continue to be reported by American media.<sup>4</sup> Even the forty-fifth president of the United States and his family were affected. In an extreme example, twenty-eight extended family members in California reportedly tested positive for Covid-19. Two of the family members who quarantined together required hospitalization, and one of them died from the infection.<sup>5</sup> In family clustering cases, multiple loved ones may suffer from the symptoms of Covid-19 and be hospitalized, in quarantine, or recovering; and family members may also have died from the infection.

Nicole R. Van Buren, Elijah Weber, Mark J. Bliton, and Thomas V. Cunningham, “In This Together: Navigating Ethical Challenges Posed by Family Clustering during the Covid-19 Pandemic,” *Hastings Center Report* 51, no. 2 (2021): 16-21. DOI: 10.1002/hast.1241