

Disease surveillance infrastructure and the economisation of public health

Claire Laurier Decoteau  | Cal Lee Garrett 

Department of Sociology, University of Illinois, Chicago, Illinois, USA

Correspondence

Claire Laurier Decoteau, Department of Sociology, University of Illinois, 1007 West Harrison Street (MC 312), Chicago, IL 60607-7140, USA.
Email: decoteau@uic.edu

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Institute for Research on Race and Public Policy; Center for Clinical and Translational Services at the University of Illinois at Chicago

Abstract

The city government of Chicago adopted a 'racial equity' approach to tackle racial disparities in COVID-19 outcomes. Drawing on experience addressing core vulnerabilities associated with HIV risk, Chicago public health experts who designed COVID-19 mitigation initiatives recognised that the same social determinants of health drive racial disparities for both HIV and COVID-19. Yet, when building an infrastructure to respond to COVID-19, disease surveillance and data collection became the priority for investment ahead of other forms of public health work or the provision of social services. The building of a *disease surveillance infrastructure* that responded to and supplied data took precedence over addressing social determinants of poor health. Community-based organisations that might have otherwise organised for social service provision were incorporated into this infrastructure. Further, public health officials often failed to heed the lessons learned from their experience with HIV vulnerability. Based on qualitative analysis of 56 interviews with public health experts and policymakers in Chicago, we argue that the prioritisation of disease surveillance, coupled with a scarcity model of public health provision, undermined the city's attempt to redress racial

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inequities in outcomes. We argue that the economisation of pandemic response exacerbates health disparities, even when racial equity frameworks are adopted.

KEYWORDS

COVID-19, economisation, epidemiology, health disparities, HIV/AIDS, lay expertise, public health

INTRODUCTION

It's the same social determinants. It's the same vulnerabilities. It's the same populations. The expertise that people in HIV have is the same. Who was put in charge of COVID stuff? It was the guy who was running HIV for the city, the deputy commissioner. [...]

(Community-Based Organization Health Worker, 27 April 2021)

In the United States (US), many experts who lead public health mitigation efforts for COVID-19 had experience working in HIV public health. These experts acknowledged that the same social determinants of health shape HIV and COVID-19 outcomes. Both infectious diseases exacerbated existing structural inequalities. And, when it became obvious early in the pandemic that COVID-19 deaths were concentrated in Black communities and infections were highest in Latinx communities, City of Chicago officials and public health experts designed and implemented a 'racial equity' approach to mitigating the disproportionate racial impact of COVID-19 on vulnerable communities.

In this article, we audit the 'racial equity' framework the City of Chicago introduced, and we argue that the City's prioritisation of disease surveillance and data collection *over* the provision of direct and immediate social supports (such as cash, utility or rental assistance) undermined its ability to meet the needs of the most vulnerable. Chicago invested in sophisticated strategies for testing and contact tracing to support epidemiological modelling while cases mounted because residents could not afford to stay home. There are three components to our argument. First, the City of Chicago adopted a scarcity approach that triaged resources and pitted communities against one another in the quest to secure resources. This approach necessitated robust data collection at the census-tract level. Therefore, city officials administratively prioritised the extension of *disease surveillance infrastructure* over social service provision. Second, despite modelling aspects of the COVID-19 response on HIV public health work, public health experts directed the bulk of COVID-19 funding to testing and contact tracing, which was meant to connect residents to social services in addition to preventing transmission and generating data. Yet, because the city did not invest in social services, contact tracers could only point vulnerable residents to private or mutual aid provisions available in their neighbourhoods, and information about these services was often outdated. Contact tracing was really only successful in increasing testing behaviours. These initiatives positioned disease surveillance as the primary public health solution to COVID-19 at the expense of effective social service provision. Finally, the city enlisted community-based organisations in its approach, actors that might have otherwise agitated for more robust social service provision for their communities. In previous pandemics, HIV especially, lay expert organisations

have been at the forefront of demanding social supports to address the social determinants of poor health.

Ultimately, we argue, the city *economised* its approach to the pandemic by presuming a scarcity of resources that required triaging aid to vulnerable communities. This scarcity model required granular data collection and disease surveillance infrastructure. Therefore, rather than spending federal funds on social safety nets in communities known to suffer from disinvestment, segregation and poor health, city officials invested in a system that supports epidemiological modelling to track positivity, hospitalisation and death rates at the census-tract level. The resulting disease surveillance infrastructure turned out to be an ineffective means to address the social vulnerabilities that were driving cases. Instead, this design enabled the extension and retraction of resources throughout the city as the virus moved, but it made achieving racial equity impossible.

In what follows, we first provide background on the specific case of Chicago and then review scholarship on economisation, epidemiological reason and infrastructure, and lay expertise. After reviewing our methods, we present findings that illustrate how the pandemic response adopted in Chicago by city officials, public health experts and community organisers prioritised disease surveillance over social service provision.

BACKGROUND ON CHICAGO

Federalism has been widely blamed for the failures of the US to effectively respond to COVID-19 (Huberfeld et al., 2020; Mervosh et al., 2021). While most of the government relief and funding programmes available have been established by federal legislation (e.g., the Coronavirus Aid, Relief, and Economic Security [CARES] Act), state governments administer these programmes. Unemployment and rental assistance programmes are paid for with federal dollars, but administered at the state and municipal level, which many have argued contributed to backlogs and delays (Haag, 2020; Iacurci, 2021). Further, it has been left up to states to mandate shelter-at-home orders, social distancing and mask requirements, and vaccine mandates—leading to widely diverse public health advice and requirements. Some have argued that this federalist structure has exacerbated race and class inequalities because states that have historically underinvested in social programmes, or which have lower taxes and higher government distrust, fail to serve the needs of the most vulnerable (Huberfeld et al., 2020).

Chicago is an important case because racial equity was centred as a core value of the local response, yet racial disparities in health, housing and economic outcomes are deep and persistent. Both the Governor of Illinois, JB Pritzker (2019–present), and Mayor of Chicago, Lori Lightfoot (2019–present), were elected as liberal Democrats and have served in these offices since the first reports of COVID-19. Both administrations adopted data-informed, health equity policies that seek to redress COVID-19 racial disparities. Further, when news first surfaced in March 2020 that 70 of the first 100 deaths from COVID-19 were concentrated in Chicago's Black communities (Eldeib et al., 2021), Mayor Lightfoot initiated the Racial Equity Rapid Response Team (RERRT), the city's hallmark 'racial equity' initiative. RERRT brought together city officials, Chicago Department of Public Health (CDPH) epidemiologists, health-care providers and one chosen CBO from the three predominantly Black neighbourhoods with the highest death rates. In April 2020, when it became clear that Latinx communities were bearing the brunt of infections, three predominantly Latinx communities were added to the RERRT initiative. Together, RERRT members designed testing and contact tracing efforts, held community education events and organised relief efforts in these six priority neighbourhoods.

CDPH also drew on the RERRT model to design an equitable vaccine rollout. CDPH epidemiologists created the COVID Community Vulnerability Index (CCVI), which merges social vulnerability matrices from the American Community Survey with COVID-19 positivity, hospitalisation and death rates. In 2021, the CCVI was used to launch Protect Chicago Plus, an initiative that prioritised the 15 most vulnerable communities in Chicago for vaccine promotion and rollout.

Despite this progressive policy agenda, racial disparities in health and welfare have not been assuaged. Chicago is a majority minority city where white, Black and Latinx residents each make-up approximately one-third of the population. Cumulatively since 1 March 2020, 47% of hospitalisations and 42% of deaths are concentrated in the Black community (City of Chicago, 2022). The zip codes with the highest cumulative rates of infections in Chicago are predominantly Latinx and working-aged Latinx residents have been most vulnerable (Del Rios et al., 2021). Black and Latinx communities also faced disproportionate housing, employment and food insecurity during the earliest surges of COVID-19 cases. Unemployment rates have remained highest among Black residents of Illinois (Illinois Department of Employment Security, 2022). At the end of 2020, 37% of Black Chicagoans and 29% of Latinx Chicagoans were experiencing food insecurity (Paddock, 2021). Currently in Illinois, 246,000 households are behind on rent, 72% are households of colour and 82% are low-income (National Equity Atlas, 2022). While Chicago adopted a racial equity framework, the worst vulnerabilities of the pandemic were still concentrated in Black and Latinx communities (Decoteau et al., 2021).

Part of the failure to achieve racial equity stems from Chicago's political infrastructure. Chicago's representative government is based on 50 wards, each led by an elected alderman¹ who represents community interests and sits on City Council, the legislative body. Officially, the City Council approves the annual city budget, but political experts often refer to the City Council as a 'rubber stamp' because of its tendency to bend to political pressure from the Mayor (Fishman, 2021; Simpson, 2001). The Mayor also controls the budget and appoints leadership of CDPH. Under emergency orders during 2020, Mayor Lightfoot completely bypassed City Council and held 'discretionary' power over CARES Act funding. Lightfoot was harshly critiqued by progressive aldermen and activists when she spent \$281.5 million of CARES Act funding on police personnel and left another \$68 million unspent (Morrell, 2021). Despite critiques, expert policy-makers continue to frame RERRT and Protect Chicago Plus as cutting-edge, community-engaged policies that can reduce racial disparities in health in Chicago.

In this article, we explain this tension by arguing that these equity-driven initiatives have built a robust disease surveillance infrastructure that centred on epidemiology without addressing disparities in care infrastructure, leaving a gap in social service provision. We also show how these initiatives quell challenges from lay populations by incorporating CBOs. The case of Chicago provides an important opportunity for theorising the costs of responding to pandemics with economised disease surveillance—but not social service—infrastructure.

LITERATURE REVIEW

Economisation

Although economisation is often used as a general term to describe processes by which behaviours and objects are constituted as 'economic' (Çalışkan & Callon, 2009, p. 370), here we refer to a specific meaning of 'economisation' within the Foucaultian biopolitical literature that highlights the management and valuation of populations according to presumptions of scarcity. Foucault

argued that the birth of the population as a target of governmental biopower was accompanied by the management of scarcity: ‘there will no longer be any scarcity in general, on condition that for a whole series of people, in a whole series of markets, there was some scarcity ... and consequently some hunger, and it may well be some people die of hunger’ (2007, p. 41). In other words, scarcity is no longer a scourge on society as a whole as long as it can be managed internal to the population, as an object of government.

Many scholars have drawn on Foucault’s analysis to present the argument that economisation (and the management of scarcity) is a core feature of neoliberalism (Brown, 2015; Laruffa, 2022; Murphy, 2017). Brown explains that neoliberal rationality does not simply marketise previously noneconomic spheres, but rather disseminates the model of the market to all domains and configures humans exhaustively as only, always, *homo economicus*—driven to consistently maximise one’s own human capital in continuous competition of a zero-sum kind (2015, pp. 31, 33). Murphy focuses on economisation as a regime of valuation hinged towards maximisation of national ‘economic’ health, which she distinguishes from exploitation, extraction and the production of surplus value (2017). Laruffa focuses on how the turn towards neoliberal austerity necessitates the economisation of welfare, education and public health, such that each is run according to economic logics *because* scarcity is axiomatic (2022).

Other scholarship highlights the fact that neoliberal, global management of public health increasingly deploys scarcity logics, wherein certain populations are extended technocratic interventions (like antiretroviral therapy) but without investment in care and structural infrastructure, which requires constant calculations of costs and efficacy (Murphy, 2017; Nguyen, 2009). ‘Under the guise of emergency, triage is an automatic function that separates those who must live from those who might die, while only the former get counted’ (Nguyen, 2009, p. 209).

We draw on this literature to highlight the ways in which the broader economisation of welfare and neoliberal rationalities of public health filtered into the COVID-19 response. In our findings, we show how epidemiological metrics, such as positivity, hospitalisation and death rates, helped state actors visualise the impact of COVID-19 and direct resources. But these metrics also enabled the triaging of care. City of Chicago officials employed a scarcity framework that assumed limited resources and employed models to justify spending and determine allocation of supplies in a data-driven manner. Investment in epidemiological infrastructure was crucial to how city officials administered their response. Rather than providing housing, welfare and health resources, people living in census tracts with high COVID-19 positivity were given educational materials, increased access to testing (in the short run) and limited vaccine programming. These resources were then redirected elsewhere as soon as the positivity rates declined.

Epidemiological reason and infrastructure

Foucault also argued that population statistics, or ‘state knowledge’, have been a major feature of biopolitical management aimed at optimising the health of the population (1990). Although early biopolitics were reliant on census surveys and hygiene campaigns, beginning in the 1950s, a shift in disease patterns and tracking emerged as countries in the industrialised North began to contend more with chronic illness than infectious disease (Reubi, 2018). The simultaneous expansion of the welfare state and federal investment in epidemiology as a discipline for tracking potential illness and behavioural trends in this era gave rise to new approaches to public health, new technological capacities associated with population statistics and the rise of surveillance medicine.

At the same time, Lakoff (2017) argues that New Deal investments in infrastructure like communications systems and dams/levies led to new kinds of national vulnerabilities to natural disaster and terrorism. As these risks multiplied towards the end of the 20th century and culminated in the attacks of 9/11 and Hurricane Katrina, the US began heavily investing in what Lakoff refers to as vital infrastructure (surveillance and communication technologies, dams/waterways, industrial agriculture) as part of its 'preparedness' for unknown risks. Rather than modelling disease response based on probabilities associated with previous infections, preparedness requires simulating unknown catastrophes and investing in critical infrastructure. In the place of 'state knowledge' about the population, emergency preparedness calculates infrastructural vulnerabilities and improves their capacities.

Yet, Lakoff does not address the aggressive retraction of care infrastructure that has occurred alongside investments in preparedness. While the US may have expanded its investment in critical infrastructures in the late 20th and early 21st centuries, this was also the era in which care infrastructure was being gutted through the neoliberalisation of welfare, housing and health-care provision. Historically, there has been a critical *disinvestment* in public care infrastructure, whereas penal, corporate and vital infrastructure has flourished (Wacquant, 2010). When disasters do hit, people marginalised on the basis of class and race are forced to work through them because they have no safety net, and then experience worse outcomes because the fragmented systems on which they rely provide no real support.

Focussing on international development projects that deploy family planning programmes to control fertility rates, Murphy (2017) argues that the bolstering of data infrastructure often comes at the price of investment in material infrastructure. The expansion of 'epistemic infrastructure' (i.e., population surveys) obscures the ongoing disinvestment (by international and national actors) in care infrastructures that could better serve vulnerable groups. We will argue that a similar tactic was used in Chicago during COVID-19. Rather than investing in housing, basic income, work protections and health-care access, cities invested in epidemiological infrastructure to illustrate their 'success through numbers'. And yet, these 'successes' are belied by the ongoing precarity of the most vulnerable to infection and death and their housing, health and financial insecurity. And in fact, incorporating the non-profit sector into epidemiological infrastructure meant actors from this sector were unable to contest the city agenda.

Lay expertise and health social movements

Scholars have argued that challenges from the laity have increasingly played larger roles in research development (Navon, 2019), diagnostic and treatment expansion (Epstein, 1996) and addressing health disparities (Brown et al., 2004; Nelson, 2013). In some ways, this broader participation undermines medical authority (Hess, 2004), but in other ways, it actually serves to advance processes of medicalisation (Barker, 2005; Landzelius, 2006). For example, Epstein (1996) analyses HIV-positive activists who challenged science by insisting on their participation in clinical drug trials for the development of antiretroviral medication. In this case, involvement of lay experts clinched rather than undermined the medicalisation of HIV.

Brown's (1987) work on health social movements describes the ways in which the laity often engage in popular epidemiology. Popular epidemiology occurs when laypeople gather statistics and marshal knowledge to trace the causes of disease. But unlike normative epidemiology, popular epidemiology 'emphasises basic social structural factors, involves social movements, and challenges certain basic assumptions of traditional epidemiology' (Brown, 1987, p. 78). Popular

epidemiology can have powerful impacts on environmental regulations but also the provision of social services to previously excluded and marginalised groups (Decoteau, 2021).

During the HIV pandemic, social movement actors influenced and helped design treatment policies and the development of wraparound services. Laypeople took part in the development of clinical trials on antiretroviral treatment and were instrumental in expanding access to therapies, thus shifting both the knowledge infrastructure and service landscape (Epstein, 1996). Additionally, HIV is perhaps the best example of how the fundamental causes of poor health are addressed in public health responses by expanding the social safety net available to impacted populations (Brier, 2009; Watkins-Hayes, 2019).

As we will show in our findings, during COVID-19, some communities in Chicago engaged in a form of popular epidemiology by conducting needs assessments of their communities. But for the most part, laypeople were immediately incorporated into the city's epidemiological infrastructure that made them accountable to data, preempting social movement challenges that could have further extended a robust social safety net to the most vulnerable. In fact, in the first 2 years of COVID-19, CBOs have largely avoided challenging the city for ignoring the social determinants of health and failing to invest in housing, financial support, workplace protections and health-care access. These supports and access were desperately needed to protect some of the city's most vulnerable residents from the devastating medical and social tolls of the pandemic (Decoteau et al., 2021). We argue that this tension stems from the incorporation of CBOs into the city's disease surveillance infrastructure that made key community-based actors accountable to data rather than responsive to their community residents.

METHODS

This study draws on 56 qualitative in-depth interviews with experts in Illinois and Chicago and was part of a broader project that also included 110 interviews with residents of three neighbourhoods in Chicago that were heavily impacted by COVID-19. Reported findings from this broader study are cited throughout this article to provide context for our analysis. We conducted a critical policy study to uncover how 'state acts' (Bourdieu, 2012) are orchestrated to 'define situations, classify people, and control access to resources' (Dubois, 2014, p. 38). Qualitative interviews with decisionmakers and experts at various levels in the state response to COVID-19 provide narratives that situate and explain both how big decisions are made and how they are rolled out by 'street-level bureaucrats' (Dubois, 2009) in communities. Specifically, this study is designed to better understand why the state acts taken in response to COVID-19 failed to meet the needs of the most vulnerable residents of Chicago.

Interviewees were purposively sampled and were recruited from three different groups of experts in Chicago: (1) community-based actors including staff from CBOs and health-care providers at neighbourhood clinics ($n = 33$), (2) public health experts including epidemiologists working with the city and state ($n = 16$) and (3) administrative decisionmakers including hospital administrators and government officials who work outside CDPH but were involved in orchestrating the response ($n = 7$). Expert interviewees were recruited based on their key positions within government agencies, health-care organisations and CBOs. For this reason, interviewees were not sampled based on race and ethnicity, gender identity or other demographic characteristics, and these data were not collected. Interviewees generally reflected the demographic profile of Chicago. Among the 16 public health experts working with the CDPH and the Illinois Department of Public Health, half of them ($n = 8$) had experience working in HIV

public health at formative moments in their careers, and several have continued to work on both infectious diseases.

Community-based actors were recruited through their known involvement in government initiatives like the RERRT or through service providers in key areas of Chicago. Staff and leaders from 14 different CBOs or clinics were included in our sample. Many of these organisations did not specialise in health or health care prior to COVID-19 but eight of them directly collaborated with city officials during COVID-19. These interviewees were able to speak candidly about the needs of communities in Chicago, especially the predominantly Black and Latinx communities where many of them live and work.

Public health experts were recruited through initial contacts at CDPH. All these interviewees had a background in epidemiology or public health. Of this sample, 11 were based at CDPH and 10 from other organisations like universities. These interviews provided accounts for how the technical work of producing disease surveillance data has been accomplished in Chicago. These experts also told us how they amassed and envisioned epidemiological infrastructure in response to COVID-19 and how that might extend into future work.

Administrators from the City of Chicago and large organisations like hospitals and foundations were sampled based on their involvement in RERRT. These interviews provided important social and political rationales for the focus on data and epidemiology as tools for combatting health disparities.

Both authors conducted data collection and analysis, and we minimised bias by checking with respondents before publishing quotes from the interviews to prevent mischaracterising data to suit our findings. Analysis of interview data followed a flexible three-step coding scheme that progressed from abductive generation of themes to deductive identification of specific quotes and examples. An initial reading identified the importance of theories of economisation to understand the scarcity approach taken by the city, infrastructure with respect to the capacity of CDPH and lay expertise with respect to community-based actors. A second reading generated broad codes that refined our engagement with these theories. A third and final reading of the data identified the specific examples that we assembled as evidence to support this argument.

FINDINGS

The response to COVID-19 in Chicago began with a major investment in public health infrastructure, which translated into the creation of a large-scale disease surveillance programme that prioritised testing, data management and contact tracing. Chicago, through CDPH, awarded \$56 million in contracts to form a contact tracing corps in 2020, an incredible investment that extended the reach of disease surveillance and aimed to link many Chicago residents affected by COVID-19 with needed resources as well (Mayor's Press Office, 2020). Despite these objectives, this approach has been problematic in three ways: (1) the city enacted a scarcity approach to the provision of all resources, which necessitated an investment in robust disease surveillance to generate data and direct public health resources to communities only after need was proven; disease surveillance infrastructure was prioritised over extending social services; (2) contact tracing failed to reliably prevent the spread of COVID-19 or connect people with resources because there were few resources available and communication lagged; (3) communities' avenues for activism and advocacy were diminished because CBOs were incorporated into public health work. As a result, while this model of public health imported individual experiences and organisational forms from HIV public health work, it failed to adequately invest in creating social

supports alongside disease surveillance—perhaps one of the greatest strengths of the HIV model. We are not arguing against disease surveillance but underscoring that disease surveillance is not an effective substitute for a social safety net even when it generates data that support policymakers' equity goals.

Economising public health

Confronted with the fact that the public health infrastructure had been systematically underfunded for decades, city officials in Chicago reactively poured money into public health in 2020. However, the city did not meaningfully expand social safety net funding that was also urgently needed. Of nondiscretionary funds, \$189 million was directed to the CDPH for public health response (Wood, 2020). Discretionary spending brought the total for CDPH up to approximately \$300 million while the Department of Family and Support Services that manages community service centres that offer shelter and food supports to residents, for example, received only \$188,000 in discretionary funds (Morrell, 2021). Despite Chicago's opaque budgetary process in 2020, it is clear that welfare, housing and other social supports that have also been systematically underfunded for decades continued to receive minimal support. Further, of the \$470 million in discretionary funding available to the city, approximately \$68 million went unspent by the end of the year (Morrell, 2021). Although the city claimed and presumed scarcity in meeting the robust needs of vulnerable Chicagoans, its 2020 allocation was not even used in its entirety. City officials spent huge sums on building up disease surveillance infrastructure, which would then be used to allocate testing, educational and vaccine resources on a case-by-case basis, rather than investing heavily in housing, welfare or food provisions to the most vulnerable.

Investment in CDPH was an obvious first response to COVID-19, in part, because Chicago has adopted a style of city government that emphasises the importance of precise, evidence-based policymaking. In many respects, this is seen as an important equity issue because it brings specificity, granularity and urgency to each initiative. When asked about why original data was needed to identify racial disparities, one city official explained that,

In Chicago, we always talk about the map of inequity ... COVID, it crept right into that same map that we all know, so in some ways, some of the results that we see could have been predicted. [But] I think you never quite can predict exactly the impact that you'll see, especially at the granular level that we saw it. Additionally, I think there's a danger in constantly seeing that map and just charging it to, "Oh, that's just structural inequity that exists in Chicago" and being sort of inactive.

(City Official, 27 April 2021)

Chicago city government actors rely on data to direct policies and avoid complacency with structural inequities. Yet, we argue that relying on data to direct policies also leads to programmes focussed on specific numbers and the administrative apparatuses that generate them rather than broad, structural interventions. And ultimately, this made it difficult for the city to counteract pre-existing structural inequalities that contributed to the disproportionate racial impact of the pandemic.

As COVID-19 emerged as an epidemic in Chicago, CDPH became a primary source of data for city policy. Public health professionals were overwhelmed with trying to process enough data

and information to keep up with the needs of policymakers. As one leading CDPH epidemiologist explained:

While we have a really adept set of epidemiologists working in communicable diseases, that unit was quickly overwhelmed with the need and the appetite for data around COVID ... Even our office, which was much more used to data requests and ... reporting out data, we still have traditionally operated on an annual cadence at best and had to pivot to weekly or even daily reporting for effective COVID response ...

(CDPH Epidemiologist, 9 March 2021)

As this epidemiologist explains, the existing disease surveillance infrastructure in Chicago was simply not equipped to work at the 'cadence' required. The expert epidemiologists at CDPH needed better tools for managing the flow of data if they were going to provide the models city decision-makers wanted. The 'appetite' for data among public officials was so great that pouring resources into CDPH became an easily defensible decision, especially given the ongoing demand for data-informed policy.

We have already indicated the tremendous funding allocated to CDPH by city officials. One public health expert explained the scale of this investment in terms of hiring for the contact tracing corps, remembering, 'That endeavour has been pretty massive in scale. Right now, we have probably about 850–900 people working on the umbrella known as contact tracing' (CDPH Official 2/10/2021). He further emphasised the importance of contact tracing to the mitigation efforts designed by CDPH:

[Contact tracing] includes reaching out to individuals diagnosed with COVID to gather data, to provide public health guidance to help them navigate to resources if they have needs that compromise their ability to follow our public health guidance, and to elicit contacts who may have been exposed to COVID. Then, following up with those contacts to provide them public health guidance around quarantine, and to support their resource needs.

(CDPH Official, 10 February 2021)

Investment in data collection in the form of detailed case reporting and contract tracing was considered the first-best option for responding to COVID-19.

While building disease surveillance infrastructure was prioritised, ramping up other areas of social service infrastructure lagged. The relative lack of investment in direct relief was notable even across city departments. By June of 2020 only \$2 million dollars was available for an emergency rental assistance programme run by the Chicago Department of Housing using funds carved out of their existing annual budget, a programme that received 83,000 applications (Department of Housing, 2021). Of the official CARES Act funding that would be dispersed later in 2020, only \$16.5 million was allocated for housing and \$4.5 million for food assistance (Wood, 2020). The heavy investment in a public health workforce that would extend the reach of disease surveillance efforts in Chicago illustrates how the priority placed on the epidemiology of COVID-19 outbreaks far overshadowed investment in social supports (like housing). Indeed, the disease surveillance infrastructure that would help identify COVID-19 cases and needs for resources was funded at a greater level than the resources themselves. Therefore, residents were simply directed to already existing resources provided by private and philanthropic organisations

in their neighbourhoods. One CBO leader explained why his organisation chose not to submit proposals for the Chicago's contact tracing funds: 'So, when people ask you, 'okay, well, how am I gonna pay my rent, groceries and the rest?' we're gonna provide them a sheet? A list of food pantries? Those pieces (housing/cash assistance) were not part of the plan' (CBO Leader 12/16/21). As this community leader articulates, the expectation was that people who needed housing and food support, people who might still be sick, must shop around for the free resources that might be available in their communities. While the public health response to COVID-19 in Chicago included a recognition of increased basic needs like food and housing, investment in disease surveillance infrastructure for testing and contact tracing to support the epidemiology of COVID-19 cases outstripped spending on programmes to meet basic needs and fundamental causes.

This should not be construed as a criticism of spending on public health. Rather, our findings illustrate the problems with spending on CDPH as the *only* essential administrative area needed to confront COVID-19. While the need for data was acute, whether this data was necessary for designing appropriate policies is a point of debate. Specifically, our study shows how the kind of epidemiology that was supported by a disease surveillance infrastructure, an epidemiology of COVID-19 cases, meant that policymakers extended resources to communities only when they were suffering the acute effects of the epidemic. We suggest that the scarcity model deployed by the city, which necessitated investment in disease surveillance over investment in social safety nets for the most vulnerable, undermined the city's ability to achieve racial equity.

Disease surveillance infrastructure

While public health experts working with CDPH had little control over how city officials allocated funds, they did make decisions about how to design the COVID-19 public health response. Concerns raised by activists that social service provision was not a priority were well founded. Despite the fact that four key interviewees from CDPH's internal COVID-19 leadership had extensive background in designing HIV infrastructure that included a robust social safety net, the response to COVID-19 centred disease surveillance over social service provision. These experts reproduced the form of the HIV infrastructure without all the substance. As a result, epidemiological data drove shallow and narrow infusions of support across the city in place of sustained investment in vulnerable areas.

Chicago is home to an innovative and robust HIV care infrastructure. Braiding together numerous funding sources, CDPH has constructed population-centred health homes with specialised medical and social service links for people living with or vulnerable to HIV. They also designed the HIV resource HUB that, after launching in February 2020, serves as a non-clinical site for people seeking resources around HIV to get connected to HIV health homes. A community health worker explained:

The HUB was seen as trying to lower barriers ... [serving as] "the only door a person." [...] They wanted to find places so that people weren't popping around so much and that these population-centred health homes—which are clinics and hospitals—gets them insurance ... If they have housing needs, they have a case manager there. If they need behaviour health services, they can get them.

(CBO Health Worker, 27 April 2021)

Importantly, this model of public health work approaches any person who seeks out HIV-related care, services, or information as part of a specific population that is eligible for medical and social resources aimed to prevent HIV transmission. At CDPH, experts (CDPH Official 9/30/21, CDPH Official 10 February 2021) refer to this as a ‘status-neutral’ approach where anyone who has engaged in activities that might expose them to HIV is linked with health care and social supports if they need them, regardless of their HIV test result.

To their credit, when faced with a massive infusion of funds, public health experts in Chicago wanted to replicate the HIV model for COVID-19, including the resource HUB. The contact tracing corps was a primary thrust of this effort. Across the US, failures in contact tracing were attributed to a high volume of cases and inadequate rapid testing capacity (Steinhauer & Goodnough, 2020). However, in Chicago, contact tracing faltered as an effective public health measure in two specific ways. First, the contract tracing corps and COVID-19 resource HUB was reliant on private programmes to provide supports for food and housing in the absence of robust public programmes to address these needs early on. So, there were chronic lags and shortages of resources and information about them. The HUB coordinator explained this problem:

If I was to refer someone to a particular organization, we didn’t know exactly the full range of services that they had. So, for example, an organization is offering diapers. But there are limitations on how much of those diapers they have, right? How long are these services available?

(CDPH Official, 19 March 2021)

Because supports for people experiencing hardships are distributed across the city and primarily offered by private or non-governmental organisations, the COVID-19 resource coordination HUB had to work extremely hard just to make sure they had the correct information to give people. As a result, there was no guarantee that residents who needed resources would get them, even if they were effectively connected to the HUB.

Second, contact tracing failed to prevent transmission of COVID-19 within individual networks due to the virology of the pathogen and difficulty soliciting contacts from residents with little formal health-care experience (Chase, 2020). Rather, the city triaged flexible testing, educational and later vaccination programmes which were rolled out in high-positivity areas of the city, and then redeployed elsewhere as case rates shifted. The city adopted a scarcity approach to distributing resources to communities. These interventions were effective for addressing local numbers but, by design, were constantly shifting public health support from neighbourhood to neighbourhood.

One expert explained the importance of retaining mobile testing resources to push down percent positivity of COVID-19 tests in neighbourhoods where these numbers had plateaued, suggesting there was not a local surge:

Over the summer, we had these stubbornly high percent positivities... We’re trying to put testing here. Why isn’t it working? That’s when we innovated and did—started doing the mobile testing sites.... If you do mobile sites, you can spread the wealth a little bit more. We have experimented a little bit with—some of our sites are only open three days a week, which allows us to take that capacity and put it elsewhere.

(CDPH Official, 29 March 2021)

Because testing served as the primary mechanism for collecting epidemiological data, mobile testing served to infuse testing capacity into neighbourhoods with high COVID-19 numbers and ultimately reduce them. This proved effective in addressing localised outbreaks as they occur but does so at the cost of providing sustained supports in each neighbourhood where they might be needed.

The effect of this approach was both that individuals who were vulnerable for and getting testing for COVID-19 did not receive systematic connections to care despite this being a cornerstone of how infectious disease professionals approach HIV. One infectious disease expert noted this disconnect with respect to wraparound services when explaining some of the differences between the local HIV and COVID epidemics:

I think with HIV linkage to care, there's a lot of effort to keep folks retained and engaged with care, versus with COVID it's more of, you're touching base at the time of their infection, maybe trying to touch base again during their isolation, and then you may or may not see them again. There's not a lot of work being done to see are those folks really being engaged in health care or health outcomes afterwards.

(Infectious Disease Physician, 16 March 2021)

By March of 2021, this infectious disease physician could already see how the disease surveillance infrastructure built to respond to COVID-19 was failing to reproduce the network of integrated health care and social services that had been proven in the HIV public health domain.

Despite economising public health resources by only directing them to places with the most clearly demonstrated epidemiological needs, however, public health experts also avoided directing COVID-19 public health mandates to specific vulnerabilities or places. Experts wanted to avert unnecessary stigma, even when their hyper-local spatial data showed clear patterns in infection that were matters of historic inequality and not merely spatial coincidence. One expert explained:

The next question might be, did we set different thresholds for different communities? We didn't do that. It's always balancing the epidemiological thresholds with the political acceptability thresholds of the community. We did not want to pit communities against each other..

(CDPH Epidemiologist, 9 March 2021)

Given the stigma and political backlash associated with HIV and other infectious diseases, this is understandable. However, by not highlighting specific communities with greater need, experts made robust care infrastructure feel impossible to implement. As a compromise, they infused short-term disease surveillance and prevention resources to communities with high positivity or hospitalisation rates. However, these resources were only sustained until epidemiological models suggested some other neighbourhood was now *more* vulnerable. So, communities were pitted against one another for limited public health resources. The shifting spatial patterns of outbreaks thus became cause for activating a disease surveillance infrastructure to manage geographic disparities in the epidemic while it precluded sustained, broad public health supports. We argue that prioritising disease surveillance *over* more robust social service provision, especially among vulnerable communities, undermined the city's efforts to redress the disproportionate health *and* social impact of COVID-19 on Black and Latinx Chicagoans.

Community incorporation and preempting activism

City and public health experts were acutely aware that CBOs are the true experts on what neighbourhoods need and how to reach residents. Ultimately, the Mayor's Office invited community leaders to serve on decision-making teams and contracted community organisations to work with CDPH in building and using epidemiological infrastructure. Organisations and leaders that might have otherwise agitated to change how resources were mobilised, as in the case of HIV activism (Epstein, 1996; Watkins-Hayes, 2019), were invited to the RERRT decision-making body and contracted to do public health work. We argue that this incorporation of key community-based actors into disease surveillance preempted community-based social service provision by selecting priority communities based on epidemiological data, making these actors accountable to epidemiological numbers produced by CDPH, and distancing them from community residents who are leery of their new status as public health authorities.

Epidemiological data was used to select CBOs for enlistment in Mayor Lightfoot's RERRT response. When interviewed, many of the leaders of CBOs that were tapped to partner with the city felt strongly that this was a positive step and that their expertise was taken seriously:

Whether you're the mayor's office, or whether you're [a health] provider [...] or a community-based organization, we all really have the same weight. And our discussions and our arguments, our visioning and planning to how things should be rolled out, that's really what makes Chicago's reaction to COVID unique.

(CBO Leader, 19 October 2021)

As narrated by this community leader, the invitation for CBOs to participate in decision-making felt novel and, given the difficulties faced by neighbourhood residents, an opportunity that should not be missed. These CBO leaders felt as though their input was respected and taken seriously.

Furthermore, CBOs were provided data produced by CDPH to improve public health numbers in their communities. One community-based leader described how 'hyper-local' epidemiological data, at the level of census tracts, enabled their organisation to improve metrics in their community with targeted educational materials on testing and vaccination.

Literally we pull up maps and go, census tract by census tract. We're not sociologists. We're not public health people. We were, every week, analysing the census tracts and looking at the change. All of a sudden, after we started going out, we saw that there was a 40 percent reduction in COVID. And we were like, "oh, this works", targeting these folks and bringing this intervention and tracking it over time.

(CBO Leader, 29 September 2021)

The circulation of CDPH data was core to their involvement in public health decision-making and enabled them to better serve the community in times of acute outbreaks.

Of course, not every community in Chicago that might have benefited from the RERRT initiative was invited, and those who were invited were not always prioritised for resource distribution. As a result, CBOs were put in the sometimes-difficult position of being accountable to what the epidemiological data processed by CDPH indicated, even when it meant that needs in their neighbourhoods would not be prioritised. By the time vaccines were available, this model of public health priority determined with epidemiological models was well-established as a method for managing scarcity.

Unfortunately, when you have a very scarce resource, and you want to give it to folks who are most likely to get the least of it, there ends up being a fighting-for-the-scrap phenomenon. We picked 15 communities [for targeted vaccine distribution], and the 16th, 17th, and 18th really needed that vaccine too. If we had spread it to 20 communities, we would've given everybody nothing, essentially.

(CDPH Official, 19 March 2021)

The involvement of community leaders in decision-making was limited by epidemiological numbers. Some of the CBOs that joined RERRT in April 2020 were not prioritised for vaccination resources because other communities had worse numbers when vaccines became available. While CDPH prioritised 15 communities whose data illustrated their vulnerability, some neighbourhoods that had experienced massive outbreaks did not rank among those 15. One CBO leader from a Latinx neighbourhood with some of the highest COVID-19 positivity rates in Illinois expressed frustration that CDPH would only commit to supporting vaccination efforts for 10% of residents (CBO Leader 9/20/21), illustrating how data-driven decisions often support only a shallow distribution of resources. Furthermore, for those CBOs and communities not directly engaged in these initiatives because they were not deemed 'collaborators' by city leaders (City Official 4/27/21), the emphasis on data created a justification for prioritising certain communities for government support but not others.

Ultimately, engagement in city initiatives that relied on epidemiological data to drive action also created distance between CBOs and neighbourhood residents. As they increasingly devote staff to public health work associated with city initiatives, some residents lose trust in these organisations. One community-based health worker explained this problem:

You know, the first thing that they see is uniforms coming from a government agenda. So, you know, every business that we seek to help for the most part, thinks we're an auditor. Residents are thinking, you know, we're the census, or that we're FEMA, come to police how people are taking care of themselves in the community. But it's honestly the exact opposite.

(CBO Health Worker, 5 October 2021)

Many of the communities that have been systematically denied government resources have adopted a reasonable, even healthy, scepticism of policies that promise intervention. CBO workers involved with the city's response sometimes face resistance from their predominantly Black and Latinx community residents which undermines their work.

This distance from communities is notable for its contrast with the close-knit HIV care infrastructure that already exists in Chicago. In that domain, rather than focussing on professionalising and expanding CBOs and their staff, the approach has been to focus on key relationships of trust and care. As one public health professional recalled, directing resources towards maintaining relationships with clients in the HIV-positive population was a huge priority:

Then our case managers have also been going out in the community to meet clients that do prefer face to face ... We did a lot of community visits where we would meet at a library, or meet in a park, or have conversations from across the street from each other ...

(Public Health Professional, 30 April 2021)

Public health professionals attempted to reproduce this level of engagement and support for COVID-19 by enlisting CBOs. However, by relying on disease surveillance so heavily, their public health efforts appeared hollow to CBOs and community residents. A CBO leader explained her team's struggle with a data-driven approach to vaccine uptake not always being well-matched to local community concerns, saying that,

Based on data, right, we know where the lowest uptake is. So we have our canvassers focus on those areas. But eventually, the people living in those areas can identify our canvassers. You know? "Oh, that's the vaccine lady". They don't answer the doors now. ... Sometimes community doesn't even want to talk about it, right? Because the message overwhelmingly is "get the vaccine, get the vaccine". And that's it, "get the vaccine", and that's it. Like, are people really addressing their concerns?

(CBO Leader, 15 October 2021)

The public health resources provided by CBOs do not necessarily fit the needs or address the concerns of community members. Because outreach is driven by compiled data and not demands from communities, service provision is perceived to be at the behest of CDPH officials rather than answering the specific needs of communities.

As a disease surveillance infrastructure was constructed to enlist and include CBOs from key community areas in Chicago, many organisations jumped at the opportunity to affect decisions made in government and channel resources to their communities. Yet, this came at the cost of accepting accountability to epidemiological data and public health initiatives that sometimes conflicted with the most pressing needs of community residents most pressing needs.

CONCLUSION

Our findings highlight how an emphasis on data-driven policy precipitated an economised approach to mitigating the uneven impact of COVID-19 in Chicago. A narrow investment in a particular disease surveillance infrastructure, like data collection and contact tracing, failed to connect vulnerable residents to social resources because *that* infrastructure had not received the same prioritisation. Further, triaging testing and vaccine efforts by investing in flexible mobilisation that followed surges failed to address core underlying vulnerabilities. This project illustrates how disease surveillance and epidemiology, while crucial public health tools, cannot redress racial inequities when they are deployed *in the place of* robust housing, welfare, food and economic resources.

Furthermore, CBO actors who might have otherwise leveraged lay expertise to agitate for a better social safety net were also incorporated into this disease surveillance infrastructure through shared decision-making initiatives, funding opportunities and the provision of hyper-local metrics by CDPH. While an innovative and perhaps important shift in local governance to include more community-based knowledge, this approach also made CBO actors accountable for balancing epidemiological numbers with the needs of community residents. Chicago's response to COVID-19 also did not include leaders from all communities that have been seriously affected by outbreaks in Chicago, illustrating the scarcity narrative evoked by city officials despite the massive investment in disease surveillance.

Our focus on the case of Chicago is a limitation of this study but also an invitation for future scholarship to investigate how local dynamics shaped public health infrastructure in other cases.

The economised framework adopted by the city of Chicago, which entailed scarcity modelling predicated on robust and granular disease surveillance, failed to meet existing needs among Chicago's most vulnerable residents. As a consequence, despite adopting a racial equity framework that incorporated community organisations, Black and Latinx Chicagoans still experienced the worst health, socioeconomic and housing outcomes of the pandemic.

AUTHOR CONTRIBUTIONS

Claire Laurier Decoteau: Conceptualization (Equal); Data curation (Equal); Formal analysis (Equal); Funding acquisition (Lead); Investigation (Equal); Methodology (Equal); Project administration (Supporting); Validation (Equal); Writing – original draft (Equal); Writing – review & editing (Equal). **Cal Lee Garrett:** Conceptualization (Equal); Data curation (Equal); Formal analysis (Equal); Investigation (Equal); Methodology (Equal); Project administration (Lead); Validation (Equal); Writing – original draft (Equal); Writing – review & editing (Equal).

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DATA AVAILABILITY STATEMENT

Participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

ORCID

Claire Laurier Decoteau  <https://orcid.org/0000-0001-5644-0361>

Cal Lee Garrett  <https://orcid.org/0000-0003-0063-4807>

ENDNOTE

¹ The City of Chicago uses 'alderman' to refer to all title holders despite its gendered implications. While problematic, we maintain this language for consistency.

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