

# Project REFOCUS

## Racial Ethnic Framing of Community-Informed and Unifying Surveillance

### Addressing Social Stigma Related to COVID-19

COVID-19-related stigma encompasses stereotypes about the origins of SARS Coronavirus-2 (the virus that causes COVID-19), concerns about its infectiousness, recognition of its lethality, and fear of contracting the virus from diverse populations and places where prevalence is believed to be high. Discrimination and social stigma are documented barriers to health seeking behavior, engagement in care and adherence to treatment across a range of health conditions.<sup>1</sup> Further, stigma related to COVID-19 is associated with some individuals' lack of knowledge about how the virus spreads, a need to blame someone, fears about disease and death, and interpersonal behaviors that spread or amplify rumors.<sup>2</sup> While fear has been shown to motivate individuals to take action to reduce their apprehension about health issues<sup>3</sup> during crises, fear can have a countereffect on access and adherence to community-level mitigation efforts. Chronic stress is an important pathway by which stigma influences physical and mental health. The negative impact (or discrimination) that results from public stigma has been shown to take four forms: withholding help, avoidance, coercive treatment, and segregated institutions.<sup>4</sup>

### PROJECT REFOCUS

Explores opportunities for the establishment (or expansion) of data collection systems and social listening protocols that effectively monitor, in real-time, the impacts of social stigma on the population as it effects COVID-19 mitigation and prevention practices

Develops model communication materials and recommendations for responding to findings from stigma monitoring systems and signals from specific communities

Leverages and empowers community-based efforts and organizations by providing tools, technical assistance and education to essential and frontline workers (e.g. CHWs, pharmacists, social workers) who work, live in and represent the communities disproportionately affected by COVID-19

Engages media outlets and journalists to collaborate and share best practices for delivering messages, while offering the views of the community to be considered and honored in community-based work



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## Reimagining Public Health Surveillance and Reducing Potential for Harm

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Public health practitioners do not typically monitor for the presence, spread and impacts of COVID19-related stigma on historically marginalized, racialized and underserved populations. Yet, prior epidemics such as HIV have demonstrated that stigma can weaken disease mitigation practices among the most disproportionately affected populations, contributes to their mistrust of public health messages, delays access to recommended services and reduces adherence to prescribed treatment regimens.<sup>5,6,7</sup> Thus, stigma plays a major role in limiting the potential of communities of color to thrive during an epidemic.

Monitoring social exposures to stigma can identify critical constraints to addressing root causes of COVID-19 inequities among disproportionately affected populations. Moreover, while public health surveillance activities and epidemiological research routinely track, identify, and describe patterns of disease and risk factors in populations, the

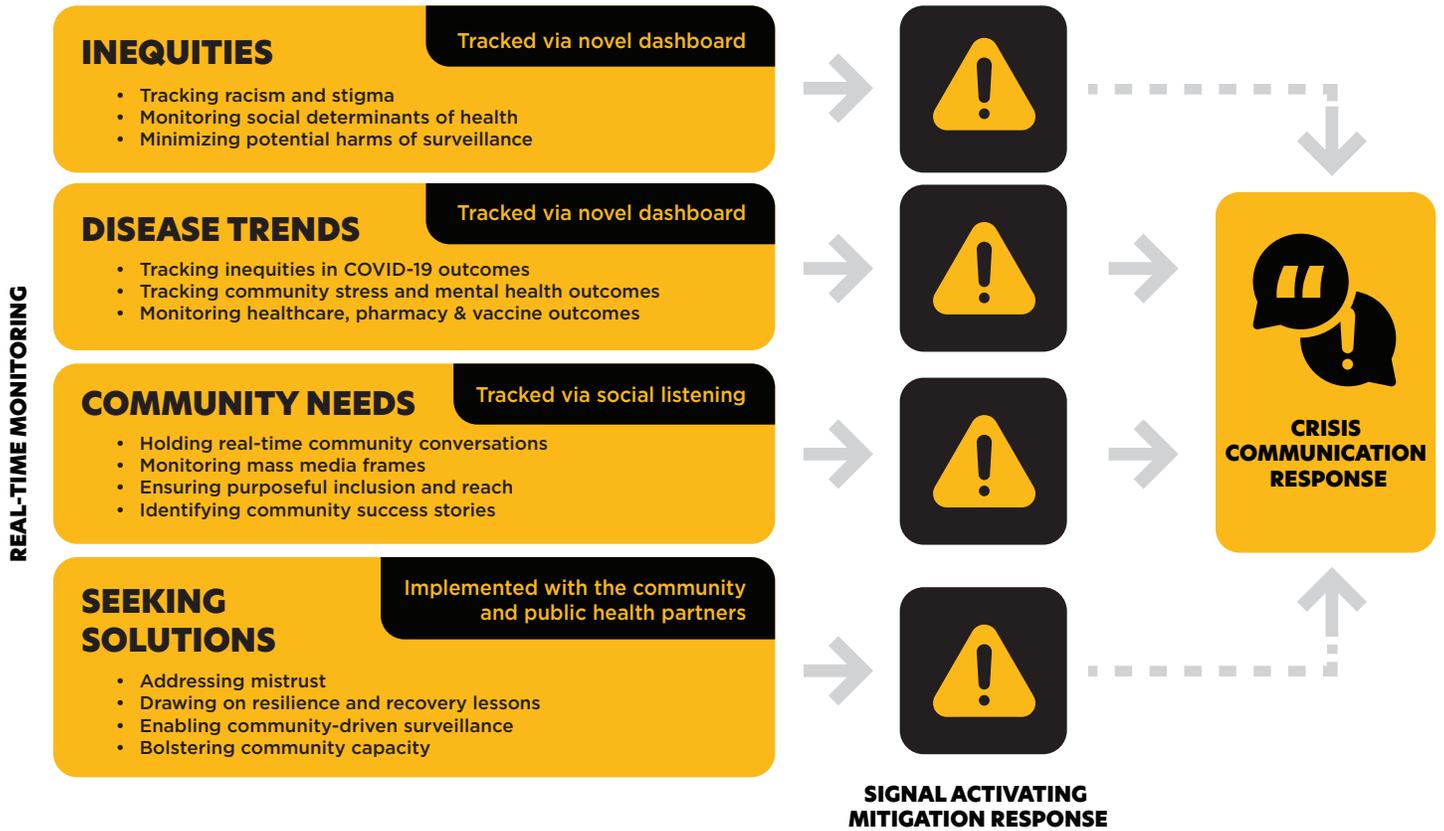


**Stigma plays a major role in limiting the potential of communities of color to thrive during an epidemic**

characteristics typically available in these data are limited (e.g., age, race, sex, geographic boundaries) and at best provide only crude proxies for culture and other shared values, beliefs, experiences and living conditions of a group.<sup>8</sup> Lack of cultural specificity in data can present a secondary challenge as targeted communication may default to single, rarely multifaceted, approaches to reach all members of a given population.<sup>9</sup> These limitations are rapidly magnified during public health crises.

# Project REFOCUS Conceptual Model

Integrated real-time public health monitoring and community-informed response.



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## About Project REFOCUS

COVID-19 has illustrated that public health practitioners need access to data and tools that appropriately identify, respond to, culturally tailor, and reach historically marginalized and/or racialized populations during crises. Project REFOCUS was conceptualized as a collaborative and community-informed effort to address these challenges. Recognizing the need for a system that monitors stigma impacting these populations, Project REFOCUS prioritizes community input and the mediating roles of interpersonal communication, media frames and misinformation in relation to individual and collective health behavior. These factors are critical aspects of a successful response to public health crises.