

## The Benefits of Community Engaged Research in Creating Place-Based Responses to COVID-19

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### Abstract

**Objective:** The DSU COVID-19 study aims to understand the response to and impact of COVID-19 in nine underserved communities in Delaware and to inform public health messaging. In this article, we describe our community engaged research approach and discuss the benefits of community engaged research in creating place-based health interventions designed to reduce entrenched health disparities and to respond to emerging or unforeseen health crises. We also highlight the necessity of sustained community engagement in addressing entrenched health disparities most prevalent in underserved communities and in being prepared for emerging and unforeseen health crises. **Method:** Our study is a longitudinal study comprised of three waves: initial, six months follow-up, and twelve months follow-up. Each wave consists of a structured survey administered on an iPad and a serology test. Through community engaged research techniques, a network of community partners, including trusted community facilities serving as study sites, collaborates on study implementation, data interpretation, and informing public health messaging. **Results:** The community engaged approach (CEnR) proved effective in recruiting 1,086 study participants from nine underserved communities in Delaware. The research team built a strong, trusting rapport in the communities and served as a resource for accurate information about COVID-19 and vaccinations. Community partners strengthened their research capacity. Collaboratively, researchers and community partners informed public health messaging. **Conclusion:** The partnerships developed through CEnR allow for place-based tailored health interventions and education. **Policy Implications:** CEnR continues to be effective in creating mutually beneficial partnerships among researchers, community partners, and community residents. However, CEnR by nature is transactional. Without sustained partnerships with and in underserved communities, we will make little progress in impacting health disparities and will be ill-prepared to respond to emerging or unforeseen health crises. We recommend that population health strategies include sustainable research practice partnerships (RPPs) to increase their impact.

### Introduction

The COVID-19 pandemic has affected poor people of color disproportionately. From the onset of the pandemic, racial/ethnic disparities in both cases and deaths were evident.<sup>1</sup> Differences have persisted as new variants of COVID-19 have emerged. What may look like small differences when aggregated within race/ethnic groups is large when cumulative mortality rate

ratios are considering. Bassett and colleagues<sup>2</sup> found that the risk of dying from COVID-19 was greater among Blacks and Hispanics than among non-Hispanic Whites. Further analysis revealed that Blacks and Hispanics younger than 65 years dying as the result of COVID-19 were deprived of almost seven more years of life than non-Hispanic Whites younger than 65 years who died of COVID-19. These disparities by race/ethnicity are more significant than other major causes of death. Feldman and colleagues<sup>3</sup> analyzed CDC data for all 50 states. They concluded that if COVID-19 mortality rates had been equal across race/ethnic categories and income levels, COVID-19 deaths among race/ethnic groups would have been 71% lower.

Studies within states highlight the race/ethnic groups most impacted by COVID-19. In Massachusetts, infection and death rates were “highly correlated with race and poverty.”<sup>4</sup> An analysis of COVID-19 death rates among Latinx in California found that COVID-19 mortality rates were highest among the poorest.<sup>4</sup> Similar trends are evident in Delaware. Early in the pandemic (July 2020), the COVID-19 infection rate was 129/10,000 with Blacks three times as likely and Hispanic seven times as likely to contract COVID-19 than were non-Hispanic Whites. COVID-19 also showed a differential impact by location and race/ethnicity. In New Castle County, the overall infection rate was 95/10,000 but only 58.6 among Whites compared to 150 among Blacks and an astonishing 387.2 among Hispanics. In Kent County, the overall rate was 100/10,000, with a 53.7 positive rate among Whites yet 145.2 among Blacks and a 180.6 among Latinx. The overall COVID-19 infection rate was 2.5 times higher in Sussex County than either Kent or New Castle counties. Similarly, the race/ethnic disparities were also exacerbated with an 80.9 rate among Whites, 294.9 among Blacks, and a staggering 928/10,000 among Latinx.<sup>5</sup>

As of July 2022, the state-wide COVID-19 death rate/10,000 persons was 24.2. The rates by county were similar in New Castle County (22.6/10,000) and Sussex County (23.6/10,000) and slightly higher in Kent County (31.5/10,000).<sup>5</sup> A closer look at the COVID-19 related death rates in underserved communities indicates alarming disparities. Looking at a selection of poorer communities, as indicated by Social Vulnerability Index scores of .90 or greater, the COVID-19 death rate is at least double and, in some cases, greater than four times the state rate. Although the factors affecting these disparities are many and complex, the impact of COVID-19 has mirrored that of many other health issues, disproportionately affecting poor communities of color. Research has established that zip code is a greater determinant of health than genetic code.<sup>6</sup> We also know that access to healthcare and other services is more difficult for the poor, particularly for poor minorities.<sup>7</sup> These realities are exacerbated by a justified mistrust of both science<sup>8</sup> and medicine<sup>9</sup> among Black and Brown Americans. Given these realities, understanding the impact of and response to COVID-19 in underserved communities requires a place specific approach.

## Study Design

In response to the early signs of COVID-19’s disproportionate impact on lower income communities with a large proportion of Black and Brown residents, we initiated a longitudinal study to examine the impact of and response to COVID-19 in nine underserved communities in Delaware. We have completed the first wave of surveying and serology testing, successfully recruiting 1,085 respondents and building a strong network of community partners. Our experience highlights the role of community engaged research in addressing COVID-19 in underserved communities. More importantly, it underscores the necessity of maintaining

partnerships with and in underserved communities if progress is to be made on reducing health disparities and if we are to be prepared for emerging or unforeseen health issues.

Our study, “Social and Behavioral Implications for COVID-19 Testing in Delaware’s Underrepresented Communities,” aims to understand the impact of and response to COVID-19 and to share what we learn with state and community partners to improve and tailor COVID-19 public health messaging. We selected nine underserved communities based on the Community Health Index (CHI), coupled with incidence of COVID-19 and COVID-19 testing rates. The CHI is a score calculated for each census tract by the Delaware Division of Public Health (DPH) based on health indicators. The CHI score ranges from 12.3 (better) to 208.6 (worse). DPH created a color-coded scoring mechanism to identify and track COVID-19 testing and positive rates by census tracts. Table 1 provides an overview of our study communities. All nine communities have high CHI scores, indicating higher rates of health issues among residents, and were ranked as medium or high priority by DPH’s COVID-19 response.

Table 1. DSU COVID-19 Study Sites

	KENT COUNTY			SUSSEX COUNTY			NEW CASTLE COUNTY		
Census Tracts	420 W. Camden MD Border	418.02 W. Dover	430 Harrington	504.06 Seaford	503.01 Bridgeville	505.03 Georgeto	6.02 NE Prices Run	22, 23 & 24 Westside	30.02 Riverside
<b>Race &amp; Ethnicity</b>	6.5%	30.9%	31.6%	37.8%	20%	12.6%	90.9%	50%	76.5%
Black	4.6%	11.4%	4.6%	13.9%	13%	48.9%	1.3%	45%	8.8%
Hispanic	89.4%	60.2%	68.8%	59.5%	78%	73.7%	7.6%	30%	21.5%
White									
<b>CHI</b>	184.3	168	164	173	194.6	156	208.6	204.3	203.5
<b>DPH COVID-19 Priority</b>	Medium	High	High	Medium	High	High	Medium	High	Medium
<b>Community Partner</b>	Sussex County Health Coalition			Sussex County Health Coalition			Wilmington HOPE Commission		
Study Sites (Trusted Facilities)	Dover Education and Child Care Center; Solid Rock Baptist Church; Harrington VWF; Harrington Public Library			First State CAA; Miracle Revival Center; Seaford Public Library; Coverdale Community Center; Bridgeville Volunteer Fire Department			WHC; Latin American Community Center; The Teen Warehouse		

Our study design is longitudinal with surveying and serology testing conducted at initial enrollment (Wave 1), six (6) months after enrollment (Wave 2), and 12 months after enrollment (Wave 3). Data collection includes the administration of a survey and a serology test. The Wave 1 survey, adapted from the COVID-19 Community Response Survey developed by Johns Hopkins University, includes questions about demographics, socioeconomic characteristics, COVID-19-related beliefs and practices, general health, and COVID-19 testing and vaccination.

We revised the survey for Waves 2 and 3 to include additional vaccination questions. The serology test provides data on exposure to the COVID-19 infection, allowing for an objective measure of exposure. The study team is comprised of a project manager, DSU graduate nursing students, and DSU undergraduate students. The study team reflects the community in terms of race and ethnicity, including several DSU bilingual students.

The study team employs COVID-19 safety protocol, including wearing masks, using partitions to separate participants while completing the survey and during serology testing and results discussion, and wiping down surfaces and iPads. Prior to entering the study site, the nurse screens potential participants for COVID-19 using CDC recommended screening procedures. If the screen indicates exposure to COVID-19 or COVID-19 symptoms, the potential participant is encouraged to get tested, provided with testing information, and asked to return to the study site when COVID-19 negative or when symptoms have resolved.

Using a community engaged approach, we leveraged existing partnerships with access to trusted service providers located in our study communities. Community-engaged research (CEnR) recognizes the historical mistreatment of marginalized groups in research and places the community first by involving research participants in all aspects of the research process (CEnR).<sup>10</sup> It is an essential approach to understanding and addressing health issues because it focuses on research participants living in close proximity and sharing similar situational characteristics affecting their health. As such, CEnR is responsive to the centrality of place in addressing health disparities.

CEnR is an essential component of translational research, primarily because it aims to include the subjects of research as participants making findings directly relevant and accessible to the target population. Much attention has been given to the importance of CEnR, including the DJPH September 2018 issue. However, less attention is paid to the difficulty of conducting community engaged research in the academic environment. CEnR emphasizes building capacity, improving trust, and translating knowledge to action. To build the trusting mutually beneficial relationship between research and community takes time and effort that is rarely funded, making it low priority and often discouraged. But without these relationships academic researchers are left flat footed when the race to secure funding starts because the time between funding announcement and proposal submission does not allow for building relationships with community partners. CEnR also emphasizes the involvement of community members in all stages of research, from framing the issue, creating the data collection instruments, and designing the study. This too is frequently not feasible in the timeframe for responding to research funding opportunities. Another set of issues emerges from the proposal review process. Proposal review panels frequently expect validated instruments or surveys in the public domain, prohibiting community input on the information collected. Validated instruments also lean toward generic and frequently academic language that excludes culturally and geographically relevant phrasing, increasing the likelihood of respondent misunderstanding. Review panels tend to score quantitative studies with large samples and sophisticated data analysis plans highest, forcing researchers to prioritize reviewer preferences over community needs. The publish or perish culture of academia coupled with its growing expectation of contributing to the institution's research portfolio by securing external funding exacerbate the barriers to CEnR.

We faced these common challenges as we responded to the NIH call for rapid response proposals to COVID-19. Although we were not able to fully engage our study communities during proposal development, we did rely on our existing community partners, Sussex County Health

Coalition (SCHC) and the Wilmington Community Advisory Council (WCAC), to help us shape our recruitment and participant engagement protocol and to connecting us to trusted facilities. Through their extended networks, SCHC and WCAC identified ten trusted facilities willing to serve as study sites.

Our proposal included SCHC as our community partner in Kent and Sussex Counties. WCAC was not able to take on the community partner role but remained a key partner in our research and dissemination efforts. Another community partner, the Wilmington HOPE Commission (WHC) agreed to serve as our community partner in New Castle County. SCHC and WHC are different in that SCHC is a coalition with an extensive network of partners and WHC is a service agency in direct contact with potential study participants. Both types of organizations benefit recruitment. SCHC relies on its network of service providers to advertise the study and recruit participants; whereas, WHC uses word of mouth and its clients to recruit. It is important to note that we compensate our community partners. Monetary compensation creates equity with community partners.

We have grown our network to include additional host sites, allowing the study team to work directly in several isolated rural communities. We have also partnered with two libraries, the Seaford and Harrington public libraries. Establishing study sites at these libraries allowed us access to potential study participants from our communities of interest. We extended our network to include two churches, both located directly in study communities and providing community outreach. Our community partners also identified individuals from the community who we compensated to translate the recruitment materials, consent forms, and survey into Spanish and Haitian Creole. Several community residents were hired to assist at the study sites, serving as translators and being a familiar face at the study site.

SCHC and WHC have primary responsibility for recruiting back and scheduling participants for Wave 2 and Wave 3, six and twelve months after initial enrollment. Our community partners lead the development of recruit-back processes, tailoring them for the study communities. Several techniques were employed, including phone calls and text messages. Participants were contacted for two weeks before and after their return date. With each contact, they are provided a study site schedule, allowing them to complete Wave 2 and Wave 3 at the most convenient site.

Our community partners also provide a platform to disseminate information about the study and findings. One of our primary study aims was to inform public health messaging by sharing findings continuously with our community and state partners. We have been fortunate to expand our network to include the Division of Public Health, university based cooperative extension programs, hospitals and COVID-19 response coalitions. We present findings as they become available, shortening the gap between research and practice. We work directly with DPH and two university cooperative extension teams informing tailored public health messaging. We also respond to partners' request for information, allowing the community to identify the topics of concern and interest.

## **The Benefits of Community Engaged Research**

Both researchers and community partners benefit from community engaged research approaches. By leveraging the expertise of our community partners, we successfully recruited 1,086 study participants, 91% of our 1,200 participant target, in eight months during COVID-19 resurgences causing site closures. The differences in our recruitment rates by county underscore the

importance of our partners. Our strongest partnerships are in New Castle County and in Sussex County. The recruitment rates in both those counties (103% in each county) were over twice the recruitment rate in Kent County (48%) where our community partners took longer to establish and were fewer than in the other two counties.

The study team's consistent presence in the underserved communities increases trust of researchers. Building trust requires commitment and patience. As an example, the study team was at one remote community site for three weeks with no community participation despite extensive recruitment efforts. The third week a trusted member of the community came to the site to inquire about the activities. She participated in the study and the next week eight additional community members enrolled. The composition of the study team which reflects the residents of many of the study communities has also been key to building trust within the community. Participants have tracked their return dates and returned without reminders. Participants come by the study sites to confirm return dates and volunteer for future studies. Our study bolsters the participants' confidence in COVID-19 initiatives such as masking, vaccination, and routine testing. We serve as a liaison to local health care resources and combat COVID-19 misinformation. The serology testing component of the study aids participants in gauging previous contact/infection and making decisions about vaccination.

Our CEnR approach has strengthened our community partners' research muscle. Presentations educate our partners on community engaged research design and implementation, they provide a platform for community partners to ask questions and provide insight and more contextual, community-specific understanding of our research findings. They encourage community partners to ask questions, guiding our analyses and producing more community relevant findings. For example, our early analyses highlighted vaccine hesitancy.<sup>11</sup> When we presented these early findings, community partners were interested in the reasons why participants were not vaccinated, more specific race/ethnic group analyses, and COVID-19 information sources used by study participants. We updated our vaccine hesitancy analyses addressing these community driven requests. We are currently engaging in small group discussions about the findings so we, research and community in collaboration, can focus on the implications of the findings for specific communities. This example also underscores how CEnR strengthens translational research. Our COVID-19 study includes an explicit aim to inform public health messaging, translating science to practice in real time. Frequent communication with community partners, provides the outreach workers critical information to better educate and advocate for their constituents.

Our collaboration with study site host agencies has allowed us to respond to two new requests for proposals, both employing CEnR. During proposal development, we solicited input from an expanded network. The community partnerships we developed while implementing the COVID-19 study allowed us to engage two new community serving partners in these proposals. Both new partners are located in communities of interest and directly serve residents in these communities, strengthening our community focus as well as strengthening community research capacity.

## **Discussion**

As with most CEnR, significant effort has been extended to implement this study. And, we have once again been reminded that community engagement of any type requires time and patience and for it to be mutually beneficial it must put community first. We also learned that CEnR, as a form of community engagement, is worth the effort for researchers, community partners, and

community residents. However, CEnR by nature is transactional. It exists as long as the study is funded, creating a new challenge: maintaining and strengthening community partnerships that are necessary to address health disparities in a tailored place/community specific approach. Without sustained partnerships with and in underserved communities, we will make little progress in impacting health disparities and will be ill-prepared to respond to emerging or unforeseen health crises.

One effective mechanism to maintain and strengthen community partnerships is to build on the foundation established by CEnR by supporting sustainable research practice partnerships (RPPs). Educational research has relied heavily on RPPs to improve teaching and learning.<sup>12</sup> RPPs are designed explicitly to address persistent or entrenched problems by creating equitable partnerships between researchers and practitioners. Through these mutually respectful partnerships, researchers understand practice context (or community) making the research more relevant and practitioners understand and participate in research increasing data informed interventions. In RPPs, researchers support practice partners in achieving their service goals. They are less about peer reviewed publications and more focused on providing practice partners data designed for decision-making. Practice oriented analysis makes RPPs key in translational research. Research partners' commitment to rigorous, scientifically sound research methodology ensures findings are valid and reliable and increases the likelihood findings are generalizable to similar contexts and populations. The methodological sound research strategy enables RPPs to inform academic and practice disciplines. RPPs offer a transformational partnership between researchers and practitioners, significantly shortening the science to practice translational gap.

Research practice partnerships (RPPs) are a natural outcome of CEnR and offer a sustainable strategy to address entrenched health disparities and to be positioned to respond to emerging and unforeseen health crises. The reality is that some health crises are unpreventable and, in some cases, unpredictable. However, we can be better prepared to respond to the unpredictable health crises and more effective in addressing the entrenched health disparities by responding to what we know and building on what we have.

We know that zip codes are a stronger determinant of health than genetic codes, underscoring the centrality of location in addressing health disparities and emphasizing the need to put location and, thus, community, first in all public health responses. We also know that mistrust of medicine and research continues to inhibit response to health disparities and health emergencies. A sustained partnership between researchers, community serving organizations and community residents through RPPs is necessary to create trust as well as produce and implement community defined responses to health disparities. Community engaged research techniques have proven effective as a research strategy and offer a starting point to create sustainable research practice partnerships that can advance science and improve the health conditions in underserved communities. Including RPPs in all population health strategies would increase the likelihood of decreasing health disparities and increase our preparedness to address emerging and unforeseen health crises.

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## Disclosures

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## References

1. Mackey, K., Ayers, C. K., Kondo, K. K., Saha, S., Advani, S. M., Young, S., . . . Kansagara, D. (2021, March). Racial and ethnic disparities in COVID-19–related infections, hospitalizations, and deaths: A systematic review. *Annals of Internal Medicine*, *174*(3), 362–373. [PubMed https://doi.org/10.7326/M20-6306](https://doi.org/10.7326/M20-6306)
2. Bassett, M. T., Chen, J. T., & Krieger, N. (2020, October 20). Variation in racial/ethnic disparities in COVID-19 mortality by age in the United States: A cross-sectional study. *PLoS Medicine*, *17*(10), e1003402. [PubMed https://doi.org/10.1371/journal.pmed.1003402](https://doi.org/10.1371/journal.pmed.1003402)
3. Feldman, J. M., & Bassett, M. T. (2021, November 1). Variation in COVID-19 mortality in the US by race and ethnicity and educational attainment. *JAMA Network Open*, *4*(11), e2135967. [PubMed https://doi.org/10.1001/jamanetworkopen.2021.35967](https://doi.org/10.1001/jamanetworkopen.2021.35967)
4. Chen, J.T., Testa, C., Waterman, P., Krieger, N. (2021). Intersectional inequities in COVID-19 mortality by race/ethnicity and education in the United States, January 1, 2020–January 31, 2021. Harvard Center for Population and Development Studies Working Paper, 21(3)
5. Delaware. (2020). Coronaviruse Disease (COVID-19). Retrieved from <https://coronavirus.delaware.gov/>
6. Lakhani, C. M., Tierney, B. T., Manrai, A. K., Yang, J., Visscher, P. M., & Patel, C. J. (2019, February). Repurposing large health insurance claims data to estimate genetic and environmental contributions in 560 phenotypes. *Nature Genetics*, *51*(2), 327–334. [PubMed https://doi.org/10.1038/s41588-018-0313-7](https://doi.org/10.1038/s41588-018-0313-7)
7. Lazar, M., & Davenport, L. (2018, January-March). Barriers to health care access for low income families: A review of literature. *Journal of Community Health Nursing*, *35*(1), 28–37. [PubMed https://doi.org/10.1080/07370016.2018.1404832](https://doi.org/10.1080/07370016.2018.1404832)
8. Scharff, D. P., Mathews, K. J., Jackson, P., Hoffsuemmer, J., Martin, E., & Edwards, D. (2010, August). More than Tuskegee: Understanding mistrust about research participation. *Journal of Health Care for the Poor and Underserved*, *21*(3), 879–897. [PubMed https://doi.org/10.1353/hpu.0.0323](https://doi.org/10.1353/hpu.0.0323)
9. Birkhäuer, J., Gaab, J., Kossowsky, J., Hasler, S., Krummenacher, P., Werner, C., & Gerger, H. (2017, February 7). Trust in the health care professional and health outcome: A meta-analysis. *PLoS One*, *12*(2), e0170988. [PubMed https://doi.org/10.1371/journal.pone.0170988](https://doi.org/10.1371/journal.pone.0170988)
10. Balls-Berry, J. E., & Acosta-Pérez, E. (2017, June). The use of community engaged research principles to improve health: Community academic partnerships for research. *Puerto Rico Health Sciences Journal*, *36*(2), 84–85. [PubMed https://doi.org/10.1353/hpu.0.0323](https://doi.org/10.1353/hpu.0.0323)



11. Wang, S. X., Bell-Rogers, N., Dillard, D., & Harrington, M. A., & the FNP-c. (2021, September 27). COVID-19 vaccine hesitancy in Delaware's underserved communities. *Delaware Journal of Public Health*, 7(4), 168–175. [PubMed](#)  
<https://doi.org/10.32481/djph.2021.022>
12. Sjölund, S., Lindvall, J., Larsson, M., & Ryve, A. (2022) Mapping roles in research-practice partnerships – a systematic literature review. *Educational Review*, DOI.  
<https://www.tandfonline.com/doi/full/10.1080/00131911.2021.2023103>

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