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Centering Patient Voices Through Community Engagement in Cardiovascular Research

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We are experiencing converging pandemics. The coronavirus disease 2019 (COVID-19) pandemic has highlighted and exacerbated the cardiometabolic disease pandemics globally. Obesity, diabetes, and cardiovascular disease (CVD) prevalence remains stagnant or is rising across populations and geographic regions. These pandemics intersect in the midst of increasingly glaring social inequities and systemic discrimination that promote health disparities across racial/ethnic and sex/gender groups.¹ Moreover, persistent disparities in CVD outcomes emphasize the critical role of social determinants of health (SDH), or socioeconomic, environmental, and psychosocial factors to which we are exposed over the life course, in defining health care access and CVD outcomes.² We can characterize obesity, diabetes, and CVD as parts of a syndemic, with these diseases acting synergistically to worsen population health and the effects of these converging diseases defined by SDH (Figure). A syndemic is also characterized by diseases in which biologic pathways connect social and psychological factors to clinical outcomes.³ A syndemic approach to the treatment of obesity, diabetes, and CVD may help to frame potential solutions to improve population-level cardiometabolic health.⁴

The current clinical care model on which we have relied to reduce CVD mortality, in which patients are required to access treatment and preventive care in the clinical setting, will not be sufficient to stem the tide of worsening and interrelated cardiometabolic diseases. Our current care model does not work in a syndemic given that it depends on solutions that have not been designed to account for structural barriers to health care access

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Disclosures
None.

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for marginalized populations.^{3,4} Moreover, health care organizations do not traditionally adapt their clinical care models based on feedback from those who are most invested in improving population-level cardiometabolic health: individuals from communities that are most vulnerable to cardiometabolic diseases. Emerging patient care frameworks have started to incorporate SDH into clinical care to address patients' social needs by targeting upstream barriers to cardiometabolic health, such as structural racism that produces differential housing access or health literacy.¹ Professional organizations are developing guidance on creating standardized SDH metrics that can be included in electronic health records, providing targeted resources to patients with high levels of social need, and developing care practices that account for SDH. However, community engagement approaches provide a voice for populations most affected by CVD and can involve a variety of methods that span from work with community health advocacy groups, community–academic partnerships, or full community-based participatory research. Community engagement can be used more extensively to codevelop clinical interventions or patient care models on the basis of iterative community input.¹ Community engagement can garner trust among populations that have been historically mistreated in the health care system and fits within a syndemic approach for improving population-level cardiometabolic health.

The cardiovascular research community must also consider the syndemic of cardiometabolic diseases as an impetus to identify sustainable solutions for the limited representation of diverse populations in clinical research. Asian, Latinx, non-Hispanic Black, Native American/Alaska Native, and Native Hawaiian/Pacific Islander populations, as well as women and sexual and gender minority populations of all racial/ethnic groups, are underrepresented in cardiovascular clinical trials, particularly compared with the burden of cardiometabolic disease in these communities.⁵ This underrepresentation exists despite recruitment requirements in federal funding for biomedical research; limited representation fundamentally limits the generalizability and effects of research findings in at-risk populations. The same structural barriers to adequate health care and longstanding mistrust of the medical community that lead to CVD disparities also contribute to inequities in referral for clinical trial participation and subsequent underrepresentation of minoritized populations in cardiovascular research studies.

To address limited representation in clinical trials from a syndemic perspective, we must center community engagement as a critical part of recruitment strategies from the inception of a study. A recent systematic review of National Institutes of Health–funded CVD clinical trials that started between 2000 and 2019 demonstrated that 21% of trials described specific recruitment strategies for reaching under-represented populations, 13% described using community-based recruitment strategies, and only 5% of trials described engaging with community members in study design efforts.⁵ Explicitly defined targets for patient recruitment representative of the disease burden, which can be specified in CVD research study protocols, were associated with greater recruitment of non-Hispanic Black participants.⁵ Community engagement in CVD clinical trial design and implementation can become more common if funding agencies incentivize community-engaged research methods by providing the necessary training to clinical investigators who have not previously done this work. A syndemic approach to training about the full spectrum of community engagement methods that can be used in clinical trial design would highlight the

structural and social factors that create complexity within communities and would provide a historical and current-day perspective for the trauma experienced in underresourced and marginalized communities, particularly during the COVID-19 pandemic and current social justice movement.³ Training would help investigators build interdisciplinary research teams that reflect the diversity of a community and develop the cultural humility to gain the trust of those from underrepresented populations. Ultimately, training built on a syndemic framework would emphasize the multidimensionality and inherent assets of communities that can be leveraged through partnerships to build interventions targeting CVD that are sustainable beyond trial implementation (Figure).³

Intentional steps are needed to support the current generation of community-engaged investigators in cardiovascular research, many of whom have worked with communities throughout the COVID-19 pandemic.³ Many in this current generation of community-engaged researchers are members of the minoritized groups with whom they work. They not only have been personally affected by their own experiences during the pandemic, but they also have internalized the devastation from lives lost and financial stress experienced in the communities with whom they partner.³ If the current cohort of community-engaged investigators is to help bring forward new generations embarking on community-engaged cardiovascular research, they must be provided with adequate research funding and resources to share their knowledge and lessons learned as they recover from the COVID-19 pandemic. The syndemic of cardiometabolic diseases requires an approach that centers community engagement in both the health care setting and in cardiovascular clinical research to identify accessible, affordable, and sustainable interventions to improve population-level cardiometabolic health.

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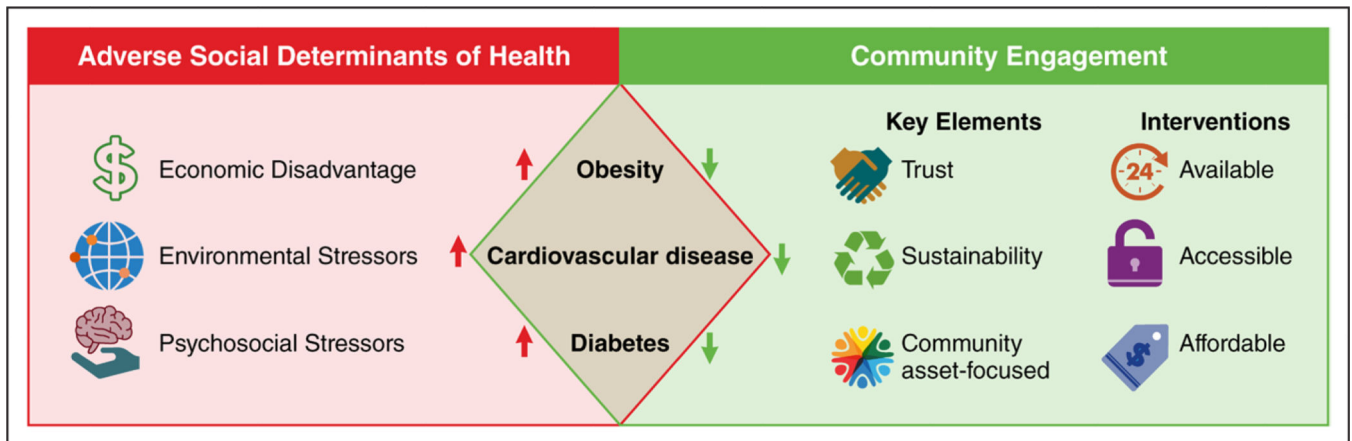


Figure. Obesity, diabetes, and cardiovascular disease are interconnected parts of a syndemic, acting synergistically to affect population-level cardiometabolic health.

This syndemic is influenced directly by social determinants of health. Using community engagement to develop interventions in both the health care setting and in cardiovascular disease clinical research can reduce the burden of obesity, diabetes, and cardiovascular disease across diverse populations.