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PERSPECTIVE

Technology, community, and equity: Considerations for collecting social determinants data

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Despite declining mortality rates of cardiovascular disease (CVD) and stroke in recent decades, these rates of decline differ considerably across racial/ethnic groups and by geography (eg, urban vs rural areas).[1] Rates of CVD deaths are highest in the southeastern United States, especially among those residing in rural areas, and these disparities are further exacerbated by social determinants of health (SDOH), including neighborhood-level stressors such as reduced access to affordable health care and lower-quality housing, which further increase the CVD risk among rural Americans.

Established cardiovascular cohort studies such as the Multi-Ethnic Study of Atherosclerosis (MESA) have demonstrated associations between neighborhood environments and CVD risk,[2] emphasizing the importance of addressing SDOH as important intervention opportunities to reduce the burden of CVD.[3,4] To that end, the Risks Underlying Rural Areas Longitudinal (RURAL) Heart and Lung Study, a collaboration between the National Heart, Lung, and Blood Institute and 16 academic institutions throughout the United States, was designed to investigate the SDOH linked to the disproportionate burden of heart, lung, blood, and sleep (HLBS) disorders in rural southern communities.

This longitudinal cohort study selects participants from 10 rural counties in Alabama, Kentucky, Louisiana, and Mississippi with varying prevalence of common CVD risk factors, thereby capturing a diverse sample of rural communities to gain a broad understanding of the underlying risk and resilience factors integral to CVD pathogenesis.

Potential participants are mailed invitation letters briefly describing the study and are screened for eligibility via a telehealth call. Inclusion criteria include being between 25 and 64 years old and current residence in a county of recruitment for the past 2 years and next 2 years. Upon enrollment, each participant is mailed a Fitbit wearable activity tracker and an accompanying smartphone, if needed, for phase 1 of RURAL, the mobile health (mHealth) component of the study. The primary aim of the mHealth-focused portion is to understand the disparities of chronic HLBS disorders in the rural southeastern United States by employing mHealth solutions to provide more accessible methods for collecting activity metrics and general health information.

Once participants receive their devices, they are assisted with device registration and general use via a call from research staff. Participants are asked to wear their Fitbit devices for 6 months and to complete periodic questionnaires about their general health status as well as a myriad of SDOH on their smartphone via MyDataHelps (CareEvolution, Inc, Ann Arbor, MI), a health care app used by the study for survey deployment. Figure 1 shows the list of mHealth questionnaires deployed to participants. Data collected from these questionnaires relate to features of neighborhood physical and social environments that have been found to be associated with increased risk of developing CVD and a worse prognosis.[5] Over the course of the study, research staff provide participants with technical assistance, if needed, and booster calls to encourage study engagement in participants with low device interaction.

Figure 2 illustrates the utilization of mHealth technology for collecting and processing data regarding SDOH and other key health metrics. Survey responses and Fitbit data (steps, sleep logs, heart rate, etc) are periodically synced to CareEvolution's secure data cloud and exported to the Study Data Coordinating Center's data repository for future analysis of significant SDOH patterns. These data are also presented in automated daily reports for the mHealth team to monitor adherence.

Upon conclusion of the mHealth phase, participants undergo a comprehensive physical health examination on a mobile examination unit, providing valuable physical health data to augment the self-reported health information and actigraphy results, allowing for a more holistic understanding of the participants' health and any potential associations with measured SDOH.

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KEY FINDINGS

- Gathering detailed information on an individual's neighborhood environment is becoming increasingly recognized as a crucial component of understanding the impact that social determinants have on individual and public health.

- Digital tools, such as wearable activity trackers and smartphones, can reduce accessibility barriers for research participants in rural and underserved populations to allow for effective data collection.

- When using digital interventions, researchers should develop strategies (eg, consistent outreach via e-mail or phone calls and fair compensation) to encourage study engagement and enthusiasm among participants in order to overcome potential participation hesitancy and the significant time burden possibly conferred by participation.

social determinants have on individual and public health, and this has been further highlighted by the ongoing COVID-19 pandemic. Emerging research clearly demonstrates COVID-19's differential impact on underserved and rural communities, and it is imperative to adequately capture important neighborhood-level predictors of health outcomes to better understand the extent to which these communities have been affected, and to equitably promote their recovery and healing. mHealth tools have drastically transformed the framework of data collection within clinical and population health research and can significantly reduce accessibility barriers for research participants to allow for convenient, continuous real-time health and activity space assessments. Digital interventions leveraging remote data collection, and providing study participants with requisite devices when necessary, serves to bridge the digital divide that would otherwise preclude rural populations' participation in key research opportunities for advancing health equity.

Additionally, multiple modes of data collection (telephone calls, smartphone applications, wearable sensors, etc) can further increase the accessibility for this population.

For participants who are unfamiliar with technology, research study staff can enlist the help of more technologically adept relatives or use screen-sharing capabilities of online meeting modalities (eg, Zoom) during mHealth calls to ensure successful device use and data acquisition. Lastly, and perhaps most importantly, researchers must develop strategies (eg, consistent outreach via e-mail or phone calls and fair compensation) to encourage study engagement and enthusiasm among participants to overcome potential participation hesitancy and the significant time burden possibly conferred by participation.

While in-person engagement remains crucial for academic researchers to build trust with vulnerable communities, mobile and digital health tools additionally serve as a promising modality for outreach. The RURAL Heart and Lung Study seeks to demonstrate that an mHealth protocol, supplemented with in-person outreach and community engagement, can result in successful rapid, real-time SDOH data collection in under-resourced communities, improving our current knowledge and understandings of the prevalent HLBS disorders.

Authorship
All authors attest they meet the current ICMJE criteria for authorship.

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Given his role as Editor-in-Chief, Dr David McManus had no involvement in the peer review of this article and has no

Figure 1   Questionnaires administered to RURAL study participants during the mHealth phase.
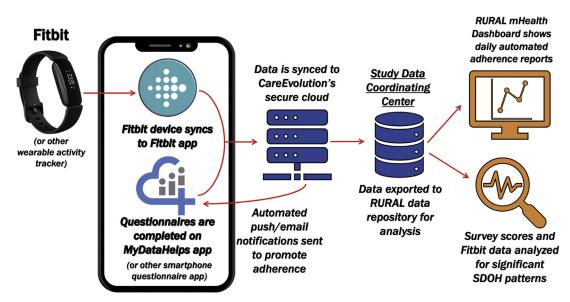
Figure 2   Collection of social determinants of health (SDOH) and other key health metrics using mHealth technology.

access to information regarding its peer review. Full responsibility for the editorial process for this article was delegated to Isabelle Breakwell.

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