Evaluation of Wellness Determinants and Interventions by Citizen Scientists

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Most medical research focuses on disease rather than health. Yet people are interested predominantly in health and wellness. Wellness refers to diverse and interconnected dimensions of physical, mental, and social well-being that extend beyond the traditional definition of health. It includes choices and activities aimed at achieving physical vitality, mental acuity, social satisfaction, a sense of accomplishment, and personal fulfillment. Equally healthy people may differ vastly in terms of their wellness, eg, whether their life is filled with creativity, altruism, friendship, and physical and intellectual achievement. Disease is incompatible with health, but not with wellness. For example, a dying patient who has led a rewarding life and is surrounded by a loving family and friends may still enjoy high wellness.

Little is known about what affects wellness, as opposed to what causes disease. Lifestyle choices and behaviors (eg, physical activity, meditation, nutrition), technology, social participation and engagement, genetics, work, school, neighborhood, and other environmental exposures may shape wellness. Most medical research evaluates the effectiveness of drugs, rather than nondrug interventions, even for indications for which nondrug alternatives such as exercise may be excellent choices. This creates a vacuum of evidence, which is subsequently filled by nonscientific claims of a wellness market that is not driven by rigorous science. For example, popular talk shows and celebrities create proselytes of diets and treatments that promise miraculous outcomes despite the lack of credible scientific support.

The current body of scientific evidence on lifestyle choices and other interventions that may affect wellness also has significant limitations. Many interventions are complex and nonstandard, and research evaluating their effectiveness consists of small and underpowered studies, with heterogeneous and inconclusive findings. Study registration is uncommon, and reporting of intervention and population characteristics remains inadequate.

There is a clear need for rigorous research evaluating wellness and wellness-enhancing interventions. The choice of study design has significant implications for the validity and relevance of this research. Theoretically, the best way to establish whether an intervention is effective is to perform a randomized trial. Randomized trials are generally operationally complex and expensive and often take a long time to recruit participants and complete. However, randomized trials can become simpler, cost less, and have external validity similar to that of observational large population studies. Such trials should be the default option for evaluating wellness interventions.

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Indeed, it is possible to leverage the strengths of both randomized and nonrandomized population studies, while minimizing their oft-cited limitations, in so-called hybrid designs.7 The general premise of hybrid designs is embedding randomized trials in large observational cohorts and biobanks, which collect longitudinal information on a target population. Hybrid designs could allow performing intervention research on large numbers of real-world participants at low cost with long follow-up.

Population cohorts and biobanks could simultaneously provide a real-world view of lifestyle behaviors, exposures, and outcomes. Investment in collecting standardized data for large sample sizes recruited from the general population with long-term follow-up has gained momentum over time. For example, the Ontario Health Study in Canada is a population cohort of more than 225,000 participants with data collection efforts focusing on key risk factors for chronic diseases. In a joint biobank, biological and genetic data are also collected for a subsample of the population.

Ensuring efficiency with such hybrid designs is particularly important when evaluating wellness-enhancing interventions owing to the large sample sizes required to detect modest effect sizes. When conducting simple trials, large observational studies can serve as an efficient platform for both participant recruitment and data collection.8 Such studies may also link additional data sets, whenever these are available on the enrolled participants. These could include administrative claims, electronic health records, personal genomic tests, or smartphone-collected data, among others. In recent years, routine monitoring of wellness-related behaviors has become increasingly common thanks in part to wearable tracking technologies and mobile applications. According to PWC Health Research Institute, in the United States an estimated 1 in 5 individuals owns tracking devices and uses health applications on their smartphones.9 Such inexpensive devices and applications already allow for monitoring vital signs and even diagnosing conditions. By offering data collection capabilities to motivated people with access to a smartphone, such technological advances could transform the conduct of nondrug intervention studies.

The time is ripe for engaging people in deciding how to study their own wellness. With health consciousness at an all-time high, motivated people with a genuine interest in health and wellness represent an unfulfilled potential in research. Often called “citizen scientists,” networks of nonscientists could help identify scientific questions and conduct studies. Wellness research could effectively accommodate the involvement of citizen scientists, and social networks can be used to funnel the quests, worries, and interests of people about their wellness.

There is already significant interest in such participatory research, as evidenced by the widespread media coverage of health-related behaviors. Over the past 2 years, studies evaluating dietary habits (eg, consumption of milk, coffee, nuts, and the Mediterranean diet), physical activity, and other lifestyle behaviors such as sleep patterns have received substantial attention online. This interest could be leveraged to facilitate both the efficient recruitment of participants and their higher adherence to lifestyle and other wellness-related interventions. Adherence could be further enhanced by encouraging participants to propose questions and interventions that they want to see studied. They can then choose from interventions to which they want to be randomized and tailor their own personal trial experience by customizing intervention options that can form part of their everyday lives.

Several additional challenges remain for wellness research. As opposed to disease outcomes that require long-term follow-up and linkage to reliable outcome registries, wellness outcomes are meaningful to assess in both the short-term and long-term. Nevertheless, their validity and accuracy still need careful verification. Moreover, ensuring representativeness in lifestyle intervention research may prove challenging, given that citizen scientists participating in population cohorts and agreeing to be randomized to various interventions may be different from those not participating in cohorts or those who do not consent to be randomized. A special effort may be necessary to recruit and retain in such studies underserved and disadvantaged minorities. Wellness research should aim to reduce rather than entrench disparities.

For too long, the research enterprise has not adequately reflected the preferences and values of people, widening the gap between the interests of researchers and study participants. Encouraging motivated people participating in high-quality cohorts to contribute to the design and conduct of simple trials could align the interests of investigators and citizen scientists interested in wellness.

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**ARTICLE INFORMATION**

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**REFERENCES**


