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Ethical Community Engagement: Lessons Learned

Experiences from participatory research provide guidance for healthcare leaders.

ACHE's *Code of Ethics* devotes a full section to "The Healthcare Executive's Responsibilities to Community and Society." The first of these duties, outlined in Section V of the code, is the mandate to "work to identify and meet the healthcare needs of the community." While it is clearly ethical to meet these needs, a healthcare executive may wonder: What is the most ethical way to identify the community's needs?

It is no longer considered appropriate to speak of patient "compliance" in the care process. Rather, the term "adherence" is preferred.

In answering this question, it is useful to look at the evolution of research ethics with respect to the community. The National Center for Bioethics in Research and Health Care at Tuskegee University has identified trust as the key issue that stands between researchers and the people of a community, according to the center's "Ethics Across Generations" course, held in April 2018. This is no less true for

executives, although their goal of research for the sake of effective program development is different from the pursuit of scientific discovery.

In light of the renewed emphasis in the field on eliminating health disparities, executives and researchers alike have devoted increased resources to addressing these concerns. Writing in an Oct. 10, 2019, issue of *The New York Times*, Peter Goodman profiles the Healthcare Anchor Network of 45 health systems, which seeks to invest in local communities to achieve improved health of community residents.

The article illustrates how Kaiser Permanente sought community input for a new medical campus in the Los Angeles neighborhoods of Crenshaw and Baldwin Village. The need for a medical campus was clear given that for many of the area's residents, the nearest hospital was a 25-minute drive away. Yet, when asked what the community desired, its members responded "jobs"—an answer that might address health disparities through provision of steady incomes, but certainly goes beyond the usual scope of medical services. Kaiser Permanente addressed this community desire in part by devoting a portion of construction funds to

female- and minority-owned businesses and workers. This is one example of how healthcare organizations can seek community input and then reasonably respond to that input to build trust and meet needs.

Ethical Engagement: Hard, but Necessary Work

As much as health systems have evolved to adopt new approaches to community partnerships, researchers have confronted similar obstacles in ensuring the community's needs are being considered. In his book *Ethics in Health Services Management*, Kurt Darr of The George Washington University writes that the "respect for persons principle" mandates health administrators are obligated to protect and preserve individual autonomy (self-determination) and the trust of those affected by managerial decisions.

The world of research has not always been as progressive in its view of the community's role in research efforts. Community members in research studies have traditionally been referred to as "subjects." The term implies that the investigator conducting the study is accorded greater power in a relationship through her or his professional expertise. One of the most egregious historical examples of how this power has been exploited—with devastating results—is the infamous Tuskegee syphilis study, which ran from 1932 to 1972 with funding provided by the Centers for Disease Control and Prevention. The aim of the study was to assess the effects of untreated syphilis infecting adult males. The subjects of the study, African-American men, were not

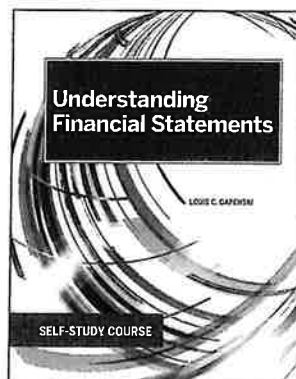
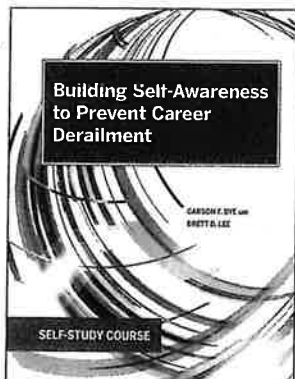
informed of the existence of therapies, and were actually told that they were receiving treatment. Public outcry in 1972 led to congressional hearings and, ultimately, a formal apology in 1997 by then President Bill Clinton. The eventual result was the requirement throughout the healthcare industry for

informed consent in both patient care and research.

In patient care settings, providers and executives now speak of the patient's essential role as being a "partner" in her or his healthcare. The language in the field has evolved to reflect this changed thinking. For example, it is

no longer considered appropriate to speak of patient "compliance" in the care process. Rather, the term "adherence" is preferred, as this reflects patients' autonomy and the necessity of their willing cooperation in maintaining their health. While compliance is passive on the part of the patient, adherence means willing partnership with the healthcare team and greater outcomes and benefit to the patient as a result.

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The WK Kellogg Foundation Community Health Scholars Program defines community-based participatory research as "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings." Terence Gipson from the University of Oklahoma Hudson College of Public Health refers to community-based participatory research as the "gold standard" of participatory research. He argues that community participation should address disparities in opportunities, conditions and outcomes across disadvantaged communities that are directly reflected in poor health status. Unlike traditional research that is investigator initiated, community-based participatory research begins with a topic of importance to the community and combines knowledge with action. Ultimately, it aims to achieve social change to improve health outcomes and eliminate health disparities. At that point, the interests of the community, the researcher and the health executive are in accord—an ideal situation.

What Does the Community Want From Research?

Benjamin Springgate, MD, and his research team at Louisiana State

University and the University of California, Los Angeles, have concluded that community research participants want several key items from their participation that historically have not been part of traditional investigator-driven research. One item is inclusion in research topic selection and project design.

In working with a community group in Los Angeles, the researchers noted an expressed desire by community members for improved information about the mentally ill that might in turn lead to creation of services for these persons and preventive services for the community. Involvement of community members to monitor progress throughout the study was deemed

essential. At the study's conclusion, a reporting of the results to participants was most essential to confirm respect for the contribution of study participants.

Lessons for the Healthcare Executive

In her "Perspectives" column in the March/April 2019 issue of *Healthcare Executive*, ACHE President/CEO Deborah J. Bowen, FACHE, CAE, notes the importance of the guidance of ACHE's *Code of Ethics*, especially in "transformational times," stating that our concept of stakeholders has expanded to "the wider community and even society." A similar broadening of vision is underway in the research community.

Above all, the "respect for persons" ethical principle demands that trust be established and sustained between researcher, practitioner and community. This requires a good faith demonstration of community involvement in the design and development of a research project from formulation through completion. Finally, no study or project is final until results are shared with the community in recognition of its invaluable participation. Transparency is key. ▲


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