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MODULE 4

Community-Based Practice and Research: Collaboration and Sharing Power

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Contemporary public health is dedicated to a community orientation and the premise that community-based activities are essential to sound practice and research. The central importance of community as a public health value is clearly reflected in the 2001 Public Health Code of Ethics and its accompanying statements. Five of the Code's twelve principles and six of its eleven key assumptions address the nature of community, the interdependence of individuals and groups, the links between communities and the environment, and the role of communities in public discourse and collaboration with public health organizations.¹ Defining public health as "what we, as a society, do collectively to assure the conditions for people to be healthy,"¹ the authors of the Code declare that effective public health practice and research depend on informed community trust and participation.

The practical ethical issues in community-based practice and research are as wide-ranging as community life itself. Many important ethical questions depend upon the meaning of community, but the word typically has no clear, consistent usage in public health, either as a social concept or as an ethical value. Moreover, identifying the key characteristics and rightful members of any particular community may raise ethical and political questions even before one considers the community's appropriate roles in assessment and priority setting, research, intervention, or public health policy.

This essay begins with an examination of some common definitions of community, community participation, and community representation, and considers the ethical presuppositions that lie behind the ways the terms are often used in public health. It then reviews how surveillance activities that focus on a given community may identify important public health problems and disparities within the larger population, and discusses the vital role of community members' own views and health concerns in assessment and priority setting. Next the essay reviews the tensions inherent in community-based practice by considering the ideals and experience of community-oriented primary care. Finally, it will address the increased emphasis on community participation in research and the challenge of applying research findings to interventions and ongoing practice in the participant communities.

Defining Community and Communities

The term *community* comes from the Latin root for "common" or "shared". The most general meaning of community is a group of people united by their common features. However, there is no agreement on precisely which common features create community, and the key features of even an established community may seem to vary when viewed by group members as opposed to outsiders.²

The theoretical public health literature on community is generally based in sociology. Early sociological efforts to describe communities focused on the importance of shared values and shared experience. Sociologists typically define a community in terms of group norms, personal relationships, and members' clear roles and expectations of each other. Health promotion researchers have identified six such aspects of community:³

- membership (a sense of belonging and clarity of roles)
- common symbol systems (language, religious rituals, national symbols)
- shared values and norms (from shared experience or handed-down belief)
- mutual influence of its members (based in communication)
- shared emotional bonds (a sense of personal connectedness)
- shared needs and a shared commitment to meeting them (a sense of "us" that transcends personal interests).

This set of characteristics also has parallels in the concept of the religious community of faith, which is characterized by fellowship, shared values, spiritual and emotional bonds, and mutual support. Many social scientists and ethicists maintain that human beings naturally seek community and are eager to experience the meaning and personal fulfillment that true community offers.

The use of the term community in public health practice often differs dramatically from the somewhat romanticized sociological notion seen in theoretical literature. Often the term is used to refer to a group of people from the same geographic location or catchment area (e.g., the westside community). It may also refer to a group with a common racial or ethnic background, socioeconomic status, religion, profession, health condition, or who share some other important experience (e.g., the African-American community, the indigent community, the Greek Orthodox community, the medical community, the HIV/AIDS community, or the women veterans' community). Public health agencies and practitioners typically use the word to refer to individuals and groups linked by one or more characteristics that, however vaguely defined, give them recognizable common needs and interests of concern to public health.

Often the intent of identifying a group as a community determines what features will be emphasized and who will be counted as a community member. Although self-defined communities figure prominently in the work of many public health agencies and professionals, many so-called communities are more rightly just "target populations", constructs defined by the goals of a particular public health project or mandate (e.g., sexually active teenagers; households within 3 miles of a toxic waste site; the mentally ill homeless) rather than any natural social grouping. The description of a community targeted for public health practice or research may also be based on allegedly objective and readily measurable classifications, such as socioeconomic or demographic profiles, specific health conditions, or risk factors for disease. But because even these characteristics can be too complex to measure or verify, many projects define their communities of interest in terms of surrogate measures (i.e., income below 200% of poverty level, families of children enrolled in the local school district) or by arbitrary geopolitical boundaries (zip code, county, tri-state area) established by governments' or funders' priorities rather than characteristics that members of the resulting cohort would recognize as important to their identity.

Even within a "true" sociological community, professionals' views of the important relationships and commonalities among individuals and groups may be quite different from the views of the individuals

and groups themselves. Insiders typically see important distinctions between themselves and others who public health professionals might link as a community. For example, similarities of linguistic and ethnic heritage may link Hispanics of many national backgrounds, but their differing political and economic interests and cultural differences can significantly affect the cohesion of the “Hispanic community” as viewed from the inside. Similarly, the “public health community” of practitioners, researchers, and academics may appear splintered to insiders who emphasize such differences as discipline, professional training, and area of work. A true community can be quite diverse, because people of vastly different backgrounds can often create and maintain a sense of community when they have a common cause or a common adversary against which to define themselves and their goals. However, as common goals are met or the perceived benefits of solidarity fade, such a community may become divided or even dissolve. Because of the many forces that can affect a group’s cohesiveness, community should be seen as a dynamic phenomenon in which change is both natural and expected.

Many people may consider themselves members of more than one community, or may fall under definitions of membership in several communities of interest to public health. Beginning with membership in a household, individuals are often formal or informal members of self-identified communities based in professional activities and the workplace, religious or spiritual beliefs and practice, sexual orientation, political affiliations, civic and charitable service, athletic activities, academic institutions or experience, social organizations or hobbies. Many individuals’ community affiliations overlap and serve parallel interests. However, different communities’ values and their expectations of members may also conflict, challenging individuals with multiple loyalties to choose sides or live with unresolvable ethical tension. Conflicting loyalties can be a risk for public health professionals when the goals and methods of public health practice challenge the traditions or beliefs of their religious, ethnic, or other value-oriented community. However, public health professionals who can successfully reconcile these tensions in their own lives can be quite valuable as interpreters and change agents who can negotiate the conflicts and facilitate understanding where others cannot work effectively.

Some uses of the term community in public health contexts are themselves ethically problematic. “The community” is often used as shorthand to refer to outsiders to public health — “them” in relation to public health professionals’ “us”. This phrase can serve as a useful reminder that public health activities always take place in a community context and that professionals must always be aware of the community’s response. However, it can also imply an adversarial or hierarchical relationship between public health professionals and the people they serve, a perspective that conflicts with the stated goal of collaborative, participatory public health. At times, it can also carry negative implications of the community’s ignorance, misunderstanding, and apathy as opposed to the professionals’ skills and knowledge and dedication to society’s welfare.⁴

An even more ethically dangerous phenomenon is that public health practitioners and researchers may consciously or unconsciously use the concept of community as a marketing strategy to promote activities, perceptions, and goals to a target population. Referring to a cohort as a community can create the impression of underlying community values, norms, and expectations that hide “a giant reinforcement schedule.”⁵ Use of the term community and its accompanying sense of mutual values and responsibility to encourage behavior change or acceptance of certain health values has been criticized as being cynically manipulative when it substitutes marketing and implied peer pressure for real moral and psychological support.⁵

Community as a Public Health Value: Communitarianism and Public Health Ethics

The meaning of community as a central value in public health is at least as complex as its definition in practice. The preamble to the Public Health Code of Ethics states that one of the key principles “that follow from the distinctive characteristics of public health ...is the interdependence of people ... (which) is the essence of community.”¹ Community is an essential value for public health because “the health of individuals is tied to their life in the community.”¹ In this light, public health theorists and practitioners typically interpret the good of the community and the good of the individual as interdependent.

Unfortunately, public health’s community orientation is often misunderstood by ethicists trained in the principle-based frameworks of bioethics, which presume a certain natural conflict between the needs, interests, and goals of individuals and those of society at large. In mainstream bioethics, the principle of respect for autonomy requires that health professionals recognize and honor the right of individual patients to be self-determining, unless respecting one individual’s rights would violate the rights of another. Many bioethicists likewise emphasize the need for health practitioners and policy makers to avoid unduly restricting the rights of individuals in the just distribution of health-related benefits and burdens across society. In this context, critics of policies that seek community-oriented goals mistakenly label public health as “utilitarian”, in reference to the ethical framework that promotes the goal of the “greatest good for the greatest number” with less concern for individual rights than for social benefit.

While public health is not officially linked to any specific ethical theory or school of thought, its community orientation has many parallels to the philosophy of communitarianism. Communitarianism developed in the 1980s in response to a perceived overemphasis on individual rights.⁶ Like public health, communitarian theory maintains that individuals are ultimately inseparable from community life, and that no one person and no one community can ever be completely self-determining. In contrast to more familiar ethical frameworks’ presumption of a natural antagonism between individuals and society—and particularly the state—communitarianism recognizes that human beings need *both* autonomy and social relationships. Communitarians insist that while individuals make their own moral choices, their moral commitments and values are shaped by community norms and experiences.

Traditional bioethics often interprets public health’s concern for community to be anti-individual, and its models for public health reflect a tension between individuals and society in which benefit is often a zero-sum game. For example, seatbelt legislation is often identified as a case in which the state enforces a paternalistic limitation of individual rights (to drive unrestrained) in pursuit of a greater social good (fewer collision-related injuries and lower related costs to society). In contrast, a communitarian approach to this issue focuses not only on the individual’s direct benefit from using seat belts, but also on the benefit that the individual enjoys as a member of a community that reduces driving-related injuries and deaths.⁷ Communitarian models of ethical analysis are still relatively new, but a communitarian perspective on human dignity, social relationships, and community values can also suggest new approaches and strategies for resolving ethical controversy in public health practice and research.

Community Participation and Representation

Ethical community-based practice and research depend not only upon a clear understanding of community and identification of the community’s interests but also on the way in which community participation and representation are understood. Community participation in public health appears both

as a grass-roots phenomenon linked to political activism and as a practical organizational effort to involve individuals and communities in promoting and protecting their own health. Just as there is no standard definition of community, the meaning of *participation* is ambiguous in many contexts where the term is often used. Community participation is commonly understood as the involvement of the community in the planning, organization, operation, administration, financing, and control of a project or enterprise. However, the goal of grass-roots community participation is not simply involvement, but rather the redistribution of power that deliberately includes traditional “have-nots” in the sharing of information, setting of priorities and policies, allocation of resources, and distribution of benefits and services.⁵

An early governmental step toward the promotion of community participation in public health programs came in the Economic Opportunity Act of 1964, which provided federal grants to state and local public and private non-profit agencies for community action projects, and which required “maximum feasible participation” by community members. Subsequent efforts to evaluate the effects of community participation in funded projects were frustrated by the wide variability in the definition, format, and implementation of relevant programs nationwide, and proponents of mandatory communication in federally funded activities were largely unable to respond when government requirements were cut back or eliminated. Moreover, the early efforts at engaging community participation in governmentally funded public health activities were criticized by grass-roots activists as mere tokenism that did not get the public very far up the “ladder of citizen participation,”⁸ and which permitted “maximum feasible manipulation” of lay people rather than promoting partnership or citizen control.⁹

The concept of partnership or shared governance has been increasingly important in the literature on community participation over the past decade. The fundamental ethical challenge of authentic partnership and true sharing of authority with community groups lies in overcoming the significant disparity in power between community members and public health professionals, who have specialized knowledge, technical skills, and institutional or governmental support. Establishing a partnership requires mutual trust, which is built only over time and after visible results have been achieved. Sustaining a partnership in which collaborators have significantly different degrees of access to power typically requires ongoing financial, political, and community support, reinforced by demonstrated positive outcomes from the collaborative project. Important characteristics of authentic collaboration include the six “R’s” of participation: recognition, respect, role, relationship, reward, and results.¹⁰ Without these components, the community is likely to discount the professionals’ sincerity and disengage from the project.

Because many communities of greatest interest to public health are precisely those whose members have limited technical skills, knowledge and access to power, promoting community participation in public health activities has necessarily involved professional efforts to empower individuals and the community at large. Empowerment relates to a person’s ability to affect his or her own situation. Individual, organizational, and community empowerment are interrelated in the development of social support and interpersonal, social, and political skills. Increasingly public health efforts to empower communities are also dedicated to capacity building, which typically involves the education, development, and support of community members who will then have the specialized knowledge, skills, and abilities to carry out the roles previously played by public health practitioners from outside the community. Capacity building creates a cadre of individuals who both understand the needs and values of the community as only members can and understand the theories and methods of public health that can help meet those community needs appropriately. The ethical advantage of capacity building is also

an important practical strength, as community members are ultimately able to work effectively toward their own goals without the potentially overpowering presence of public health professionals.

The effectiveness and ethical quality of community participation in any public health activity are also dependent upon the authenticity of the individuals and groups representing the community of interest. In theory, community representatives are able to provide insight into the norms, values, experiences, questions, objections, and appreciation of the community they represent, expanding, correcting, and ideally validating the approach taken by public health professionals in practice and research. Community representatives ideally serve as a bridge between their respective communities and the public health professionals with whom they work, representing the community to the professionals and the professionals back to their communities. However, in the same way that public health professionals often define communities based largely on the reason for engaging specific groups, professionals often identify community representatives in light of the purposes they are expected to serve. Even sincere efforts to include community representation in public health activities may result in tokenism if the primary purpose of inclusion is simply to satisfy external requirements for community participation or to secure the approval of proposed projects.

Engaging community representatives in a public health project is subject to logistical and ethical problems similar to those described in defining a community. Public health professionals who seek input from “average” members of the communities they serve may not be able to recognize the significant differences among members of even a small community, especially if that group is unfamiliar to or quite different from the professionals themselves. In an effort to identify “authentic” community members, public health professionals often look for individuals who are recognized as leaders or spokespersons for their group. However even identifying these individuals requires both an understanding of how the community perceives its own essential characteristics and recognizes who speaks for the community in its interaction with others. It also requires understanding of the group’s organizational and power structures. In more than a few situations, the official leaders of a given community have only titular or symbolic positions while others hold the true power or command the real respect of its members.

Similarly, an individual’s authority in one area of community affairs may not translate into authority in another, and an acknowledged community leader from an unrelated area may not provide the desired access to the group’s needs and views related to public health. Even powerful community leaders may be intimidated by health professionals whose work they may not fully understand and whose language and approach are unfamiliar. In order to maximize the effective participation of community representatives, it is essential for them to receive careful orientation to the project and to get to know its organizers. Ongoing education about the work in which they will be involved and its larger context can further empower community representatives, particularly when it is coupled with an active role for the community in defining its own needs and strengths, a process discussed below. Nonetheless, public health professionals should avoid the temptation to pick the most visible community members for multiple projects, as the repeated participation of a select few may not only exacerbate existing power differentials within a community, it may also create career community participants who are increasingly estranged from and resented by the group they are intended to represent.

The potential barriers to the effective involvement of community representatives often make it appealing to find health professionals from specific backgrounds to interpret the needs of targeted communities. In many ways this practice can provide a natural bridge between the professionals and the groups they

hope to serve. However, depending on the individual's background and the nature of the project, the socialization of professional training and work experience may distance professional members of a targeted community from the group's mainstream perspectives and even more so from its most vulnerable members. The difficulty of striking a balance in this regard argues for all but the smallest projects to include multiple representatives of any targeted community, in order to include a broader and ideally more representative spectrum of its voices. It also emphasizes the need for professionals to become more educated about the communities they serve in order to recognize important community characteristics and more easily overcome the barriers to community participation.

Since the end of the 1990s, two initiatives intended to improve the access of an increasingly multi-ethnic population to effective health services have also shown promise for increasing community participation in public health activities. The first is cultural competence education for professionals. Standards of cultural competence and related professional education are intended to improve public health professionals' recognition and understanding of the role of culture in health-related activities and the history, beliefs, values, and practices of members of the communities they serve. Concern for cultural competence was originally directed toward ethnic, religious, and linguistic differences in direct patient care, but increasingly the concept is being extended into social and political action and the organizational development of services and programs that accommodate communities' cultural differences.¹¹

The second initiative is based in new federal standards for language assistance for people who use governmentally funded health-related services. These standards are aimed at institutions and agencies that provide health services, directing them to provide various forms of language assistance to individuals whose limited proficiency in English may be a barrier to their effective care.¹² The standards also apply in other settings where limited English proficiency affects some groups' access to health-related services. By facilitating communication and improved mutual understanding, language assistance and cultural competency programs should foster public health professionals' engagement of the diverse communities they serve and improve their ability to recognize changing community needs. Language assistance programs, in particular, should also expand many community groups' awareness and understanding of public health activities and ability to participate in them more fully.

Community Surveillance, Assessment, and Priority Setting

Characterizing the health of the population through epidemiologic surveillance and identifying its health needs through formal assessment are essential public health activities that depend heavily on health professionals' presuppositions about distinctions and similarities among communities. Basic health statistics can be significantly affected by whether and how the larger population is analyzed by subgroups. Interpreting the meaning of such statistics, and identifying appropriate public health responses to them can also be affected by whether the members of the subgroups share community values or experiences. For example, the high low birth weight and infant mortality rates for the United States as a whole are often regarded as an embarrassing puzzle in light of national expenditures on prenatal and perinatal medical care. When national rates are evaluated by racial/ethnic group, socioeconomic status (SES), and age, the problem can be seen to affect young African-Americans of lower SES most severely, but the rates for all groups of African-American women are disproportionately higher than for their counterparts' from other racial/ethnic groups. In seeking to understand this disturbing phenomenon, public health researchers and women's health advocates have recently emphasized such potential causes as the experience of institutionalized racism and its associated stress

over possible biological or medical factors. Defining and measuring the experience of institutionalized racism and associated stress requires not only the observational and analytic skills of behavioral scientists and social epidemiologists, it demands the participation of the communities being studied and insight into community members' interpretation of their experiences.¹³

Community health professionals have long recognized that community members view health and illness and their respective causes differently than do practitioners and researchers. Even when community members and professionals identify the same health problems, needs, and resources, their emphases often differ. Professionals' emphasis on organizations and the delivery of service typically contrasts with community members concern for social, economic, and interpersonal issues. Knowledge of community members' subjective experience is considered essential for a comprehensive view of a community's health status, both in terms of the lived meaning of surveillance data and the importance attributed to specific health problems in daily life. But because of difficulties in involving the community at large in assessment and the logistical and ethical difficulties of identifying and engaging community representatives in the process, community assessment may be left largely to professionals in all but major projects or when funding guidelines require community participation.

In practice, community assessment and priority setting are twin components of health planning that inevitably affect each other. Formal assessment is typically based on an overview of a community's strengths and needs that effectively establishes some general priorities before the evidence is gathered, but funding for community projects requires data to support their feasibility and likely community benefit. Community members who enter into the assessment and planning process are typically much less concerned with developing and analyzing comprehensive and well-documented data and much more interested in action, change, and the provision of services. Maintaining community involvement in planning and priority setting often requires public health planners to balance their professional responsibility to use sound research methods and the need to provide meaningful opportunities for community participation that will keep community members interested and active in the process.

The best-known and most ambitious community-based priority-setting project in the United States, the Oregon Health Plan, illustrates both the ethical strengths and limitations of community involvement in planning for health services.¹⁴ The Oregon Health Plan was the result of Oregon's 1989 revision of Medicaid in response to the state's growing number of uninsured residents. Under the plan all state residents who met federal poverty guidelines were eligible for Medicaid coverage, but fewer conditions and fewer types of treatment were covered under the revised system. In order to clarify which conditions and interventions should be covered under the plan, the state created the eleven-member Oregon Health Services Commission to develop a prioritized list that would be the basic benefits package. The Health Services Commission was created in part in response to the efforts of Oregon Health Decisions, a civic organization responsible for grass-roots education and community outreach centered around health care rationing. Between 1983 and 1984, Oregon Health Decisions conducted 300 community forums and town hall meetings designed to raise awareness of the practical and ethical issues related to health care rationing. The process involved some 5000 Oregonians and led to the 1984 Citizen's Health Care Parliament, which outlined the values that its participants believed essential to an acceptable rationing plan. In 1989 the Health Services Commission continued the community-based discussion in town hall meetings in every county across the state, discussing with participants how to allocate health care resources consistent with community values. The Commission subsequently used its findings to create a list of 709 condition-treatment pairs for which priority for coverage was based largely on the values and preferences expressed in the community forums.

From the outset the Oregon Health Plan was both hailed and criticized from many directions, but analysis of the priority list and the way in which it was developed received particularly strong criticism from some ethicists and community advocates. In particular, they pointed out that the community values and preferences that informed the prioritizing of coverage were not necessarily the values and preferences of Oregon's Medicaid-eligible population. The community forums and town meetings at which rationing, priorities, and values were discussed were typically attended by health care providers, and other educated, middle class Oregonians. Although organizations representing Medicaid patients took part in the discussions, only 5% of the participants were actual Medicaid recipients. Despite efforts to schedule sessions at convenient times for all community members and to publicize the meetings actively, members of the lower socioeconomic groups most affected by Medicaid's restructuring did not participate. Questions about the community that the Plan was meant to serve, the willingness and ability of health professionals and educated citizens to speak for the poor, and how the Commission might have engaged more participation from members of Oregon's lower socioeconomic groups continue to pose a serious challenge to health planners and the establishment of community-based practice.

Community-based practice

Community-based practice, particularly the delivery of health services, is distinguished by both logistical and ethical aspects. Logistically, community-based practice is rooted in a particular, defined community, whose needs and goals define the purpose and activities of the practice. Ethically, community-based practice is committed to honoring the values and culture of the defined community being served and to shared governance of the practice itself. Community-based practice in this sense means the strategic and sustained cooperation of public and private health and social service agencies, neighborhood associations, local funders, businesses, schools and universities, consumer advocacy groups, public officials, and public agencies, which provide the resources and key players needed to maintain a comprehensive approach, a community focus and shared control, an epidemiological understanding of the community's health and well-being, and responsive and flexible interventions that recognize the importance of improving the health of both individuals and the community as a whole.

While few practices achieve this combination of ideals, across the country, diverse broad-based community partnerships such as Healthy Cities/Communities, Healthy Start, Ryan White Planning Councils, comprehensive community initiatives, and community health worker/promotora programs have made some inroads.* One of the most successful models of community-based practice, community-oriented primary care (COPC), attempted to integrate community participation with clinical primary care and the basic features of public health. The history of COPC, which was quite popular in the United States in the 1980s, illustrates the ethical ideals as well as several ethical tensions inherent in community-based practice.

COPC was originally developed in 1940s South Africa by Drs. Sidney and Emily Kark and further developed in Israel. COPC was based upon the idea that decision making for health needs to hinge on an epidemiological understanding of the principal factors influencing health, including social, biological, and cultural characteristics and the natural and man-made environment. The Karks taught that health interventions should target both the individual and the community as a whole, and that the community should be involved in the promotion of its own health. In 1982 a U.S. Institute of Medicine

* See Best Practices sheet for general references on such programs.

(IOM)-sponsored conference on COPC defined the essential elements of COPC as (1) complementary use of epidemiology and clinical practice; (2) a defined target population, for whose health improvement COPC service takes responsibility; (3) defined health interventions based on epidemiological findings; (4) community involvement in its own health promotion; and (5) accessibility without financial, social, cultural, geographic, and other barriers to care.¹⁵ Attracted to this model because of its comprehensive, democratic approach, many practitioners worldwide introduced COPC into public health practice, particularly in clinics for the indigent.

Over the past 20 years, however, COPC in the United States has come to be understood largely as a primary care medical practice with a geographically defined service area, where resource allocation and program design decisions are based at least in part on periodic health needs assessments. A few years after it defined a active role for communities in COPC, IOM reduced its definition of COPC to four key tasks performed by professionals: (1) defining and characterizing the community; (2) identifying the community's health problems; (3) modifying programs in response to health needs; and (4) monitoring the program's impact. Not surprisingly, today most U.S.-based COPC practices do not take a comprehensive approach to health that encompasses social, cultural, and environmental determinants, or target interventions to the health of the community as a whole (as compared to a large number of individuals). Similarly, although community health centers and other such practices may have consumer representation on advisory or governing boards, COPC practices today do not incorporate any significant degree of community involvement. Moreover, financial, geographic, cultural, and other barriers to access to health care continue to present tremendous challenges to indigent communities across the United States even where COPC programs exist.

The shift in COPC's ethical commitment to community participation and a holistic approach to community health may be the result of the persistent U.S. belief that health problems can be corrected by the delivery of professional health and social services and Americans' dedication to medical experts and institutions. Moreover, the dominant biomedical model of health and illness still overlooks the importance of connections among individuals for both creating and solving health problems, and doubts the wisdom or feasibility of sharing authority or responsibility with a given community for the promotion of its own health. And, perhaps most importantly, as the U.S. population grows more diverse and more mobile, the concept of "community" remains difficult to define in theory or practice, making community engagement particularly difficult to achieve. The original vision of COPC might well be highly effective if implemented faithfully, but the interaction of practical and ethical restrictions on its goals makes such implementation unlikely for the near future.

Community-Based Research

The ethical issues in public health research, as in all human health-oriented research, relate primarily to the tensions between the real and potential benefits that research offers participants and the possible harms that the investigation may cause them.[†] Like epidemiologic surveillance, public health research attempts to answer questions related to the health of populations that may have markedly different answers for different communities. Nonetheless, presumptions about the similarities and differences between communities on which research agendas are built can pose ethical challenges for investigators and communities. The history of public health research is indelibly stained by the U.S. Public Health Service's 40-year study of untreated syphilis among poor, uneducated African-American men in Macon

[†] Module 3 addresses the ethics of public health research in more detail.

County, Alabama, under the premise that the “Negro” biological response to syphilis was different from that of Caucasians.[‡] Despite national ethical standards that required the informed consent of participants over the four decades of the trial, researchers in the Tuskegee Syphilis Study betrayed the trust of the community and deceived individual participants by portraying the study as special medical attention.

Since the late 1960s, regulatory authorities have sought to protect research participants from study-related harms by through reinforced standards of informed consent for individuals enrolled in research protocols. In the late 1980s, however, AIDS activists demanded greater access to the therapeutic options offered only in drug trials. Their claims began a shift in the interpretation of informed consent from a largely defensive right to refuse experimental intervention to a positive right to be involved in research protocols as an informed partner.¹⁶ Since the late 1990s federal regulations have reflected this new attitude, as evidenced by the substance and the language of new policies. Both governmental agencies and many researchers have abandoned use of the implicitly passive “research subject” in favor of the more active “research participant.”

“Participatory research” has gained particular currency for community-based studies. In the mid-1990s, international AIDS researchers faced significant ethical conflict in reconciling U.S. standards of individual informed consent with the accepted paternalism of medicine in most developing countries.¹⁷ Some proposed models of community consent in which community leaders were asked to speak on behalf targeted participants.¹⁸ Often the community members recruited for drug studies had no understanding of the western concept of self-determination and who respected the authority of community leaders to make important decisions in the group’s interests. For many ethicists this practice raised the crucial dilemma of how to respect individuals who do not believe in autonomy without supporting the potential exploitation use of vulnerable persons whose own interests might differ from those of their larger community. Although U.S. federal funding commits international research to U.S. ethical standards, the ethical controversy surrounding community consent remains largely unresolved, particularly with respect to privately funded drug studies.

In the United States, communities have begun to seek partnership with researchers in addressing health problems that they both recognize. Researchers, in turn, have realized the benefits of community participation in defining important research questions, implementing protocols, and interpreting results. The National Institutes of Health has increasingly called for protocol design to be consistent with the goals of participatory research, and recommends that applicants for certain federal funding consult published guidelines from the University of British Columbia on participatory research.¹⁹ These guidelines highlight the importance of community involvement and partnership in health promotion research and define five basic categories for evaluating partnership and community participation:

- the **characteristics** of the participant community of interest;
- the **origins** of the research question and the **community’s support** for it;
- whether the research will **foster self-determination** among community members and **facilitate collaboration** with external resources;
- whether the community and the researchers can **learn about each other** during the process; and
- whether the participant community will **benefit from the research outcomes** and how.

[‡] Module 2 discusses the history and legacy of the U.S. Public Health Service’s Tuskegee Syphilis Study in detail.

These criteria speak to the potential for researchers and communities to serve their mutual needs and link traditional concepts of research protection with new interpretations of collaborative trust.

Conclusion

New attention to community in theory and practice offers the promise for a public health that is of the people and by the people as well as for the people. Integrated community-based efforts at surveillance, intervention, and research close an important circle for health professionals by bringing a wider range of knowledge, skills, and resources to bear on complex public health concerns and deepening broad commitment to solutions by involving people in decisions that affect them. For community-base research and practice to be successful, however, public health professionals must be alert to its inherent tensions and use conflicts to gain a greater understanding of how to balance the many worldviews, goals, and strategies at play. A strong mutual commitment to power-sharing and the collaborative process, and honest approach, careful attention to relationship, and the pursuit of “win-win” outcomes can go a long way to overcoming the may obstacles that remain.



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