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Community-based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century

Margaret W Leung,[1,2] Irene H Yen,[3,4] and Meredith Minkler[1]

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Summary Despite the advances of modern epidemiology, the field remains limited in its ability to explain why certain outcomes occur and to generate the kind of findings that can be translated into programmes or policies to improve health. Creating community partnerships such that community representatives participate in the definition of the research problem, interpretation of the data, and application of the findings may help address these concerns. Community based participatory research (CBPR) is a framework epidemiologists can apply to their studies to gain a better understanding of the social context in which disease outcomes occur, while involving community partners in the research process, and insuring that action is part of the research process itself. The utility of CBPR principles has been particularly well demonstrated by environmental epidemiologists who have employed this approach in data gathering on exposure assessment and advancing environmental justice. This article provides examples of how popular epidemiology applies many of CBPR's key principles. At this critical juncture in its history, epidemiology may benefit from further incorporating CBPR, increasing the field's ability to study and understand complex community health problems, insure the policy and practice relevance of findings, and assist in using those findings to help promote structural changes that can improve health and prevent disease.

In recent years a number of epidemiologists have called for a paradigm shift, arguing that modern epidemiology's approach of applying a risk-factor paradigm overemphasizes the individual level of risk to the exclusion of other organizational levels of risk.[1–6] To address the social dynamics of disease as proponents of the sanitary movement once did (before the narrowing of focus that accompanied epidemiology's entry into the eras of infectious and then chronic disease), some have argued that health and disease must be studied at a population level within a social context. Consistent with the call for a paradigm shift, epidemiologists are also calling for increased community participation in the research process.[4,7–9] As Schwab and Syme[9] suggest, such an approach:

> implies working across disciplines and with the population itself, in defining variables, designing instruments, and collecting data (qualitative and quantitative) that reflect the ecological reality of life in that population, as people experience it.

Within such collaborations, they note, 'Epidemiologists would not be required to surrender rigor, but they would be required to share power!' (ref. 9, pp. 20,50) By adopting a participatory population perspective that emphasizes the social influences on health and disease, epidemiology is in a position to reassert its public health roots by (1) extending the search for causes from the individual to the community and to sociopolitical systems, (2) broadening the methodologies to include qualitative and participatory research methods, and (3) integrating lay knowledge into scientific knowledge.[10]

Community based participatory research (CBPR) increasingly is being recognized as a promising approach for both incorporating epidemiology's historic concern with the social context of disease and integrating the participatory and action elements that often have been missing from contemporary

[1] Division of Health and Social Behavior, University of California, Berkeley, School of Public Health, 140 Warren Hall, Berkeley, CA 94720-7360, USA.

[2] School of Medicine, University of California, San Diego, 9500 Gilman Dr., La Jolla, CA 92093, USA.

[3] Health Inequities Research Unit, Environmental Health Section, San Francisco Department of Public Health, 1390 Market Street, Suite 910, San Francisco, CA 94102, USA.

[4] Division of Occupational and Environmental Medicine, Department of Medicine, University of California, San Francisco, Box 0920, San Francisco, CA 94143, USA.

Correspondence: Margaret W Leung, University of California, San Diego, School of Medicine, 9500 Gilman Dr., Mail Code 0606, MTF Building, Room180 La Jolla, CA 92093, USA, E-mail: mileung@meded.ucsd.edu

epidemiological research. An overarching term that encompasses a number of approaches including popular epidemiology,[8,11,12] CBPR is defined as:

> systematic inquiry, with the participation of those affected by the issue being studied, for the purposes of education and taking action or affecting social change. (ref. 13, p. 1927)

As will be suggested below, popular epidemiology, like other forms of CBPR, complements the accent placed by many of the other 'new epidemiologies' on understanding and preventing disease in a historical, political, economic, cultural, and social context. At the same time, adoption of CBPR principles stressing research *with*, rather than *on* communities, affirms the value of communities' experiential knowledge and stresses a collaborative process. In doing so, the field of epidemiology would move away from a tendency towards positivism (a belief, introduced by Comte De Saint-Simon and developed by Auguste Comte, Ernst Mach, Kurt Godel, and others,[14] that the scientific method and direct observation are the only sources of knowledge) and instead towards constructivism through which researchers and communities co-create knowledge.[15] With its attention to action as an integral part of the research process, CBPR further encourages epidemiology to expand beyond a science that measures associations of exposure and disease, to become a data-driven approach to improve community health and well-being.

Following a brief review of some of the limitations modern epidemiology faces, this paper will describe CBPR's roots and underlying principles and compare and contrast CBPR with modern epidemiology's framework of inquiry. The particular CBPR approach known as popular epidemiology, which distinguishes itself from modern epidemiology both epistemologically and methodologically[8] will then be examined in more depth, with examples used to illustrate its utility in studying and acting to address complex health problems. We conclude by highlighting the benefits of CBPR for epidemiology at this critical juncture in its history. Although this paper focuses primarily on CBPR within the social context of the contemporary US, the arguments presented and examples offered should have relevance in a broader international context as well.

Modern epidemiology and its limitations

With the decline of infectious diseases and the rise in non-communicable diseases in the mid-20th century, modern epidemiology emerged with a paradigm of associating exposure to the outcome without necessarily identifying the intervening factors or pathogens—an approach sometimes referred to as 'black box' or risk factor epidemiology.[1] Risk factor epidemiology research questions tend to isolate one item as the exposure of interest, holding constant or controlling for other variables rather than examining combinations of exposures or the interrelatedness of factors. In doing so, this single factor approach shifts the focus away from social and contextual factors and instead conceptualizes risks in individual terms. The classic example of the success of risk factor epidemiology is the discovery that cigarette smoking causes lung cancer. Yet to date, very little is known about the physiological mechanisms that connect smoking to lung cancer or any of the other cancers with which smoking is associated. In addition, applying the knowledge that smoking causes lung cancer translates most directly to urging people to stop smoking. It does not look at the social or contextual factors that promote smoking, such as marketing cigarettes to teenagers or tobacco subsidy policies.

Modern epidemiological studies tend to rely on surveys or questionnaires for data and sometimes also have values obtained from clinical measure or samples (e.g. blood pressure or blood glucose level). The survey instruments are usually developed under the direction of expert researchers without community collaborators. Since individuals are providing the responses, the level of analysis is at the individual rather than community or population. For example, a study on leisure physical activity might gather information about type and frequency of activity and may even monitor heart rate or pulse during activity, but is unlikely to take into consideration contextual or social factors (e.g. access to recreational facilities or safety of neighbourhood environment) that influence whether and how a person engages in leisure physical activity.

Because of the underlying assumption that studies are designed to discover facts, some epidemiologists assume that it is the responsibility of others, specifically policy makers and public health advocates, to incorporate epidemiological findings into health promotion and disease prevention programmes and policies.[16] Yet, the origins of epidemiology suggest otherwise, as famously illustrated in John Snow's research and subsequent actions which tested the political inaction of local authorities and the Board of Health. Using the data he gathered from the cholera epidemic as a guide for what action to take, Snow made a pragmatic decision to remove the handle from Broad Street's water pump despite the refusal on the part of the Board of Health and local authorities to accept Snow's theory and their insistence that cholera spread through the atmosphere.

A number of new approaches have been developed or borrowed from other disciplines which help address some of the objectives mentioned above. Among these are well-designed epidemiological studies combining quantitative and qualitative methods,[17–19] ecological approaches to the epidemiology of illness and disability,[2,20–22] and the use of statistical techniques such as hierarchical linear modelling (HLM).[23–26] This paper is premised on the belief that CBPR offers an additional and particularly promising approach for helping achieve these objectives and increasing epidemiology's relevance in the 21st century.

A comparison of the frameworks of inquiry: CBPR and modern epidemiology

In contrast to the positivistic assumptions of modern epidemiology, CBPR recognizes that:

> knowledge is constructed socially and therefore … research approaches…allow for social, group, or collective analysis of life experiences of power and knowledge. (ref. 27, p. 20)

The accent on both participation and action in CBPR reflect in part the roots of this approach in both the 'action research' school developed by German social psychologist Kurt Lewin[28] in the 1940s and the alternative research paradigms developed by Paulo Freire[29] and other third world scholars in the 1970s.[30,31] Lewin's action research approach stresses actively involving people affected by a problem in practical problem solving through a cyclical process of fact finding, action, and evaluation. It remains popular in the UK and some other parts of

Europe, and to a lesser extent in the US, where its applications tend to be primarily limited to settings such as private industry.[32] In contrast, and growing out of the popular education movement in many third world nations, approaches such as participatory action research (PAR) often developed as a direct counter to the often 'colonizing' nature of the research to which oppressed people in Latin America, Asia, and Africa were subjected.[29,33–35] As such, PAR and other early CBPR traditions in third world nations were premised on the importance of 'breaking the monopoly over knowledge production by universities' not as anti-intellectualism but rather in recognition of the 'different sets of interests and power relations' to which academic researchers and the community people they study are linked. (ref. 36, p. 35) Although contemporary CBPR is composed of a variety of research approaches, such as PAR, feminist participatory research, and popular epidemiology, which vary in their goals and change strategies, they tend to share a set of core principles and values.[35,37] As articulated by Israel and her colleagues[38] the fundamental characteristics of CBPR are that: (1) it is participatory; (2) it is co-operative, engaging community members and researchers in a joint process to which each contribute equally; (3) it is a co-learning process; (4) it involves systems development and local capacity building; (5) it is an empowering process through which participants can increase control over their lives; and, (6) it achieves a balance between research and action.

As suggested above, CBPR is not a method *per se* but an orientation to research which may employ any of a number of qualitative and quantitative methodologies. As Cornwall and Jewkes suggest, what is distinctive about CBPR 'is not the methods used but methodological contexts of their application.' What is new is:

> the attitudes of researchers, which in turn determine how, by and for whom research is conceptualized and conducted [and] the corresponding location of power at every stage of the research process. (ref. 39, p. 1667)

Explicit throughout the CBPR process are the deconstruction of power and the democratization of knowledge. CBPR exposes and challenges the structural powers that oppress groups of people whether subtly or overtly.[40] As noted earlier, CBPR shifts the decision-making authority away from experts and embraces the experiential knowledge of the average citizen. Through the process of participation, knowledge becomes democratized such that it is accessible both intellectually and physically, as well as being locally relevant to participants. As a result, participants take equal ownership of the research question and process, making the research outcomes accessible, understandable, and relevant to their specific interests and needs. In contrast, research findings from most conventional epidemiological studies often are inaccessible and irrelevant to the communities that are under study. Researchers report their findings in academic journals using technical language but the affected communities are not usually informed of the overall findings.[41] Thus, researchers retain control over the knowledge. We now turn to a closer look at CBPR as an approach that epidemiologists can employ in working to make their research more relevant to communities by co-creating knowledge and generating meaningful data-driven change.[39]

CBPR is composed of three major and overlapping components: participatory research, education, and social action. Epidemiology can potentially contribute richly to each of these three domains if it can return to the basic value which holds that the field's knowledge base is to support '*organized community efforts* aimed at the prevention of disease and promotion of health.'(ref. 42, p. 41) The first step, participatory research, involves people in collectively analysing their community and determining what issues need to be investigated. Selecting issues which the community wants to address validates experiential knowledge and respects the cultural context of the community.[38] Moreover, it creates a dialogical process between epidemiologists and community members that can help ensure that the issues addressed are relevant to local interests. With the community playing a key role, epidemiologists may have to put aside their topic of interest and pre-determined methods so that the community can help determine the issue and how it is to be investigated, as well as toward what ends.[27] Although epidemiologists lose some power in this process, this is counterbalanced by their gains, as they can learn a great deal about community networks and concerns that may help in generating informed hypotheses and data collection.[43] At the same time, the community acquires new skills for conducting research and thus may enhance its community competence or problem solving ability.[38]

Through education, participants engage in dialogue to develop a critical awareness which in turn enables them to see the relationships between their own community-level health and disease and the larger social structure.[44] As noted earlier, although techniques such as HLM increasingly are being used to enable individual health outcomes to be seen in broader community contexts, much modern epidemiology still fails to attend to context because disease can be more easily attributed to individual lifestyles and behaviours that are divorced from the social milieus that influence them.

Findings from epidemiological studies may not be communicated with the community under study for fear that this knowledge would be upsetting, confusing, or both.[45,46] By failing to share such knowledge, however, epidemiologists deny the community the opportunity to become more critically conscious of their situation and ultimately to confront the problems uncovered. In this way, epidemiologists may enable further study of different relationships between exposure and outcome, yet at a potentially high cost to the affected communities. By accenting education as a critical part of the research process, CBPR attempts to redress this imbalance.

The third component of CBPR, action, is perhaps the area that most strongly distinguishes this approach from conventional research. In most published epidemiological studies, the implications and translation of findings into research are superficially covered, often in a few brief sentences in the discussion section. In other cases, policy recommendations may be explicitly discouraged or disallowed. In its instructions to authors, for example, the journal *Epidemiology* notes that:

> opinions or recommendations about public health policy should be reserved for editorials, letters, or commentaries, not presented as the conclusions of scientific research.[47]

In contrast CBPR is inherently political, integrating the action step throughout the process. Although the specific course of action to be taken in CBPR depends, of course, on the outcomes and on collaborative decision-making by the community and its outside research partners, action is viewed, as noted above, as an integral component of the research process itself.

A bridge between knowledge and action: popular epidemiology

In response to the limitations modern epidemiology presents in using knowledge to change social, political, or economic structures, a number of epidemiologists have called either for a return to the analytical approach of epidemiology's origins based on the sanitary movement[3] or the adoption of 'new' epidemiologies.[4,6,8,11,12,48–50] The 'new' epidemiologies emphasize (1) socializing epidemiologists to the profession's core value of improving the public's health through the understanding of disease causation, (2) analysing social context and systems, and (3) developing epidemiology that draws from the humanities, ethics, human ecology, or political economy.[6] Of the 'new' epidemiologies, one—popular epidemiology—fits well within the rubric of CBPR. Although the 'new' epidemiologies adopt some aspects of CBPR's theoretical framework, popular epidemiology stands apart from the others by returning to some of the roots of epidemiological inquiry by recognizing social factors as part of the disease causal chain through a participatory process.

Although popular epidemiology has been embraced in the field of environmental epidemiology,[11,12,51,52] particularly with calls for 'community-driven research' by the US federal National Institute of Environmental Sciences (NIEHS), other areas within epidemiology have been slow in adopting CBPR. The importance of using such an approach bears repeating because of the significant implications epidemiological studies may have in helping to shape policy that in turn can promote community and population health. Major findings from epidemiological studies are not restricted to the academic arena. Popular media plays a powerful role in how issues are framed, influencing the way the public views issues and policymakers make decisions about health policies and practices.[53] Epidemiologists therefore have a heightened responsibility to ensure that the outcomes of their studies will be beneficial to the communities that participate.[45,46]

Popular epidemiology uses lay knowledge and observations to challenge social structural factors and uses political and other means to seek solutions.[8] It usually begins with lay observations of health effects and pollutants. As communities begin to organize to find a common perspective, they frequently reach out to external experts to corroborate their experiences, engage in health studies, and act as a primary source of information to those living in affected areas. Throughout this process communities ideally remain in control of the scientific inquiry (or at minimum a respected equal partner).[11,12] In Tillery, North Carolina, for example, a low income, African American community suffering from high rates of respiratory and related problems, suspected that these symptoms were related to the rapid proliferation of the hog production industry, with its open cesspools and lagoons that fouled the air and seeped waste water into their wells and yards.[51] Community members mapped the location of the hog facilities, determined the depth and construction dates of local wells, and used these data to advocate for change.[54] Their popular or 'barefoot' epidemiology laid the ground work for a successful multi-year collaboration with an epidemiology faculty member at the University of North Carolina's School of Public Health, and the local health department. This partnership culminated in a major and multi-pronged US government supported CBPR project that validated the community's initial findings and concerns with carefully co-designed surveys. It also demonstrated a persistent pattern of racial discrimination in the placement of hog industry plants. The research in turn has been used by the community and its academic and professional partners to help bring about ordinances and other actions to help curb these unhealthy practices.[51]

Popular epidemiology also includes community partners in the interpretation and translation of data. In Contra Costa County, California, for example, community members who were involved in the Healthy Neighborhoods Project, sponsored by the local health department, played a leading role in the interpretation of data they collected from some 500 residents.[55] As the health department epidemiologist on this project later reported, their analysis revealed a sophisticated understanding of the connections between problems and issues identified which might otherwise have been completely missed.[54]

Popular epidemiology differs from traditional epidemiology in its approach to advocacy and activism. Because it is rooted in political action and social movements, it is more aggressive in advocating for larger structural changes. Activism in popular epidemiology can be achieved through three means: seeking to obtain more resources for the prevention and treatment of already recognized diseases, seeking to win government and medical recognition of under-recognized diseases, or seeking to affirm the knowledge of yet unknown aetiological factors in already recognized diseases.[11,12] Popular epidemiologists do not shy away from using scientifically accepted methodologies. In some cases, the community may strongly support the need for quantitative documentation.[51] In the process of working with researchers, communities can help remedy issues of bias as they learn about the scientific method and the way the scientific community reacts to non-traditional research methodologies.

Environmental epidemiologists have benefited considerably from using CBPR to advance environmental justice[51,56–60] under the auspices of the NIEHS. They have begun working closely with communities on environmental health issues to increase the understanding of aetiologies and exposure assessment research.[43] The environmental scientific community has acknowledged health disparities by race/ethnicity and social class, the disproportionate burden of pollution particular communities face, and the impacts of multiple and cumulative exposures.

Why should epidemiologists bother with CBPR?

As suggested above, the application of CBPR principles to epidemiological studies has both empirical and epistemological benefits for epidemiologists. The careful adherence to these principles in the San Francisco Department of Public Health's Transgender Community Health Project, for example, has been given much of the credit for the success of this unique epidemiological study in which epidemiologist Kristen Clements-Nolle and her community partners were able to gain access to a heavily stigmatized and hidden population.[61] Together they formulated questions and collected and interpreted the data in ways that reflected both important 'insider knowledge' on sensitive topics and the epidemiologist's concerns with validity and rigor.

This unique partnership between researchers and the local transgendered community also led to effective action for change, including the securing of funding for new health and prevention services, improved gender discrimination protection, changes in gender categories on data collection forms, and enhanced community and health department capacity for such work.[61] Both the Centers for Disease Control and Prevention and researchers in several other cities around the US have in turn helped apply and build on some of the lessons and findings of this project.

The above case study demonstrates some of the advantages of CBPR as an approach to epidemiological research. O'Fallon and Dearry similarly have identified a number of benefits for scientists who conduct CBPR.[43] The points listed below expand upon their list and include some additional points with specific relevance to epidemiology.

Trust between researchers and communities

Medical research has a troubling history of abuse epitomized in the notorious Tuskegee Syphilis study[62] of the effects of untreated syphilis in black men long after a treatment was discovered, and the US Army's testing of the psychological effects of LSD.[63] Such abuses have contributed to community distrust of researchers—particularly communities of colour in the US. Some of the hesitation to participate in research can be countered by having communities become full partners in the research process, beginning with community identification of an issue. CBPR methods particularly lend themselves to research projects undertaken in populations that are 'other' to the researchers. The participation of Australian Aborigines in a diabetes research project conducted by a non-Aborigine enhanced the quality of the data collected and provided immediate benefits for the community by developing and distributing diabetes education material tailored to this community as part of the research process.[64] This action component further strengthened community trust and commitment to the research project. With epidemiologists sharing the decision-making in determining the research question, communities that actively participate will perceive the benefits of owning or sharing ownership on the research project. Equal partnership between researchers and communities will increase the likelihood for a successful project with mutual benefits.[35,38]

Increased quantity and quality of data

With community buy-in and participation, participants are more motivated to ensure that data gathered are meaningful for the local community. Epidemiologists' concerns with poor response rates may be countered, as community leaders and trusted lay people assist in recruiting, retaining, collecting, and recording data from harder-to-reach members of a community. With the community invested in the research process and outcomes, attrition in longitudinal studies may decrease. In a collaborative study between a university and a community based healthy agency surveying for breast and cervical cancer screening behaviour among Korean women, community participation along with cultural sensitivity and competence contributed to a 79% response rate.[65] This rate was particularly impressive since the survey targeted an immigrant population that has low response rates for polls and telephone surveys. Community ownership in projects such as this helps validate epidemiological findings and the acceptance of epidemiological instruments in the community.[64] For epidemiologists, increased participation, apart from its other benefits, means more data and greater statistical power.

The importance of such increased statistical power is particularly underscored in epidemiological studies looking at racial/ethnic differences in health outcomes, and in which low response rates from already numerically smaller groups often lead to the dropping of these groups and/or the aggregating of participants into an 'other' category.[64,66] As the above case study involving Korean women illustrates, active community involvement in recruitment and other aspects of the research may enable epidemiologists to achieve far higher responses rates from traditionally harder-to-reach populations. This in turn may make possible the use of statistical tests in comparisons of multiple racial groups, providing a far richer basis for analysis than is possible when comparing only two or three aggregated groups.

Emergence of new research questions

As in many research projects, secondary research questions may arise that may be directly or indirectly related to the primary research question. These secondary questions can paint a more complex picture of risk than modern epidemiological models of observational studies at the individual level. In the Transgender Community Health Project, discrimination and a lack of primary healthcare for human immunodeficiency virus (HIV)-positive transgendered individuals were common themes.[67,68] Studies like this one play a valuable role in pointing to the need for health services research to evaluate how to improve the quality of medical care and public health services for marginalized populations.

Translation of research into locally relevant policy and/or action

Academic epidemiology has been charged with losing touch with public health, focusing on the biomedical aspect of distribution and determinants of disease, and neglecting the politics associated with developing policies for population health.[16,69] In Little's words, 'there is a danger that epidemiology may lose sight of the values which justify its existence' as it moves so heavily into a narrowly 'computational domain.' (ref. 70, p. 1144) Some epidemiologists argue that taking a public stand hinders 'a self-critical approach to scientific research.' (ref. 71, p. 1270) However, proponents of CBPR are among those who argue that despite its position as the 'hard science' of public health, epidemiology should not divorce itself from the field's primary mission which is to advocate, create, and assure the conditions in which people can be healthy.[42]

Applying CBPR principles can also help make findings from epidemiological studies locally relevant and context specific, which is particularly important in the development of meaningful policy and practice. For example, as gun violence was becoming a major public health issue in the US, participation and collaborative research and action on the part of community based organizations, grassroots advocates, health professionals, and law enforcement resulted in a victory for a suburban town in California in its efforts to ban 'junk guns' or poor quality, low cost, and easily concealable hand guns popular among youth.[72] Moreover, epidemiologists do not need to wait until after all the data have been collected and analysed before suggesting implications for public health action and practice. Given the

gravity and high prevalence of some health outcomes, health education can became part of the data collection process. In the earlier mentioned CBPR study with Aboriginal Australians—a population that has twice the prevalence of diabetes as non-Aboriginal Australians—a community based diabetes intervention involving education materials like a patient handbook evolved from the participatory research process itself.[64]

Re-evaluation of the nature of epidemiological inquiry

Application of CBPR to research will prompt epidemiologists to consider how their research is conceptualized and conducted within the context of their own biases and the relevance it has to promoting larger structural change to improve the community's health. By 'broadening the bandwidth of validity' (ref. 73, p. 204) to include new 'choice points' or criteria for validity (including, for example, whether the methods chosen 'will provide a systematic way of engaging people on issues of importance, drawing on many ways of knowing in an iterative fashion,' (ref. 73, p. 214), popular epidemiology and other CBPR approaches can inform and enrich the methodological debates and related inquiry. Wing provides a seven-point criteria for how epidemiologists should conduct their research to answer the fundamental questions of 'why' rather than 'how' exposure and disease are related.[7] Of all the points, perhaps the most ethically relevant to epidemiologists and their research are the display of humility about the scientific research process and an 'unrelenting commitment to playing a supportive role in larger efforts to improve society and public health.' (ref. 7, p. 84)

CBPR in the future of epidemiology

The field of epidemiology has reached a critical juncture. It is undergoing a self-reflective process to determine whether or not it wants to continue pursuing individual-level epidemiology, return to the former days of traditional epidemiology, or adopt a 'new' epidemiology. If epidemiology is to move away from the individual level and embrace the population level, its strategies for working with communities to collect and analyse data must change as well. The shifting of paradigms must go hand-in-hand with changes in methodologies and approaches to research. CBPR, while not providing specific methods and techniques for researchers, does offer a coherent theoretical framework from which innovative methodologies can emerge.

CBPR is labour and time intensive and involves numerous other challenges as well.[74] Epidemiologists must be willing to build relationships with participants, learn from the community, and share both power and their own training and abilities for the good of the community. At the same time, the community must perceive a benefit in the project and the results, be willing to participate in the process and the tasks, and grapple with new concepts such as validity and reliability. The use of CBPR may not always be appropriate. Such an approach should not be attempted, for example, without a commitment to community capacity building and a timeline that permits education and action as part of the research process.

Finally, the motivation for conducting epidemiological research should include not only increasing the knowledge base for public health but also applying that knowledge to support structural changes to promote health and prevent disease. The application of the principles of CBPR in such studies provides guidance for epidemiologists who wish to use their skills and training to advance health promotion and disease prevention *with and for* the public rather than *on* the public. At this critical point in its history, epidemiology itself may benefit from further incorporating CBPR, improving the field's ability to study and understand complex community health problems, and demonstrating its commitment to translating findings into action to improve the public's health.

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Commentary: The people know best

Michael Calnan

One trend which has characterized health policy in the western world over the last decade or so is an attempt to shift away from expert dominated, 'top-down' policy towards 'bottom-up' policies which aim to articulate and mobilize the interests of individuals and/or populations. One example of this is in public health where traditional legislative, regulatory, or educational policies, prescribed by government and increasingly linked to expert 'evidence', have lost popularity. Policies aimed at community empowerment where policy development involves a 'negotiation' between scientific and lay groups are now in favour. There are a variety of reasons for such a shift in emphasis such as the need for policy to be more accountable and legitimate, to counteract the democratic deficit, or to increase the likelihood of social change by ensuring initiatives have more meaning and relevance to the population or to the local community. Such bottom-up policies are sometimes 'mobilized' through provision of resources to help facilitate community involvement or occur 'spontaneously' as a result of the development of social movements or self-help groups.

A similar trend has occurred in health-related research where there has been an increasing call for users (defined in a broad way from individuals to consumer agencies) to be involved in research.[1,2] Once again a number of reasons might explain such a development but the popular one is that research needs to be increasingly salient and relevant to users' needs. Commentators vary in the extent to which they advocate users' involvement, ranging from the initial phase of shaping the research agenda or priority setting through being fully involved in different stages of the research process, such as research design, data collection, and analysis and interpretation.

Epidemiological research has also been encouraged to adopt an approach to involve community representatives in the research process. This is well illustrated in the article by Leung, Yen and Winkler,[3] which advocates a community-based participatory research (CBPR) as the way forward for epidemiology. CBPR is defined, according to these authors, as a systematic inquiry, with the participation of those affected by the issue being studied for the purposes of education and taking action or affecting social change. More specifically CBPR is characterized by participation and engaging community members and researchers in a joint process to which each contribute equally; it is a co-learning process; it involves systems development and local capacity building; it is an empowering process through which participants can increase control over their lives, and it achieves a balance between research and action.

The motive behind such a call for a shift in paradigms is the perceived failure of epidemiological research to influence policy. This is accounted for, at least in part, by the inherently apolitical

Department of Social Medicine, University of Bristol, Canynge Hall, Bristol BS8 2PR, UK. E-mail: M.W.Calnan@bristol.ac.uk