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## Interdisciplinary, Translational, and Community-Based Participatory Research: Finding a Common Language to Improve Cancer Research

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## Interdisciplinary, Translational, and Community-Based Participatory Research:

### Finding a Common Language to Improve Cancer Research

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### Abstract

Preventing cancer, downstaging disease at diagnosis, and reducing mortality require that relevant research findings be translated across scientific disciplines and into clinical and public health practice. Interdisciplinary research focuses on using the languages of different scientific disciplines to share techniques and philosophical perspectives to enhance discovery and development of innovations; (i.e., from the “left end” of the research continuum). Community-based participatory research (CBPR), whose relevance often is relegated to the “right end” (i.e., delivery and dissemination) of the research continuum, represents an important means for understanding how many cancers are caused as well as for ensuring that basic science research findings affect cancer outcomes in materially important ways. Effective interdisciplinary research and CBPR both require an ability to communicate effectively across groups that often start out neither understanding each other’s worldviews nor even speaking the same language. Both demand an ability and willingness to treat individuals from other communities with respect and understanding. We describe the similarities between CBPR and both translational and interdisciplinary research, and then illustrate our points using squamous cell carcinoma of the esophagus as an example of how to deepen understanding and increase relevance by applying techniques of CBPR and interdisciplinary engagement.

### Introduction

Although the terms community-based participatory research (CBPR; ref. 1), translational research (and translation more generally; ref. 2), and interdisciplinary research (3) are being used with much greater frequency in the medical literature and especially as they relate to cancer, there is virtually nothing written linking the three concepts. In this article, we will show

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that they share both philosophical underpinnings and practical means for applying and sharing knowledge and techniques.

All authors are CBPR-committed members of the South Carolina Cancer Disparities Community Network<sup>5</sup>, 1 of 25 Community Networks funded as a cooperative agreement by the National Cancer Institute. The third author of this paper, CAA, is a member of the African-American faith community, the target group of the South Carolina Cancer Disparities Community Network.

## Defining and Describing CBPR

“Community-Based Participatory Research (CBPR) is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings” (4). CBPR emerges from a tradition in environmental health and social justice that encourages social activism and recognizes unique strengths and perspectives through active participation in the research process (5). As part of the Community Networks Program, the South Carolina Cancer Disparities Community Network is committed to CBPR that is conducted as an equal partnership between traditionally trained “experts” and members of the community.

As with any concept or set of methodologies, those scientists at all familiar with CBPR tend to conceptualize it in many different ways. Interpretations can range from a “science shop” where the “laboratory door” (usually in academic settings) is open to community members who “employ” or “engage” the scientist to conduct research on their topic of interest; to an opportunity to participate in “roundtable discussions” where the community and scientists come to a consensus about health problems and the research to be conducted; to a view that CBPR is the process by which scientists have the “kernel of an idea” that they bring to the community to attempt to further refine the idea, determine research approaches, and reach consensus on the interpretation and dissemination of research findings. To a large extent, the actual process of CBPR used will depend on the question being asked and the context in which it is to be answered. Nevertheless, if the research is true to CBPR tenets, the principles of partnership, and mutual respect must underlie the entire process.

## Defining and Describing Translation/Translational Research

Translation is the means by which technology, driven by intellectual exchanges across disciplinary boundaries, moves to places of perceived need. According to the NIH Roadmap, in order “to improve human health, scientific discoveries must be translated into practical applications. Such discoveries typically begin at ‘the bench’ with basic research—in which scientists study disease at a molecular or cellular level—then progress to the clinical level, or the patient’s ‘bedside.’” Furthermore, it is stated that, “scientists are increasingly aware that this bench-to-bedside approach to translational research is really a two-way street (6).” In more expansive definitions of translation, basic science comprises more than just bench (i.e., “wet laboratory”) research. It also includes epidemiologic research. Likewise, the target is more than just the clinic (or “bedside”), but also includes whole communities and populations (7).

## Overview of Interdisciplinary Research

According to the NIH Roadmap (8), “Health research traditionally has been organized much like a series of cottage industries, lumping researchers into broad areas of scientific interest and then grouping them into distinct, departmentally based specialties. But, as science has

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<sup>5</sup><http://sccdcn.sph.sc.edu/index.htm>

advanced over the past decade and the molecular secrets of life have become more accessible, two fundamental themes are apparent: the study of human biology and behavior is a wonderfully dynamic process, and the traditional divisions within health research may in some instances impede the pace of scientific discovery.” In response to this the NIH states that, “initiatives have been undertaken that should make it easier for scientists to conduct interdisciplinary research. New awards will include funding to: train scientists in interdisciplinary strategies; create specialized centers to help forge new and more advanced disciplines from existing ones; supplements to existing awards which will encourage interdisciplinary depth for ongoing projects; and other means to catalyze collaboration among the life and physical sciences, important areas of research that historically have had limited interaction.”

## Understanding the Research Continuum and the Role of CBPR in Translational Research

Health research spans a continuum (Fig. 1) ranging from: (a) *discovering* the causes of disease occurrence, severity, and progression; (b) *developing* novel products, devices, procedures, and preventive interventions that may be tested in trials in human beings; (c) monitoring and evaluating activities aimed at *delivering* innovations; to (d) *disseminating* knowledge or technological improvements to the population in general (9). CBPR can provide a means for actively engaging academic and community partners in the processes of discovery and development. These same principles can be applied to learning and teaching around practices known to decrease disease risk (i.e., established primary preventives such as tobacco cessation), to explore and identify evidence-based methods for testing the most effective ways to deliver proven methods of disease prevention and control to communities of need. Of course, engagement also can entail research aimed at secondary prevention (to increase survival and, thereby, prevalence of disease) and tertiary prevention (to improve quality of life without changing incidence or prevalence).

Typically, study populations differ dramatically from those that experience really high disease risk. For example, most cohort studies (10), including the Black Women’s Health Study (11), enroll highly educated, affluent individuals who probably experience different levels of risk from that of very high-risk groups in places such as inner cities throughout the United States and those living in the rural South. The processes of CBPR, which often begins by approaching “innovators” and other community leaders first, can lead to increased access to such populations. Ideas for study that emanate from the collaborative process of engagement may help to enlighten the process of discovery.

Although the research continuum (Fig. 1) seems to be a linear progression from discovery to dissemination, the reality, well-recognized by the National Cancer Institute’s Translational Research Working Group (7), is that the findings acquired in delivering and disseminating interventions can be fed back to the discovery/development end of the continuum. Given the extraordinary health disparities that have been refractory to many decades of very competent basic science research, including epidemiologic studies, CBPR has an important potential role in ensuring relevance to people in high-risk communities (12). Indeed, the gap between the huge amount of research-study derived information and relevant policy action continues to widen (13). By engaging the community in defining, guiding, and implementing the research agenda, as well as actively participating in the dissemination process, feedback loops can be completed. In so doing, CBPR has a unique capacity to help ensure study validity—both internal validity, which is the *sine qua non* of any research, and external validity (i.e., generalizability).

## CBPR in Relation to Interdisciplinary Research

Both CBPR and interdisciplinary research are called to conduct intellectual exchanges across disciplinary boundaries. Without interest in and respect for the knowledge and experiences of the “other”, there is no impetus to engage in exchanging information and expertise. There is virtually nothing written on the connection between CBPR and interdisciplinary research.

## Impediments to Engagement

Things that impede interdisciplinary communication also hamper efforts aimed at translation and CBPR. Groups, whether defined by vocation, philosophical orientation (worldview), ethnicity, race, socioeconomic status, geographic proximity, or some combination of these tend to invent new words or attach new, different meanings to old words to convey the meaning of concepts commonly encountered by the group. An example from epidemiology is the word “confounding.” It is an elegant use of a word from ordinary English that has special meaning that would take many more words (indeed, whole sentences) to describe otherwise. The use of jargon, though often well-meaning (i.e., to improve efficiency), excludes those unfamiliar with both the concept and the group—creating a club of the “initiated.” Human imagination is a powerful thing; so anything that increases or enhances “foreignness,” may (indeed, usually does) instill feelings of fear and mistrust. To advance the science and to ensure that what we do know gets to places of need, it is important that individuals not be in a state of fear and that they are trustful and respectful of one another.

## The Example of Squamous Cell Carcinoma of the Esophagus

We use the example of squamous cell carcinoma of the esophagus to illustrate:

1. limitations imposed by the conventional way that we have defined a problem.
2. how to deepen understanding of disease causation by inviting individuals from other (in this instance, other than epidemiology) disciplines into the process of formulating and testing a novel hypothesis to explain evident disparities.
3. ways to broaden the inquiry yet further by involving the community in hypothesis generation and designing future studies.

## Describing the Problem

African-Americans tend to have high incidence rates of many cancers, and especially high mortality per-unit incidence (14,15). African-Americans have an incidence rate of SCCE that is about four times higher than that of European Americans nationally. In South Carolina, rates in African-Americans are >7.5 times higher than in their European American counterparts (16). Conventional epidemiologic wisdom asserts that 95% of all variability in this cancer is due to tobacco smoking, drinking, or a combination of the two (16,17). Consequently, one would expect that rates of tobacco use, alcohol, or both are much higher in the African-American community. However, this has not been observed (18). In fact, in South Carolina, where SCCE rates are particularly high in African-Americans, rates of tobacco use are quite low (19).

The discordance between rates of tobacco exposure and esophageal cancer motivated us to develop a hypothesis back in the 1980s related to menthol cigarette exposure, the sales of which do track closely with changes in incidence (20). These observations and formulation of the hypothesis linking mentholated cigarettes to esophageal cancer led to a number of studies on esophageal and other tobacco-related cancers beginning in the late 1980s all of which have shown no, or only weak, association between menthol cigarettes and cancer (20-22). As we have noted (23), many of the collaborating hospitals in these studies are university-teaching

facilities. Individuals seeking care at these facilities are atypical of the general African-American population who are at elevated risk of esophageal, lung, and other tobacco-related cancers (23). As such, the type of hospitals used in these studies could underrepresent the poor African-Americans who might be more likely to smoke menthol brands, and have higher disease rates. Indeed, reported use of mentholated cigarettes among African-Americans in all published studies is lower than the prevalence rate in the general population. For example, in Brooks' study (21), ever use of mentholated cigarettes was slightly under 51% in African-American controls, compared with average prevalence in African-Americans ranging from ~63% over most of the period of etiologic relevance (24) to about 75% currently (18,25).

## Reorienting the Problem from an Interdisciplinary Perspective

Notwithstanding issues regarding population selection, our original hypothesis may have been limiting. Originally, we thought that the primary effect of menthol was in attenuating sensations of heat, thereby allowing exposures of longer duration and greater heat intensity (20). This provided a potential etiologic link to populations in the world in which esophageal cancer rates are very high but in which individuals neither smoke nor drink, such as the Caspian Littoral (i.e., Azerbaijan, the Islamic Republic of Iran, Kazakhstan, Turkmenistan, the Russian Federation, and neighboring Uzbekistan). There, in alcohol- and tobacco-abstinent populations, we find some of the highest rates of esophageal cancer in the world (26). Similarly, mate-drinking populations in South America have anomalously high rates of esophageal cancer (27). In these regions, it is customary to drink very hot beverages (usually teas) by pouring the scalding fluid onto the surface of the proximal esophagus, the anatomic subsite of virtually all SCCE (26).

In 2003, one of us (JRH) was asked to speak on cancer epidemiology to an undergraduate biology class at the University of South Carolina. A faculty member from the School of Pharmacy was present when the discordance between the descriptive statistics and analytic epidemiology of SCCE was mentioned. Up until that time, we had not considered that menthol, as a highly effective penetrant, is often used to deliver drugs through skin and mucous membranes (28). Thus began a series of interdisciplinary exchanges that resulted in our working together to conduct and publish a study showing that menthol, especially in the presence of ethanol (remember that these exposures, which often occur together, seem to act synergistically to increase cancer risk), increases permeation and reservoir formation of two known tobacco carcinogens, 4-(methylnitrosamino)-1-(3-pyridyl)-1-butanone and benzo(a)pyrene (29).

## Next Step: CBPR on SCCE

Although beginning a line of interdisciplinary research that now includes an analytic chemist, pharmacist, and epidemiologist is an important first step, we also want to use the opportunity to engage the community that experiences very high rates of SCCE. In the same way that we presented the menthol hypothesis and the methodologic problems we encountered to colleagues from other disciplines as the first step in developing our interdisciplinary research program, we could describe the problem as we currently see it, and engage the community in helping us to see more clearly what could be happening from their perspective. Engaging the community in considering what is really important and in paying attention to important clues that would be discernable only from their vantage point would be the first step in CBPR. Continued adherence to principles of CBPR would result in designing future studies that would lower the chance of type III error, i.e., incorrect inference resulting from a faulty conception of how the world works, or selection of a study design that produces an answer (even if correct) to the wrong question (30).

SCCE is a very lethal cancer and research conducted up until now (including ours) has been limited in important ways that inhibits definitive description of the role of menthol. Unlike the populations in which research was conducted previously, and in other parts of the country, the African-American population in South Carolina, which is more typical of most African-Americans, experiences a very high rate of SCCE and other tobacco-related cancers (31-33). Additionally, sociodemographic factors differ in important ways from those groups who live in urban areas and have access to teaching hospitals typically represented in medical research (34).

### Further Down the Line: Translation

Currently, we do not know the role, if any, of menthol in the extremely high rate of SCCE among African-Americans. Also, we do not know if tobacco is less or more important as an etiologic agent in high-risk African-American populations. Therefore, we cannot recommend any action beyond the sound practice of urging tobacco cessation among those who smoke and discouraging tobacco uptake among those who do not smoke. If we were able to mount a study using CBPR principles, what we will have learned will make the translation step much easier because members of the community will be active partners in conceptualizing, implementing, and evaluating the study findings. Indeed, this represents applying the same sort of skill sets that were used in the original interdisciplinary engagement of colleagues from other fields in thinking about this important problem and in formulating a plan to understand the reasons why the disease is so much more common in African-Americans than in European Americans.

### Summary and Conclusions

Progress in science often is nonlinear, resulting from breakthroughs against limits imposed on ideas that define them as “thinkable” at certain times and expansion of the intellectual options and strategies considered “available” at those times. That is, theory change in science depends more on changing intellectual circumstances and possibilities than on accumulating knowledge within a discipline; or in relation to “out-reach” or translation (35). On the other hand, slow and steady progress is necessary for the accumulation of knowledge, for the testing of scientific (i.e., falsifiable) hypotheses, and for verification of results from one set of observations or a single experiment (36). CBPR, as is true for other methods of interdisciplinary engagement, helps to ensure that other viewpoints, perspectives, and types of expertise are brought to bear on the process of scientific inquiry. Thinking about CBPR, translational research, and interdisciplinary research as perspectives that strongly reinforce one another provides an important key toward advancing science in the service of solving the most difficult human health challenges of our age. Keeping in mind that our first order of business is the accumulation of knowledge and this requires designing and executing studies with a high level of internal validity:

We will never know the real causes of many health disparities until we engage with, and study, individuals and communities who are at highest risk.

The passive approaches we have taken to study those who are easiest to contact and most compliant probably will not lead to success in knowing why disease rates are so much higher in certain groups.

The same perspectives and skills that we would use in engaging colleagues from other disciplines are appropriate for CBPR.

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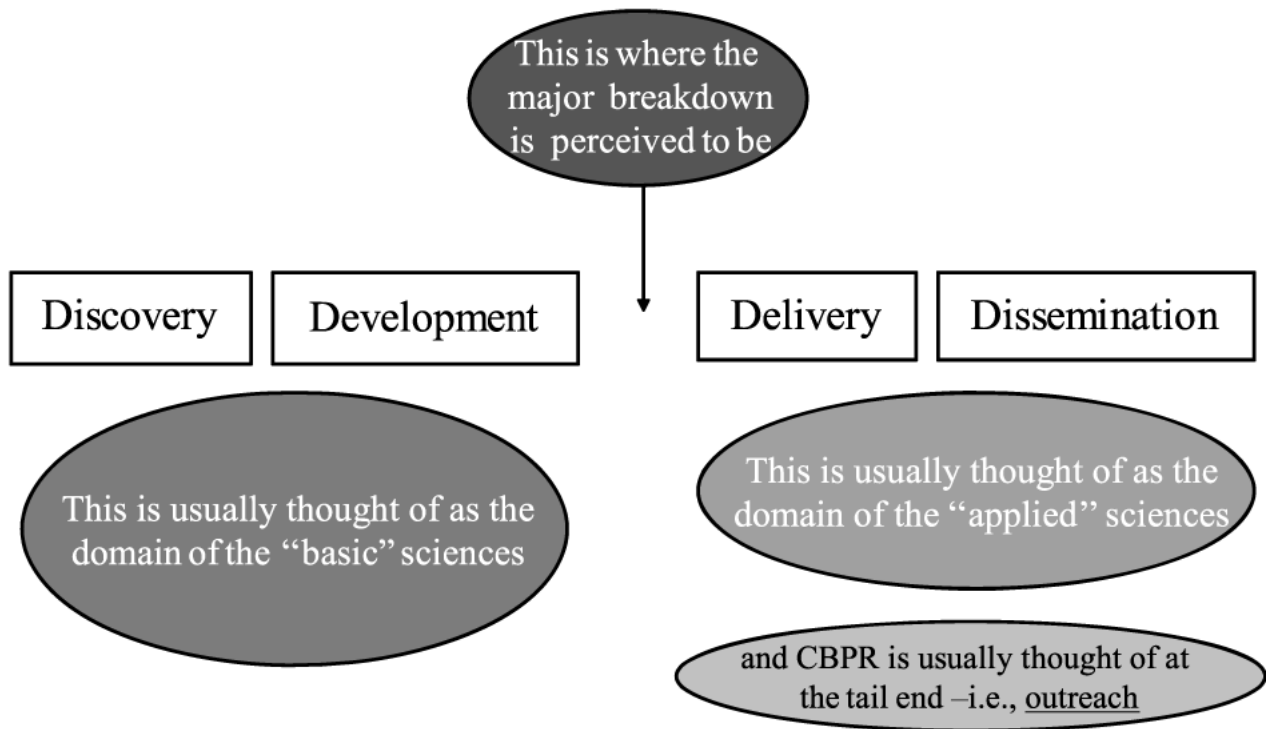
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# The Cancer Research Continuum



**Figure 1.** The research continuum as described by the National Cancer Institute (9).