

COMMUNITY BASED PARTICIPATORY RESEARCH BIBLIOGRAPHY

Search Strategy I

Search Keywords: community based research, community driven research, community based participatory research

Search Engine: OVID Medline

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Search Strategy II

Search Keywords: community based research, community driven research, community based participatory research (TS)

Search Engine: Current Contents

Search Period: 1997 to Spring 2001 (search on April 30, 2001) -- File Depth "Extended File"

Search Strategy III

Search Keywords: community based research, community driven research

Search Engine: Social Sciences Abstracts (SocialSciAbs)

Search Period: 1989 to 2000 (search on April 30, 2001) (?)

Results

Sorted by year (descending) and author (ascending)

References found: (1-86)

Selected Abstracts/References to get from the library:

(1) Higgins DL, Maciak B, Metzler M. CDC Urban Research Centers: Community-based participatory research to improve the health of urban communities. *Journal Of Womens Health & Gender Based Medicine* 2001;10:9-15.

(5) Arcury TA, Quandt SA, McCauley L. Farmworkers and Pesticides: Community-Based Research. *Environ Health Perspect* 2000;108:787-792.

In this paper we summarize the results of a workshop conducted to disseminate information about community-based research on the environmental health risks of exposure of farmworkers to pesticides. Community-based research is an approach that is advocated for addressing issues of environmental justice such as exposure of farmworkers to pesticides. This workshop brought together scientists, community organization members, and agency representatives to review and discuss the research methods and organizational relationships that have been successful in

conducting past community research so these principles can be applied to new situations. The objectives of this workshop were to a) be a forum in which those conducting community-based research with farmworkers could share what they had learned; b) delineate the successes and barriers across different projects to further develop models and methods for conducting community-based research; and c) determine future directions and needs of farmworker community-based research for environmental justice.

(6) Dennis BP, Neese JB. Recruitment and retention of African American elders into community-based research: lessons learned. Arch Psychiatr Nurs 2000;14:3-11.

Factors influencing the recruitment and retention of African Americans into research studies are not well understood. Studies show that their numbers continue to be low in clinical trials and other nursing studies. However, African Americans have disproportionately high incidences of disease, illness, and death, an important reason for their inclusion in ongoing research. Two urban, community-based intervention studies with elderly African American participants are used to show different issues and strategies in recruitment and retention. The sample selection and attrition experiences in the studies are examined using 3 theoretical approaches. Six concepts emerge as fundamental to successful recruitment and retention of diverse population groups: (1) historical cognizance; (2) sanctioning; (3) trust-building; (4) mutuality; (5) recognition of heterogeneity; and (6) researcher self-reflection and introspection.

(8) Jordan C, Lee P, Shapiro E. Measuring developmental outcomes of lead exposure in an urban neighborhood: the challenges of community-based research. J Expo Anal Environ Epidemiol 2000;10:732-42.

The Developmental Research on Attention and Memory Skills (DREAMS) Project measures developmental outcomes of approximately 330 children at risk for lead exposure within an ethnically diverse, inner-city neighborhood. This study is one project of the Phillips Neighborhood Healthy Housing Collaborative, a 6-year-old collaboration between residents of the Phillips community in Minneapolis, university researchers, and representatives of various public and private agencies. Our experience carrying out this research is used to highlight both the benefits of, and the challenges to, measuring exposure outcomes in inner-city children using a community-based research approach. Challenges to working within a community collaborative, to studying an ethnically diverse and economically disadvantaged neighborhood, and to utilizing neighborhood residents as project staff are discussed. The strategies used to address these issues are presented to offer ideas for surmounting the challenges inherent in community-based research. The investigation of community environmental health problems through a community-based research approach can result in improved methodology, enhanced quality of data collected, and increased effectiveness of data dissemination. In addition, it can lead to important findings that inform the scientific community and create positive community changes. It is paramount, however, that potential obstacles be anticipated and planned for, or else be detected early and promptly responded to, in a manner that preserves scientific rigor while respecting community needs and values.

(9) Kinney PL, Aggarwal M, Northridge ME, Janssen NA, Shepard P. Airborne concentrations of PM(2.5) and diesel exhaust particles on Harlem sidewalks: a community-based pilot study. Environ Health Perspect 2000;108:213-8.

Residents of the dense urban core neighborhoods of New York City (NYC) have expressed increasing concern about the potential human health impacts of diesel vehicle emissions. We measured concentrations of particulate matter [less than/equal to] 2.5 micro in aerodynamic diameter (PM(2.5)) and diesel exhaust particles (DEP) on sidewalks in Harlem, NYC, and tested whether spatial variations in concentrations were related to local diesel traffic density. Eight-hour (1000-1800 hr) air samples for PM(2.5) and elemental carbon (EC) were collected for 5 days in

July 1996 on sidewalks adjacent to four geographically distinct Harlem intersections. Samples were taken using portable monitors worn by study staff. Simultaneous traffic counts for diesel trucks, buses, cars, and pedestrians were carried out at each intersection on [Greater/equal to] 2 of the 5 sampling days. Eight-hour diesel vehicle counts ranged from 61 to 2,467 across the four sites. Mean concentrations of PM(2.5) exhibited only modest site-to-site variation (37-47 microg/m³), reflecting the importance of broader regional sources of PM(2.5). In contrast, EC concentrations varied 4-fold across sites (from 1.5 to 6 microg/m³), and were associated with bus and truck counts on adjacent streets and, at one site, with the presence of a bus depot. A high correlation ($r = 0.95$) was observed between EC concentrations measured analytically and a blackness measurement based on PM(2.5) filter reflectance, suggesting the utility of the latter as a surrogate measure of DEP in future community-based studies. These results show that local diesel sources in Harlem create spatial variations in sidewalk concentrations of DEP. The study also demonstrates the feasibility of a new paradigm for community-based research involving full and active partnership between academic scientists and community-based organizations.

(10) Kone A, Sullivan M, Senturia KD, Chrisman NJ, Ciske SJ, Krieger JW. *Improving collaboration between researchers and communities. Public Health Rep 2000;115:243-8.* Active collaboration between communities and researchers is critical to developing appropriate public health research strategies that address community concerns. To capture the perspectives of inner-city Seattle communities about issues in community-researcher partnerships, Seattle Partners for Healthy Communities conducted interviews with community members from the ethnically diverse neighborhoods of Central and Southeast Seattle. The results suggest that effective community-researcher collaborations require a paradigm shift from traditional practices to an approach that involves: acknowledging community contributions, recruiting and training minority people to participate in research teams, improving communication, sharing power, and valuing respect and diversity.

(11) Lemkau JP, Ahmed SM, Cauley K. *"The history of health in Dayton": A community-academic partnership. American Journal Of Public Health 2000;90:1216-1217.* Academic institutions have always found it a challenge to persuade community members to participate in academic research projects. Starting an open dialogue is usually the critical first step. To begin this dialogue with community members in Dayton, Ohio, in 1999, staff from Wright State University decided to organize a community forum, "The History of Health in Dayton." The forum was intended as the first project of a new research organization, the Alliance for Research in Community Health (ARCH), established with federal funding from the Health Resources and Services Administration in 1998. ARCH was created as a bridge between the Department of Family Medicine of Wright State University School of Medicine and the Center for Healthy Communities, a health advocacy and service organization committed to health professions education. ARCH's mission is to improve the health of citizens of Dayton through research involving community participation. Through ARCH, community members help researchers define priorities, resolve ethical issues, refine procedures, and interpret results. Guidelines for participatory research, proposed by the National Primary Care Research Group in 1998 and adopted by the alliance, emphasize the importance of open dialogue among researchers, subjects, academics, and community members. The initial response to the forum was enthusiastic, with a majority of community residents expressing interest in attending future presentations.

(12) Minarik PA. *Recruitment and retention of African American elders into community-based research: lessons learned. Arch Psychiatr Nurs 2000;14:208.*

(15) Nicola RM, Hatcher MT. *A framework for building effective public health constituencies. J Public Health Manag Pract* 2000;6:1-10.

Population-based health improvements that require behavioral and social change at the community level are dependent on effective constituency participation. To achieve needed constituency involvement, a public health leader must understand what motivates and moves constituents to action on public health issues. This article provides a framework and guidance on building effective constituent involvement to achieve community health improvement. Within this framework, aspects of managing the organizational practice of constituency building and community engagement are discussed and linked with current public health planning and mobilization models that support community-based health interventions.

(16) O'Fallon LR, Collman GW, Dearry A. *The National Institute of Environmental Health Sciences' research program on children's environmental health. J Expo Anal Environ Epidemiol* 2000;10:630-7.

This article highlights the wide array of research programs supported by the National Institute of Environmental Health Sciences (NIEHS) that address issues related to children's environmental health. Special attention is given to the interagency, collaborative Centers for Children's Environmental Health and Disease Prevention Research program. A brief description of each of the eight centers highlights scientific foci and research efforts to date. In addition to discussing NIEHS-supported research programs, the article emphasizes the NIEHS' commitment to the promotion of translating basic research findings into public health knowledge so that culturally sensitive and applicable interventions may be developed.

(17) O'Fallon LR, Tyson FL, Dearry A. *Improving public health through community-based participatory research and outreach. Environ Epidemiol Toxicol* 2000;2:201-209.

(18) Pless-Mulloli T, Dunn CE, Bhopal R, Phillimore P, Moffatt S, Edwards J. *Is it feasible to construct a community profile of exposure to industrial air pollution? Occup Environ Med* 2000;57:542-549.

OBJECTIVE: An epidemiological investigation to assess the validity of residential proximity to industry as a measure of community exposure. **METHODS:** 19 Housing estates in Teesside (population 1991: 77 330) in north east England were grouped into zones: A=near; B=intermediate; C=further from industry. With residential proximity of socioeconomically matched populations as a starting point a historical land use survey, historical air quality reports, air quality monitoring, dispersion modelling data, and questionnaire data, were examined. **RESULTS:** The populations in zones A, B, and C were similar for socioeconomic indicators and smoking history. Areas currently closest to industry had also been closest for most of the 20th century. Historical reports highlighted the influence of industrial emissions to local air quality, but it was difficult to follow spatial pollution patterns over time. Whereas contemporary NO(x) and benzene concentrations showed no geographical variation, dispersion modelling of emissions (116 industrial stacks, traffic, and domestic sources) showed a gradient associated with industry. The presumed exposure gradient of areas by proximity to industry (A>B>C) was evident for all of zone A and most of zones B and C. **CONCLUSIONS:** It was feasible to assemble a picture of community exposure by integration of measurements from different sources. Proximity of residence was a reasonable surrogate for complex community exposure.

(19) Quigley D, Handy D, Goble R, Sanchez V, George P. *Participatory research strategies in nuclear risk management for native communities. J Health Commun* 2000;5:305-31.

The Nuclear Risk Management for Native Communities (NRMNC) project is a collaborative academic, community-based, tribal project, which conducts the three essential elements of participatory research: research, education, and community action, named here as

“community-based hazards management.” This article describes the goals and outcomes of this effort in assisting Native American communities in Nevada, Utah, and Southern California affected by nuclear fallout from U.S. weapons testing in the 1950s and 1960s. The NRMNC project sought to create new models for dealing with health research and risk communication needs in an environmental justice setting. The following results of this four-year project are discussed: (1) building a community-based environmental health infrastructure, (2) building community capacities through workshops and educational materials, (3) conducting both technical and community research, and (4) facilitating community-based hazards management planning. We describe such positive outcomes as the improvements in the scientific database through participatory research activities, the development of equitable relationships between scientists and community members, and the creation of a sustaining program intervention for long-term community needs. The project's outcomes are presented as an expansion to limited scientific risk management outcomes in the environmental health field that often are solely quantitative and lack relevance to community concerns about environmental health impacts from contamination.

(20) Rotheram-Borus MJ, Rebhook GM, Kelly JA, Adams J, Neumann MS. *Bridging research and practice: community-researcher partnerships for replicating effective interventions. AIDS Educ Prev* 2000;12:49-61.

Long-term collaborations among researchers, staff and volunteers in community-based agencies, staff in institutional settings, and health advocates present challenges. Each group has different missions, procedures, attributes, and rewards. This article reviews areas of potential conflict and suggests strategies for coping with these challenges. During the replication of five effective HIV prevention interventions, strategies for maintaining mutually beneficial collaborations included selecting agencies with infrastructures that could support research-based interventions; obtaining letters of understanding that clarified roles, responsibilities, and time frames; and setting training schedules with opportunities for observing, practicing, becoming invested in, and repeatedly implementing the intervention. The process of implementing interventions highlighted educating funders of research and public health services about (a) the costs of disseminating interventions, (b) the need for innovation to new modalities and theories for delivering effective interventions, and (c) adopting strategies of marketing research and quality engineering when designing interventions.

(23) Wing S, Cole D, Grant G. *Environmental injustice in North Carolina's hog industry. Environ Health Perspect* 2000;108:225-31.

Rapid growth and the concentration of hog production in North Carolina have raised concerns of a disproportionate impact of pollution and offensive odors on poor and nonwhite communities. We analyzed the location and characteristics of 2,514 intensive hog operations in relation to racial, economic, and water source characteristics of census block groups, neighborhoods with an average of approximately 500 households each. We used Poisson regression to evaluate the extent to which relationships between environmental justice variables and the number of hog operations persisted after consideration of population density. There are 18.9 times as many hog operations in the highest quintile of poverty as compared to the lowest; however, adjustment for population density reduces the excess to 7.2. Hog operations are approximately 5 times as common in the highest three quintiles of the percentage nonwhite population as compared to the lowest, adjusted for population density. The excess of hog operations is greatest in areas with both high poverty and high percentage nonwhites. Operations run by corporate integrators are more concentrated in poor and nonwhite areas than are operations run by independent growers. Most hog operations, which use waste pits that can contaminate groundwater, are located in areas with high dependence on well water for drinking. Disproportionate impacts of intensive hog production on people of color and on the poor may impede improvements in economic and environmental

conditions that are needed to address public health in areas which have high disease rates and low access to medical care as compared to other areas of the state.

(24) Wing S, Wolf S. *Intensive livestock operations, health, and quality of life among eastern North Carolina residents. Environ Health Perspect 2000;108:233-8.*

People who live near industrial swine operations have reported decreased health and quality of life. To investigate these issues, we surveyed residents of three rural communities, one in the vicinity of an approximately 6,000-head hog operation, one in the vicinity of two intensive cattle operations, and a third rural agricultural area without livestock operations that use liquid waste management systems. Trained interviewers obtained information about health symptoms and reduced quality of life during the previous 6 months. We completed 155 interviews, with a refusal rate of 14%. Community differences in the mean number of episodes were compared with adjustment for age, sex, smoking, and employment status. The average number of episodes of many symptoms was similar in the three communities; however, certain respiratory and gastrointestinal problems and mucous membrane irritation were elevated among residents in the vicinity of the hog operation. Residents in the vicinity of the hog operation reported increased occurrences of headaches, runny nose, sore throat, excessive coughing, diarrhea, and burning eyes as compared to residents of the community with no intensive livestock operations. Quality of life, as indicated by the number of times residents could not open their windows or go outside even in nice weather, was similar in the control and the community in the vicinity of the cattle operation but greatly reduced among residents near the hog operation. Respiratory and mucous membrane effects were consistent with the results of studies of occupational exposures among swine confinement-house workers and previous findings for neighbors of intensive swine operations. Long-term physical and mental health impacts could not be investigated in this study.

(25) Witten K, Parkes M, Ramasubramanian L. *Participatory environmental health research in Aotearoa/New Zealand: Constraints and opportunities. Health Education & Behavior 2000;27:371-384.*

Within the Aotearoa/New Zealand context, this article identifies opportunities for, as well its constraints on, using participatory research to address environmental health concerns. In New Zealand, principles of partnership fundamental to the Treaty of Waitangi, and the requirements for consultation within the Resource Management Act, provide a framework for participatory approaches. Participatory environmental health research integrates knowledge from various scientific and community sources. It also fosters the innovation, evaluation, and sharing of information that new public health approaches demand. As an emerging field in Aotearoa/New Zealand, it must draw on experience from resource management, rural development, and public health research and practice. Water quality is used as an example of the complexity of environmental health issues and of the potential benefits of engaging stakeholders where long-term health and well-being require balancing ecosystem integrity, economic viability, and social processes.

(26) Baker EA, Homan S, Schonhoff R, Kreuter M. *Principles of practice for academic/practice/community research partnerships. Am J Prev Med 1999;16:86-93.*

CONTEXT: Researchers and practitioners are increasingly realizing that improvements in public health require changes in individual, social, and economic factors. Concurrent with this renewed awareness there has been a growing interest in working with communities to create healthful changes through academic/practice/community research partnerships. However, this type of research presents different challenges and requires different skills than traditional research projects. The development of a set of principles of practice for these types of research projects can assist researchers in developing, implementing, and evaluating their partnerships and their project activities. OBJECTIVE: This paper describes the different ways in which academics and

community groups may work together, including academic/practice/community partnerships. Several principles of practice for engaging in these research partnerships are presented followed by a description of how these principles have been put into operation in a family violence prevention program. CONCLUSIONS: The principles presented are: (1) identify the best processes/model to be used based on the nature of the issue and the intended outcome; (2) acknowledge the difference between community input and active community involvement; (3) develop relationships based on mutual trust and respect; (4) acknowledge and honor different partner's "agendas"; (5) consider multi-disciplinary approaches; (6) use evaluation strategies that are consistent with the overall approach taken in the academic/practice/community partnership; and (7) be aware of partnership maturation and associated transition periods. The limitations of these principles and their application in various settings are discussed.

(28) Davis SM, Reid R. *Practicing participatory research in American Indian communities. American Journal Of Clinical Nutrition* 1999;69:755S-759S.

The purpose of this article is to explore the historical issues that affect research in American Indian communities and examine the implications of these issues as they relate to culturally sensitive, respectful, and appropriate research with this population. Methods include review and analysis of the literature and examination of our collective experience and that of our colleagues. Recommendations are given for conducting culturally sensitive, participatory research. We conclude that research efforts must build on the establishment of partnerships between investigators and American Indian communities to ensure accurate findings and analyses and to implement culturally relevant benefits. *Am J Clin Nutr* 1999;69(suppl):755S-9S.

(29) Elliott SJ, Cole DC, Krueger P, Voorberg N, Wakefield S. *The power of perception: health risk attributed to air pollution in an urban industrial neighbourhood. Risk Anal* 1999;19:621-34.

This paper describes a multi-stakeholder process designed to assess the potential health risks associated with adverse air quality in an urban industrial neighborhood. The paper briefly describes the quantitative health risk assessment conducted by scientific experts, with input by a grassroots community group concerned about the impacts of adverse air quality on their health and quality of life. In this case, rather than accept the views of the scientific experts, the community used their powers of perception to advantage by successfully advocating for a professionally conducted community health survey. This survey was designed to document, systematically and rigorously, the health risk perceptions community members associated with exposure to adverse air quality in their neighborhood. This paper describes the institutional and community contexts within which the research is situated as well as the design, administration, analysis, and results of the community health survey administered to 402 households living in an urban industrial neighborhood in Hamilton, Ontario, Canada. These survey results served to legitimate the community's concerns about air quality and to help broaden operational definitions of 'health.' In addition, the results of both health risk assessment exercises served to keep issues of air quality on the local political agenda. Implications of these findings for our understanding of the environmental justice process as well as the ability of communities to influence environmental health policy are discussed.

(31) Macaulay AC, Commanda LE, Freeman WL, et al. *Participatory research maximises community and lay involvement. British Medical Journal* 1999;319:774-778.

(32) Northridge ME, Yankura J, Kinney PL, et al. *Diesel exhaust exposure among adolescents in Harlem: a community-driven study. Am J Public Health* 1999;89:998-1002.

OBJECTIVES: This study sought individual-level data on diesel exhaust exposure and lung function among adolescents in Harlem as part of a community-driven research agenda.

METHODS: High school students administered in-person surveys to seventh grade students to

ascertain information on demographics, asthma history, and self-reported and maternal smoking. Urine samples were assayed for 1-hydroxypyrene (1-HP), a marker of diesel exhaust exposure, and cotinine, a marker of tobacco smoke exposure. Computer-assisted spirometry was used to measure lung function. RESULTS: Three quarters (76%) of the participating students had detectable levels of 1-HP. Three students (13%) had an FEF25-75 of less than or equal to 80% of their predicted measurements, and 4 students (17%) had results between 80% and 90% of the predicted value, all of which are suggestive of possible lung impairment. CONCLUSIONS: These data suggest that most adolescents in Harlem are exposed to detectable levels of diesel exhaust, a known exacerbator and possible cause of chronic lung disorders such as asthma. Community-driven research initiatives are important for empowering communities to make needed changes to improve their environments and health.

(33) Omenn GS. *Caring for the community: the role of partnerships. Acad Med 1999;74:782-9.* While many members of the public are deeply interested in and supportive of the three traditional missions of academic medicine--education, research, and clinical care, they also want to know what academic health centers (AHCs) are doing to improve the overall health of their communities. Much is already being done toward this goal, but improving communities' health in a measurable way requires a far broader agenda. AHCs must bring together the approaches of medicine and public health, and need to partner with many other players. This agenda must proceed despite all the other challenges that AHCs are currently facing. The author reviews illustrative and emerging national, state, and local efforts, public and private, in both medicine and public health, in partnerships with individuals and institutions in the larger community. He also highlights the physician's role in assisting stakeholders' efforts to deal with health threats from the environment, and offers advice about how such efforts should proceed. He closes by emphasizing the importance of community-based research to learn about the health statuses, problems, and resources of particular communities, and presents a set of principles for such community-based research.

(34) Park P. *People, knowledge, and change in participatory research. Management Learning 1999;30:141-157.*

My purpose in this article is to highlight characteristics of participatory research that distinguish it from other forms of research aimed at generating action. To this end, I will single out the central role that ordinary people play in motivating and sustaining research efforts, the nature of the knowledge generated, and the social change mechanism embedded in participatory research.

(36) Paulu C, Aschengrau A, Ozonoff D. *Tetrachloroethylene-contaminated drinking water in Massachusetts and the risk of colon-rectum, lung, and other cancers. Environ Health Perspect 1999;107:265-71.*

We conducted a population-based case-control study to evaluate the relationship between cancer of the colon-rectum (n = 326), lung (n = 252), brain (n = 37), and pancreas (n = 37), and exposure to tetrachloroethylene (PCE) from public drinking water. Subjects were exposed to PCE when it leached from the vinyl lining of drinking-water distribution pipes. Relative delivered dose of PCE was estimated using a model that took into account residential location, years of residence, water flow, and pipe characteristics. Adjusted odds ratios (ORs) for lung cancer were moderately elevated among subjects whose exposure level was above the 90th percentile whether or not a latent period was assumed [ORs and 95% confidence intervals (CIs), 3.7 (1.0-11.7), 3.3 (0.6-13.4), 6.2 (1.1-31.6), and 19.3 (2.5-141.7) for 0, 5, 7, and 9 years of latency, respectively]. The adjusted ORs for colon-rectum cancer were modestly elevated among ever-exposed subjects as more years of latency were assumed [OR and CI, 1.7 (0.8-3.8) and 2.0 (0.6-5.8) for 11 and 13 years of latency, respectively]. These elevated ORs stemmed mainly from associations with rectal cancer. Adjusted ORs for rectal cancer among ever-exposed subjects were more elevated [OR and

CI, 2.6 (0.8-6.7) and 3.1 (0.7-10.9) for 11 and 13 years of latency, respectively] than were corresponding estimates for colon cancer [OR and CI, 1.3 (0.5-3.5) and 1.5 (0.3-5.8) for 11 and 13 years of latency, respectively]. These results provide evidence for an association between PCE-contaminated public drinking water and cancer of the lung and, possibly, cancer of the colon-rectum.

(37) *Pouvourville G. Public health research: between science and action? Cad Saude Publica 1999;15:889-94.*

In this text, we first propose a concept of public health research as a multidisciplinary endeavor whose aim is to identify the main determinants of people's health status, analyzed at the collective level. The public's health is thus envisioned as a socially determined reality, in which risk factors include biological phenomena as well as a given community's social and economic environment. Second, we argue that public health research should be applicable research, i.e. that it should be useful to decision-makers. But since the relationship between science and action is conflicting, it is necessary to invent mediatory practices to facilitate interaction between researchers and decision-makers.

(41) *Stoecker R. Are academics irrelevant? Roles for scholars in participatory research. American Behavioral Scientist 1999;42:840-854.*

Interest in participatory research has exploded over the past decade. Academics seem to follow three approaches in participatory research: the initiator, the consultant, and the collaborator. After discussing the approaches, this article argues that doing the research is not a goal in itself but only a means. Participatory research is actually part of a larger community change project that is dependent on four roles: "animator," community organizer, popular educator, and participatory researcher. Determining how the academic will fit in the project (as initiator, consultant, or collaborator) requires addressing three questions: What is the project trying to do? What are the academic's skills? and How much participation does the community need or want? The answers to these questions will vary according to how organized the community is.

(43) *Williams L. Participatory research, knowledge, and community-based change: Experience, epistemology, and empowerment. Research In Community Sociology 1999;9:3-40.*

(44) *Aschengrau A, Paulu C, Ozonoff D. Tetrachloroethylene-contaminated drinking water and the risk of breast cancer. Environ Health Perspect 1998;106 Suppl 4:947-53.*

We conducted a population-based case-control study to evaluate the relationship between cases of breast cancer and exposure to tetrachloroethylene (PCE) from public drinking water (n = 258 cases and 686 controls). Women were exposed to PCE when it leached from the vinyl lining of water distribution pipes. The relative delivered dose was estimated using an algorithm that accounted for residential history, water flow, and pipe characteristics. Only small increases in breast cancer risk were seen among ever-exposed women either when latency was ignored or when 5 to 15 years of latency was considered. No or small increases were seen among highly exposed women either when latency was ignored or when 5 years of latency was considered. However, the adjusted odds ratios (ORs) were more increased for highly exposed women when 7 and 9 years of latency, respectively, were considered (OR 1.5, 95% CI 0.5-4.7 and OR 2.3, 95% CI 0.6-8.8 for the 75th percentile, and OR 2.7, 95% CI 0.4-15.8 and OR 7.6, 95% CI 0.9-161.3 for the 90th percentile). The number of highly exposed women was too small for meaningful analysis when more years of latency were considered. Because firm conclusions from these data are limited, we recently undertook a new study with a large number of more recently diagnosed cases.

(45) Baker EA, Brownson CA. *Defining characteristics of community-based health promotion programs. J Public Health Manag Pract* 1998;4:1-9.

Community-based health promotion programs have flourished over the past twenty years. These programs have varied considerably in their goals and in their approaches to reaching these goals. While some flexibility is critical to program effectiveness, it is also important to determine a set of defining characteristics in order to distinguish community-based programs from other types of health promotion activities. In this article, we examine some of the defining characteristics of community-based health promotion programs, and the challenges faced by practitioners who wish to engage in this type of work.

(46) Israel BA, Schulz AJ, Parker EA, Becker AB. *Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health* 1998;19:173-202.

Community-based research in public health focuses on social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Partners contribute their expertise to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to benefit the community involved. This review provides a synthesis of key principles of community-based research, examines its place within the context of different scientific paradigms, discusses rationales for its use, and explores major challenges and facilitating factors and their implications for conducting effective community-based research aimed at improving the public's health.

(47) Macaulay AC, Delormier T, McComber AM, et al. *Participatory research with native community of Kahnawake creates innovative code of research ethics. Canadian Journal Of Public Health Revue Canadienne De Sante Publique* 1998;89:105-108.

Participatory research requires ethical guidelines to incorporate the needs of the partners, i.e., the researchers and the community. This paper describes the background, development and implementation of an innovative Code of Research Ethics developed for a participatory research project with a Native community in Canada. The document ensures that responsibility and control will be shared by both researchers and community throughout the project including joint publication of the results. It defines community control of data, means of resolving dissension at time of publication, incorporation of new researchers and the differences between community-based and academic researchers.

(51) Parker EA, Eng E, Laraia B, et al. *Coalition building for prevention: lessons learned from the North Carolina Community-Based Public Health Initiative. J Public Health Manag Pract* 1998;4:25-36.

This article examines the four-year development of the North Carolina Community-Based Public Health Initiative consortium (NC CBPHI). The NC CBPHI consisted of four separate county coalitions and differed in both its agenda and membership from the many examples of coalitions described in the literature. This article presents and describes evaluation findings that identify six factors as important in coalition functioning and success in the CBPHI coalitions. These factors are: participation, communication, governance and rules for operation, staff/coalition member relationships, technical assistance and skills training, and conflict recognition and containment. Selected CBPHI coalition activities are also described and implications for public health practitioners are presented.

(53) Schell LM, Tarbell AM. *A partnership study of PCBs and the health of Mohawk youth: lessons from our past and guidelines for our future. Environ Health Perspect 1998;106 Suppl 3:833-40.*

This paper describes a research partnership between the people of Akwesasne and researchers from the State University of New York at Albany for the study of polychlorinated biphenyls and the health of Mohawk youth. The study is distinctive because its goals have been set by the scientists and the community members and is being conducted jointly by these groups. The research partnership recognizes the history of relationships between native and nonnative peoples, particularly scientists, and seeks not only to fulfill certain scientific goals but to further community ones as well. The relationship is based on three principles: mutual respect, mutual equity, and mutual empowerment. These principles guided every aspect of the research process. The project goals were determined jointly to maximize data quality and minimize the intrusion of research activities into the lives of community members. Data collection is performed by research assistants who received extensive and ongoing training in data collection methods, and who are members of the community. Feedback procedures were designed by community members and scientists jointly to maximize understanding. Feedback regarding individuals' pollutant levels and assessments of growth and development are provided to each individual. Information about community pollutant levels are provided to the community. Hypothesis testing is carried out by research scientists, and the results presented first at a community meeting. Research conducted in this way--as a partnership--requires more communication, discussion, and travel, but the result is mutual satisfaction and growth.

(54) Schulz AJ, Parker EA, Israel BA, Becker AB, Maciak BJ, Hollis R. *Conducting a participatory community-based survey for a community health intervention on Detroit's east side. J Public Health Manag Pract 1998;4:10-24.*

This article describes a participatory action research process that brought together community members, representatives from community-based organizations and service providers, and academic researchers to collect, interpret, and apply community information to address issues related to the health of women and children in a geographically defined urban area. It describes the development and administration of a community-based survey designed to inform an intervention research project; discusses the establishment of a community/research partnership and issues that the partnership confronted in the process of developing and administering the survey; and examines the contributions of participants, and implications for research and collective action.

(56) Smith MH. *Community-based epidemiology: community involvement in defining social risk. J Health Soc Policy 1998;9:51-65.*

In traditional epidemiologic research, the concept of risk emerges from a biomedical paradigm which draws heavily upon Cartesian-Newtonian ontological assumptions. Rational assessment of individual risk is based on a culturally conditioned metatheoretical framework that seeks specific causes for specific disease conditions. This leads to the identification of "risk factors" that can be individually modified. Research within this orientation tends to produce interpretations of data which further condition and mold cultural understanding of individual and social risks and the available choices that can be made to modify these risks. Community-based eco-epidemiology balances reductionist tendencies of individual risk-factor analysis against social context and local knowledge gained through community involvement in the research process. The community-based partnership model can contribute to a greater understanding of the interrelatedness of social problems and individual risks on the part of community participants and researchers alike.

(57) Tandon SD, Azelton LS, Kelly JG, Strickland DA. *Constructing a tree for community leaders: Contexts and processes in collaborative inquiry. American Journal Of Community Psychology* 1998;26:669-696.

This paper presents collaborative research between a university-based team and a grass roots community organization on the south side of Chicago. The purpose of the work is to document the nature of community leadership as expressed by members of the host organization. Using a semistructured interview, 77 community members nominated by the host organization were asked about various aspects of their community work. Qualitative analyses of interview text generated a set of 56 codes concerning different aspects of community leadership as reported by grassroots leaders. These codes were subsequently grouped together into five conceptually linked dimensions of community leadership. A "leadership tree" that simultaneously analyzes and visually displays each of these five dimensions of community leadership was created. Implications of the methodology used to create the leadership tree are discussed for the salience of qualitative methods in community research.

(60) Schwab M, Syme SL. *On paradigms, community participation, and the future of public health. Am J Public Health* 1997;87:2049-51; discussion 2051-2.

(61) Aschengrau A, Ozonoff D, Coogan P, Vezina R, Heeren T, Zhang Y. *Cancer risk and residential proximity to cranberry cultivation in Massachusetts. Am J Public Health* 1996;86:1289-96.

OBJECTIVES: This study evaluated the relationship between cancer risk and residential proximity to cranberry cultivation. **METHODS:** A population-based case-control study was conducted. Cases, diagnosed during 1983 through 1986 among residents of the Upper Cape Cod area of Massachusetts, involved incident cancers of the lung (n = 252), breast (n = 265), colon-rectum (n = 326), bladder (n = 63), kidney (n = 35), pancreas (n = 37), and brain (n = 37), along with leukemia (n = 35). Control subjects were randomly selected from among telephone subscribers (n = 184), Medicare beneficiaries (n = 464), and deceased individuals (n = 723). **RESULTS:** No meaningful increases in risk were seen for any of the cancer sites except for the brain. When latency was considered, subjects who had ever lived within 2600 ft (780 m) of a cranberry bog had a twofold increased risk of brain cancer overall (95% confidence interval [CI] = 0.8, 4.9) and a 6.7-fold increased risk of astrocytoma (95% CI = 1.6, 27.8). **CONCLUSIONS:** Residential proximity to cranberry bog cultivation was not associated with seven of the eight cancers investigated; however, an association was observed with brain cancer, particularly astrocytoma. Larger, more detailed studies are necessary to elucidate this relationship.

(62) Brown L, Vega W. *A protocol for community-based research. Am J Prev Med* 1996;12:4-5.

(63) Cole DC, Tarasuk V, Frank JW, Eyles J. *Research responses to outbreaks of concern about local environments. Arch Environ Health* 1996;51:352-8.

Traditional epidemiological approaches based on biomedical models may be limited with respect to their response to "outbreaks of concern" among work-force or community populations. Three published Canadian "outbreaks" were reviewed in this study. In all three instances, research was initiated because lay persons were concerned about either nonspecific symptoms or hazardous exposures, and individuals publicly called for a response. Epidemiologic analyses were inconclusive as to the reasons for the outbreaks, and they contributed little toward the resolution of concerns. There is a need for a fuller recognition of the role of social context and of the action-oriented nature of such research. The elucidation of multifactorial and culturally mediated causation, as well as the development of remedial actions, require a rethinking of research methods. We specifically call for (a) an expansion of the

disciplinary base of research teams to include social scientists, and (b) the adoption of combined qualitative and quantitative research approaches.

(66) Goldman LR, Anton-Culver H, Kharrazi M, Blake E. Banking of human tissue for biomonitoring and exposure assessment: utility for environmental epidemiology and surveillance. *Environ Health Perspect* 1995;103 Suppl 3:31-4.

Human tissue banking could provide a tool to address a number of public health concerns. We can potentially use it to monitor trends in human exposures, serve as an early warning system for new environmental exposures, assess low-level exposures around hazardous waste and other point sources of pollutants, evaluate the effectiveness of regulatory programs, and study etiologies of diseases (e.g., childhood cancer and birth defects) that are likely to be related to the environment. This article discusses opportunities to establish human tissue banks in connection with pre-existing public health surveillance programs for cancer and adverse reproductive outcomes. This is a cost-effective way to conduct surveillance and enhances the ability to carry out epidemiologic studies. The article also discusses ethical issues that are particularly important for public health practice. One is the issue of risk communication and the need to explain risks in a way that provides people with the information they need to determine appropriate action on the individual and community levels. Second is the issue of environmental justice. We recommend early involvement of communities that are likely to be involved in tissue-banking projects and full explanation of individual and group social risks from their participation.

(67) Kelley BR. Community-based research: a tool for community empowerment and student learning. *J Nurs Educ* 1995;34:384-6.

Teaching Nursing Research is most often done close to the end of the student's educational experience. This article describes Northeastern University College of Nursing's experience using community-based research projects as a method of teaching nursing concepts and skills to beginning nursing students. By using Paulo Freire's model of Community Empowerment, a group of inner-city teens developed a drug awareness manual that is used to teach elementary school students about drugs and drug use. Through this model, students also learn that healthcare is a partnership among individuals, communities and professionals.

(68) Lillie-Blanton M, Hoffman SC. Conducting an assessment of health needs and resources in a racial/ethnic minority community. *Health Serv Res* 1995;30:225-36.

This article examines strategies and methodologic issues for researchers to consider when conducting community-based research within a racial/ethnic minority community. Members of minority communities have considerable skepticism about the health care system and researchers who work under its auspices. To facilitate quality research, it is necessary to build a mutually beneficial partnership between the community and researchers. Suggested strategies for accomplishing this goal, such as seeking out information on the social and political forces shaping the community and developing the community's capacity to undertake research of this type, are described. Methodologic issues include the importance of community input in defining the minority population group and its leadership, the benefits and limitations of conducting comparative analysis, and the need for measurement tools and techniques that are culturally and socially appropriate. Minority and nonminority researchers must make a concerted effort to gain knowledge of and respect for a community whose culture, values, and beliefs may differ from their own.

(76) Aschengrau A, Ozonoff D, Paulu C, et al. Cancer risk and tetrachloroethylene-contaminated drinking water in Massachusetts. *Arch Environ Health* 1993;48:284-92.

A population-based case-control study was used to evaluate the relationship between cases of bladder cancer (n = 61), kidney cancer (n = 35), and leukemia (n = 34) and exposure to

tetrachloroethylene from public drinking water. Subjects were exposed to tetrachloroethylene when it leached from the plastic lining of drinking water distribution pipes. Relative delivered dose of tetrachloroethylene was estimated, using an algorithm that accounted for (1) residential history and duration, (2) whether lined pipe served the neighborhood, (3) distribution system flow characteristics, and (4) pipe age and dimensions. Whether or not latency was considered, an elevated relative risk of leukemia was observed among ever exposed subjects (adjusted OR = 1.96, 95% CI = 0.71-5.37, with latency; adjusted OR = 2.13, 95% CI = 0.88-5.19, without latency) that increased further among subjects whose exposure level was over the 90th percentile (adjusted OR = 5.84, 95% CI = 1.37-24.91, with latency; adjusted OR = 8.33, 95% CI = 1.53-45.29, without latency). When latency was ignored, there was also an increased relative risk of bladder cancer among subjects whose exposure level was over the 90th percentile (adjusted OR = 4.03, 95% CI = 0.65-25.10). Given that tetrachloroethylene is a common environmental and workplace contaminant in the United States, its carcinogenic potential is a matter of public health concern.

(77) Bullard RD, Wright BH. *Environmental justice for all: community perspectives on health and research needs. Toxicol Ind Health* 1993;9:821-41.

Some individuals, groups, and communities are at special risk from environmental threats. This is especially the case for low income persons, the working class, and people of color whose health may be imperiled by lead in their houses, pollution in their neighborhoods, and hazards in their workplace. Moreover, many of their children face potential health threats in the parks where they play. The environmental justice perspective unmaskes the ethical and political questions of "who gets what, why, and in what amounts." An environmental and public health strategy is needed to ensure that all Americans are protected.

(78) Hatch J, Moss N, Saran A, Presley-Cantrell L, Mallory C. *Community research: partnership in black communities. Am J Prev Med* 1993;9:27-31; discussion 32-4.

(80) Ostry AS, Hertzman C, Teschke K. *Community risk perception: a case study in a rural community hosting a waste site used by a large municipality. Can J Public Health* 1993;84:415-8.

Using a model of risk perception which divides the community into attitudinal and behavioural subgroups based on awareness, concern and action in relation to a waste management facility, we conducted a survey in a community with an operating landfill and a ten-year history of controversy over the unsuccessful siting of a hazardous waste facility (HWF). The purpose of the survey was to study community attitudes to waste management in general, attitudes specific to landfills and HWFs, and to identify factors which shape community attitudes in both cases. Levels of concern and activism were lower for the landfill; activism and concern were more likely among younger subjects and those with children. In the case of the HWF, greater concern and activism were more likely among married people and those without a university education. Gender differences in relation to environmental "concern" were not found for either the landfill or the HWF siting attempts.

(81) Brown P. *Popular epidemiology and toxic waste contamination: lay and professional ways of knowing. J Health Soc Behav* 1992;33:267-81.

Building on a detailed study of the Woburn, Massachusetts, childhood leukemia cluster, this paper examines lay and professional ways of knowing about environmental health risks. Of particular interest are differences between lay and professional groups' definitions of data quality, methods of analysis, traditionally accepted levels of measurement and statistical significance, and relations between scientific method and public policy. This paper conceptualizes the hazard-detection and solution-seeking activities of Love Canal, Woburn, and other communities as

popular epidemiology: the process by which lay persons gather data and direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease, treat existing and prevent future disease, and remove the responsible environmental contaminants. Based on different needs, goals, and methods, laypeople and professionals have conflicting perspectives on how to investigate and interpret environmental health data.

(82) Sandman PM. *Emerging communication responsibilities of epidemiologists. J Clin Epidemiol* 1991;44:41S-50S.

Epidemiologists are increasingly called upon to communicate with affected publics when designing, interpreting, and reporting their work. The author offers eight guidelines for public communication: (1) Tell the people who are most affected what you have found--and tell them first. (2) Make sure people understand what you are telling them, and what you think its implications are. (3) Develop mechanisms to bolster the credibility of your study and your findings. (4) Acknowledge uncertainty promptly and thoroughly. (5) Apply epidemiological expertise where it is called for, and do not misapply it where it is unlikely to help. (6) Show respect for public concerns even when they are not "scientific"; (7) Involve people in the design, implementation, and interpretation of the study. (8) Decide that communication is part of your job, and learn the rudiments--it's easier than epidemiology.

(83) Sherman JA, Sheldon JB. *Values for community research and action: do we agree where they guide us? J Appl Behav Anal* 1991;24:653-5.

(84) Braithwaite RL, Lythcott N. *Community empowerment as a strategy for health promotion for black and other minority populations. Jama* 1989;261:282-3.

(85) Braithwaite RL, Murphy F, Lythcott N, Blumenthal DS. *Community organization and development for health promotion within an urban black community: a conceptual model. Health Educ* 1989;20:56-60.

The community organization and development process is not new and has its roots in social action ideology from the 1960s. The difference between the 1960s and the 1990s is in bringing together of target community consumers with representatives of private and public sector resources (with consumers in the majority), to form a community coalition board. This community coalition board must make policy decisions. Combining these community organizers and development techniques with the mission of health promotion is a viable methodology for addressing the needs of medically underserved and unserved communities. The approach is a multifactorial one, as illustrated in Figure 1. The Health Promotion Resource Center at Morehouse School of Medicine seeks to combine the ideology of community organization and development with culturally sensitive and linguistically appropriate health promotion curriculum materials and intervention strategies. Within the HPRC lies the Statewide Coordinating Center for Georgia which has been funded by the Henry J. Kaiser Family Foundation. Its mandate is to assist minority and poor communities in Georgia in developing community-based health promotion initiatives which address the areas of cancer, cardiovascular disease, adolescent pregnancy, substance abuse, and violence and unintentional injury. Our strategy in carrying out this mandate is the community organization and development model described in this article.

(86) Chavis DM, Stucky PM, Wanderman A. *Returning basic research to the community: A relationship between scientist and citizen. Am Psychol* 1983;38:424-434.

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