Robert E. McKeown[1], Douglas L. Weed[2]

[1] *Department of Epidemiology and Biostatistics, Arnold School of Public Health, University South Carolina, Columbia, SC*
[2] *Division of Cancer Prevention, National Cancer Institute, Rockville, MD*

Ethical choices in survey research

Ethics is about choices. Not arbitrary choices, nor matters of taste, but choices with moral weight about what ought to be done because it is the right thing to do. Ethics is about real-life dilemmas that demand we as researchers make choices between what may appear to be equally undesirable alternatives. Ethics is about rational reflection on alternatives and on the principles, values, and obligations that inform our choice among them. In the first installment of the Hints & Kinks series (Galobardes 2002), Dr. Galobardes noted that *"choices are made at each step of the survey",* choices that are not driven solely by statistical, epidemiologic, psychometric, or logistical considerations. Many choices in survey research are shaped by the principles, values, and obligations of ethics (Weed & McKeown 2001). In the short space of this article we have chosen to focus on two broad areas: the obligation of the researcher to the survey participant and ethical considerations in methodologic decision-making. Both have particular pertinence in survey research.

(1) Asking difficult or sensitive questions has been a topic within survey research for some time, often focusing on how to get the most reliable information rather than on the ethical issues involved. Much of the thinking in research ethics revolves around respect for persons who agree to be research subjects (McKeown & Weed 2002). That means, at least, being sensitive to the impact the research may have on survey participants. But there is a deeper obligation to research subjects who, after all, provide the essential data on which all research depends. By asking persons to participate in research, we enter a relationship of trust and confidence. If participation in the research carries risk or causes harm, then we have an obligation to minimize the risk and rectify the harm for these persons who have voluntarily agreed to assist us in our research.

For example, prior warnings in an informed consent of sensitive or private questions and reminders of the option to refuse to answer may not be enough. If we ask questions that can induce stress or anxiety, then we also have an obligation to assist those who are affected by those questions. If surveys include questions on topics such as suicidal behavior, physical or sexual abuse, or threats of harm to others, researchers should have in place procedures to respond, including additional measures for further assessment and referral. This perspective is grounded in a view of the researcher – respondent relationship as one of voluntary mutual commitments, with the greater obligation falling to the researcher because more is being asked of the respondent, generally without benefit in survey research.

In studies of mental disorders in children using both questionnaires and structured interviews with parents and older children, one of us (Robert E. McKeown) has developed a tiered approach to responding to participant problems. A psychiatrist is on call so that if responses indicate imminent harm to self or others, there can be an immediate assessment and referral. For in-person interviews, the child is asked to remain until someone speaks to him/her and an in-person assessment can determine if immediate action is needed. If responses are indicative of serious mental or behavioral problems without imminent threat of harm, records are flagged for later evaluation by the psychiatrist. Based on this assessment, a determination is made concerning immediate contact by phone or, failing phone contact, certified mail, to notify the parent or older adolescent of need for follow-up evaluation. If responses are suggestive of problems that are not urgent or severe, a letter is sent explaining the possible need for further evaluation or treatment, with a list of referral resources. Contact is made with the parent for those under age 16, to both parent and youth for those 16 and 17, and to the participant for those 18 and older. In all cases the letters indicate that no definitive diagnosis has been made and that some indications could be a reflection of a temporary mood. If there are no problems indicated, a letter to that effect is sent, with contact information in case there are concerns or questions.

Soz.- Präventivmed. 49 (2004) 67–68
0303-8408/03/010067–2
DOI 10.1007/s00038-003-3019-1

(2) Ethical concerns can arise with regard to methodologic decisions. For example, when defining the target population, has due consideration been given to under-represented or understudied populations? Conversely, is the target population one that has been subject to many research projects with little input in design, objectives, or uses of the results? Have the participants been studied without receiving commensurate benefits from the findings? One of the guiding principles of bioethics, typically called the principle of justice, is that the burdens and benefits of research should be fairly distributed. Under-studied populations may not share in the benefits because they have not been part of past research. Further, if there are important differences in populations, failure to include some groups means we fail to discover and understand those differences. In the United States, for example, the African American community has often been either excluded from research, especially clinical trials, or exploited in research (Shavers-Hornaday et al. 1997; Shavers et al. 2002). Exclusion makes it more difficult to understand the basis for the disparities we continue to observe in health outcomes. Past mistreatment deprived research populations of benefits, and contributed to mistrust that now makes research more difficult (Thomas & Quinn 1991). Other issues involve research in vulnerable populations. For example, the elderly have special needs and concerns that should be considered in order to avoid coercion, facilitate participation without undue burden or embarrassment, and provide special protections from harms.

Community-based research offers some interesting examples. Surveys should provide some benefit to the communities that bear the burden of the research. In small area surveys, that may take the form of input into design by representatives of the target population, or reports or feedback to affected groups. Alternatively, researchers may want to consider community focus groups to refine the survey, a community advisory board to guide implementation and response, community-based interviewers, newsletters for participants, and additional focus groups to advise and evaluate intervention materials developed based on the survey results. For large surveys, pilot testing in vulnerable populations with input from informed representatives could be implemented.

In the short space of this article we can only mention two areas of ethical issues likely to be encountered in survey research. We take the position that the choices survey researchers make at each step of the survey process often have ethical content. We have an obligation to probe the ethical dimensions of those decisions for the sake of those we hope to enroll as respondents as well as for the sake of conducting our research responsibly and with integrity.

References

Galobardes B (2002). Key steps in planning a survey. Soz Praventiv Med *47*: 349–51.

McKeown RE, Weed DL (2002). Glossary of ethics in epidemiology and public health: II, applied terms. J Epidemiol Community Health *56*: 739–41.

Rhodes SD, Bowie DA, Hergenrather KC (2003). Collecting behavioural data using the world wide web: considerations for researchers. J Epidemiol Community Health *57*: 68–73.

Shavers VL, Lynch CF, Burmeister LF (2002). Racial differences in factors that influence the willingness to participate in medical research studies. Ann Epidemiol *12*: 248–56.

Shavers-Hornaday VL, Lynch CF, Burmeister LF, Torner JC (1997). Why are African Americans under-represented in medical research studies? Impediments to participation. Ethn Health *2*: 31–45.

Thomas SB, Quinn SC (1991). The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV Education and AIDS Risk Education Programs in the Black Community. Am J Public Health *81*: 1498–504.

Weed DL, McKeown RE (2001). Glossary of ethics in epidemiology and public health: I, Technical terms. J Epidemiol Community Health *55*: 855–7.

Address for correspondence

Robert E. McKeown, PhD
Department of Epidemiology
and Biostatistics
Arnold School of Public Health
University of South Carolina
Columbia, SC 29208, USA