Re: Outram SM. Epidemiology and Bioethics: A Plea for Reconnecting With the Public. [Ethics in Public Health] *Can J Public Health* 2011;102(1):4-6.

Dear Editor:

The arguments to reconnect both epidemiology and bioethics with the public are compelling and worthy of attention. I point out that many, if not most, professional societies have developed ethics guidelines (code of ethics). Guidelines are essentially designed to promote such functions through their articulation of normative practices. Thus, it was surprising to me to read this important contribution in the January/February issue and find no reference to ethics guidelines.

Ethics guidelines were first developed in 1991 by occupational epidemiologists.¹ But it was in 1996 that the International Society for Environmental Epidemiology (ISEE) emerged as a leader in bridging the fields of epidemiology and ethics along the lines encouraged by Outram. Indeed, several of the key points that Outram appeals to are made in the ethics guidelines published by the ISEE in 1996² and present on its website since 1999.² To quote from these guidelines:

From Article 4.1.2. "Consultation with stakeholders"

Possible mechanisms of consultation with members of affected groups or their representatives should be sought wherever appropriate. Study protocols should address potential concerns of affected groups and should articulate any potential negative consequences of the study to any individuals or groups. Environmental epidemiologists should inform the public about risks and benefits for individuals and communities resulting from environmental epidemiological research and practice.

From Article 4.2.4. "Widening the scope of environmental epidemiology"

There are general obligations in environmental epidemiology to carry out research, to advance knowledge, and to protect the public health. Environmental epidemiologists should employ the means available to them to enlarge the reach of sound epidemiologic inquiry and to disseminate their findings so that the widest possible community benefits from the research. Whenever information has been obtained that would be valuable to the larger epidemiologic or public health community, the information should be shared and should remain free of distortions that might be introduced by preconceptions or organized policies – irrespective of whether the research is conducted with private or public funds.

From Article 4.2.5. "Community involvement"

Discussions should be initiated at international, national and regional levels to facilitate community involvement and resolution of issues in environmental epidemiology practice... A project steering committee made up of representatives of all stakeholder groups is suggested as one mechanism for addressing these kinds of issues.

Research involving a community ought to include from the inception, or certainly prior to the formal design stage, through to completion of the study, community representatives (a) knowledgeable about the science (e.g. union and health representatives) and (b) affected by the problem being investigated (e.g. community stakeholders and also the unempowered). The Institutional Review Board, or its equivalent in different countries (e.g. in the European Union: Research Ethics Committee; in Canada: Research Ethics Board) likely will include lay community representatives. However, the researcher's task is to ensure that community input through

the entire research process, from conception of the question to hypothesis formulation, methods selection, analysis, interpretation and dissemination is included in a partnership capacity with the principal investigator.

I believe that the above selected Articles speak to the key points made by Outram. What is alarming is that while these guidelines have been in existence for some 15 years, their degree of uptake seems far lower than what is needed. Perhaps some mechanism for including these guidelines in training programs would help to achieve greater ethical literacy among professionals in epidemiology. I point out that the ISEE is currently revising/updating its ethics guidelines.

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REFERENCES

1. Beauchamp TL, Cook RR, Fayerweather WE, Raabe GK, Thar WE, Cowles SR, Spivey GH. Ethical guidelines for epidemiologists. *J Clin Epidemiol* 1991;44(Suppl 1):151S-169S.
2. Soskolne CL, Light A. Towards ethics guidelines for environmental epidemiologists. *The Science of the Total Environment* 1996;184(1,2):137-47. Available at: <http://www.iseepi.org/about/ethics.html> (Accessed March 29, 2011).

Author's Response

Dear Editor:

I would like to applaud the comments made, especially given my academic background in environmental epidemiology and interests in global health. I was particularly struck with the line quoted from the ISEE guidelines concerning the dissemination of "findings so that the widest possible community benefits from the research." I applaud this sentiment and the ISEE guidelines and would hope that more funding review boards, epidemiology curriculum developers, and journal editorial boards would take time to reflect upon the objective of epidemiology (not just environmental epidemiology) to benefit the many, not just the privileged few. I also agree with Dr. Soskolne that the degree of uptake regarding this objective is far less than it should be. The article itself is not, and should not, be seen as a new direction in epidemiology (or bioethics). Instead, I think – and hope – that many of us coming from both epidemiology and bioethics academic backgrounds continually struggle with how to make our contribution heard outside of even a narrow academic community. But I believe that one way of possibly making that contribution heard is to take on questions that are more globally and socially worthy, rather than academically complex. The guidelines issued by ISEE appear to be a strong step in the right direction and I welcome the revision of these guidelines in the light of persistently under-addressed disparities in global health.

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