

Population Health Research Wins "Reprieve" in Europe

After some 4 years of debate, the European Parliament recently reached a decision of fundamental significance to the conduct of epidemiologic research.¹ The decision allows data files containing personal identifiers to continue to be used for large-scale epidemiologic research. Studies involving personal file linkages came to the brink of being outlawed through what was (then) termed the Proposed Data Protection Directive.

The promulgated draft legislation within the European Union had been noted by epidemiologists²⁻⁶ and by others^{7,8} for several years. It was only as the "point of no return" was approaching that some epidemiologists made a last-ditch attempt to avert the passing of potentially calamitous legislation.⁹⁻¹² Among others,¹³ the International Society for Environmental Epidemiology (ISEE) was able to play an advocacy role in averting a serious threat to the ability of epidemiologists to conduct studies involving personal data in the public health interest.

The legislation that recently passed remained essentially unchanged with but one important exception added at the final stages: an added exemption that permits the kinds of work in which epidemiologists are engaged.¹⁴

One lesson to emerge is the importance of professional organizations of epidemiologists and of others engaged in population-based research remaining abreast of developments in the area of data privacy. It is only when professional groups are sensitive to the issues being discussed in government that they can posture themselves to provide input to the legislative process and respond to threats that could unjustifiably limit their activity.¹⁴ Indeed, some Australian epidemiologists saw fit to begin the process of education right away to prevent such proposals from ever reaching their legislatures.¹⁵

In the case of the recent European data protection directive, the data protectionist movement had been applying pressure on representatives in the various legislative bodies comprising the European Union. The concern for data protection is, of course, well founded. Data protectionists, however, appear to have been operating without input about what the loss to the public interest would be if access to all

personal records for research purposes were outlawed.

Ethics guidelines for epidemiologists were initiated in the late 1980s.¹⁶ Drawing on these guidelines, epidemiologists have been able to point out that they have: (a) a demonstrated track record of protecting confidentiality, (b) ethics guidelines and standards of practice that ensure adherence to privacy protection, and (c) a track record of conducting research that has served the public interest (see Ref 13, ISEE letter to Delors). This record likely contributed to a balance struck at the last minute between the need to protect the individual's right to privacy and the public's benefit from access to population-based data for research purposes by qualified professionals.

In countries where this problem has not surfaced, it would behoove professional groups of population researchers to apprise themselves of the issues. In this way, they would be ready—when the data protection movement gains momentum—to contribute to the debate and the legislative process.^{14,17} The Australian effort in this regard serves as a good model.¹⁵

At a Workshop of the ISEE in 1994, jointly organized with the World Health Organization (WHO), a recommendation was made encouraging the WHO to convene meetings of social and health researchers with data protection advocates to address the implications of data protection on public health and social and health research.¹⁷ Such meetings could serve to prevent a repeat of the near-catastrophic legislation that could have curtailed research so helpful to the public's social and health interests. In addition, epidemiologists would remain sensitized to the need to maintain privacy.

History has shown that the data protectionist movement can easily set the pendulum swinging in the direction of protecting individual privacy. The social and health professions need to be vigilant of this and be ready to play their full and responsible role in contributing to the public debate on such matters.

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