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Guidelines on ethical and legal considerations in anonymous unlinked HIV seroprevalence research

A committee of experts has published ethical guidelines regarding seroprevalence research into human immunodeficiency virus (HIV) (*Can Med Assoc J* 1990; 143: 625-627), which researchers will be expected to follow. To do so would be a mistake, because the guidelines and the process of arriving at them are seriously flawed.

The committee, the Federal Centre for AIDS Working Group on Anonymous Unlinked HIV Seroprevalence, asserts that what is for the benefit of the public overrides individual rights regard-

ing informed consent. Yet the committee does not adequately represent either the general public or patient advocate groups. There can be no authoritative judgement without adequate representation.

Any abrogation of the right of informed consent has to have a very strong justification; the guidelines do not satisfactorily provide this. Indeed, there is confusion about the topic. The committee argues that "it would be reasonable not to require individual informed consent when testing leftover, permanently unlinked serum for HIV antibodies." Yet on the very next page is stated: "After learning more about the research [from public notices] some patients may request that their leftover serum not be included in the random selection of samples." So some patients — those who know and who object — do have consent regarding the use of their body fluids. But Canadians are a diverse group: a significant proportion is illiterate, and many have little understanding of their legal or moral rights. The committee's recommendations thus favour a highly educated, middle-class group.

Similarly, the question of what is in the public interest is not uncontentious; in fact, elections are fought over it. The working group was composed almost entirely of experts in research. This largely middle-class group asserts its own definition of what is to the benefit of Canadians generally. The committee has no legitimacy whatsoever in doing so, because its definition of the public interest is one bounded by the rather restricted horizons of its participants. Furthermore, this is true for ethical reviews of research

generally. We recommend that ethical committees assessing research that involves human subjects include representatives of the general public and of the subjects of the proposed research.

It might be argued that the presence of bioethicists in the working group was designed to reflect public interests. Yet even ethicists have particular values. Bioethics itself is a social movement with its own recruitment and organizational patterns and as such cannot provide a neutral point of view or represent the public interest.

Even with a better process for making ethical decisions, what then? What mechanisms exist to make sure that the processes approved by ethical committees actually take place? The answer seems to be Absolutely none! It is only assumed that researchers will carry out the procedures described in their research proposals. At present the discrepancy between proposal and practice, in so far as ethics is concerned, is completely unknown. We need ongoing monitoring of the adherence to ethical procedures.

Thus, the recommended guidelines regarding HIV seroprevalence research — and the composition of ethical review committees as a whole — are inadequate. They can be improved and given legitimacy through further emphasis on the importance of informed consent, increased public and subject participation and the establishment of monitoring mechanisms.

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