

Response to Dermot Maher article “The ethics of feedback of HIV test results in population-based surveys of HIV infection”

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Abstract

In the December issue of the Bulletin of the WHO Dermot Maher re-opened the debate about HIV testing and counselling in the context of research studies, arguing that researchers have a duty to inform participants of HIV test results if testing is done as part of the study. While we agree that this is desirable, there are practical and ethical reasons why participants should have the right to opt-out of receiving HIV test results.

Text

Maher [1] and others [2] argue that HIV testing and counselling benefits are so important that participants in studies that carry out HIV testing must be given their HIV test results, and subjects who decline to receive their test result should be excluded from study participation.

In early HIV surveillance studies there were many logistical issues that complicated the return of test results, and few advantages to infected individuals in receiving their HIV results [3]. Maher rightly points out that the situation has changed radically with the widespread roll-out of HIV treatment and care, which not only prolongs life, but also reduces sexual transmission of HIV. We agree that researchers now have an obligation to offer and encourage post-test counselling as part of a research encounter, but argue that there are both practical and ethical reasons to allow study participants to opt-out of post-test counselling.

In African populations with HIV prevalence above 4%, between 30 to 81% of infected men [and](#) women have ever tested for HIV [4]. Those who know they are HIV positive may be willing to donate blood samples for research purposes but may not want to repeat pre- and post- test counselling. This may also apply to those who feel certain that they are uninfected. Sexually active men and women are encouraged to test regularly, and for experienced testers, research studies should provide the option of receiving HIV results in a short format and allow opting-out of post-test counselling. They should also be prepared for participants who do not wish to collect test results in any format. All participants, including those who provide blood samples for research but opt-out of post-test counselling can be asked to report their testing histories and testing motives.

Importantly, these opt-out provisions align with general principles of research ethics. We agree with Maher that there is public health utility in informing people of their HIV status, but we think this does not override the ethics of respect for individual autonomy. Informed consent procedures typically tell willing subjects that they have a right to not answer questions that make them uncomfortable, or to withdraw from the study at any time without completing all the activities/procedures. Declining to receive a test result is an example of the right of participants to opt-out of part of a study. Whether in research or clinical practice, public health utility would be better served through understanding peoples’ reasons for not wanting to receive an HIV test result, whilst informing individuals about all available testing and counselling options.

Rather than excluding those who decline post-test counselling, we have the obligation to better understand reasons for research participation, including attitudes to learning/confirming one’s HIV status. Longitudinal studies with repeated HIV testing are particularly well-placed to investigate decision-making around HIV

testing, [and](#) could demonstrate whether refusal could lead to biased HIV prevalence estimates affecting the public health utility of the data [5,6], and [can](#) teach us about people's motivations to test [7], leading to improved design of HIV testing programmes.

References

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Cover letter

This contribution is written by a group of scientists who are actively engaged in community-based HIV surveillance studies in Africa. It argues that the viewpoint expressed in the article by Dermot Maher: "The Ethics of Feedback of HIV test results in population-based surveys of HIV infection" published in *Bull WHO* 91:950-956 missed some important circumstances in which it would be practical or ethical to allow a study participant to decline to know their HIV test result.