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Round table discussion

Understanding why people participate in HIV surveillance

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People have argued that the benefits of human immunodeficiency virus (HIV) testing and counselling are so important that participants in HIV surveys must be given their HIV test results and that individuals who decline to receive their test results should be excluded from participation in such surveys.^{1–3}

In early attempts at HIV surveillance, there were many logistical issues that complicated the return of test results and few advantages to infected individuals in receiving their test results.⁴ Now the situation has changed radically with the widespread roll-out of HIV treatment and care – which not only prolongs life but also reduces sexual and vertical transmission of HIV.² 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% and 81% of infected men and women have ever been tested for HIV.⁵ 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. The same may be true of those who feel certain that they are uninfected. Sexually active men and women are encouraged to be tested regularly. Research studies should provide the option for those who arrange to be frequently retested – so-called repeat testers – to be given their test results in a short format and be allowed to opt out of post-test counselling. They should also be prepared for participants who do not wish to collect their 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, the opt-out provisions we discuss here align with the general principles of research ethics. We agree that there is public health utility in informing people of their HIV status but we think that this should not override the ethics of

respect for individual autonomy. Informed consent procedures typically tell willing subjects that they have a right not to answer questions that make them uncomfortable and a right to withdraw from the study at any time without completing all the activities and 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 – while informing individuals about all of the available testing and counselling options.

Rather than excluding those who decline post-test counselling, we have the obligation to understand the reasons for research participation – and non-participation – better, including attitudes to learning or confirming one's HIV status. Longitudinal studies with repeated HIV testing are particularly well placed to investigate decision-making around HIV testing. The results of such studies could demonstrate whether refusal to participate or receive test results lead to biased estimates of HIV prevalence that weaken the public health utility of the data.^{6,7} They could also teach us about why and how people become motivated to be tested⁸ and that knowledge could lead to improvements in the design of programmes of HIV testing. ■

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Accurate information as a tool to decrease HIV test refusals in research studies

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It has been argued that researchers conducting surveys that include testing for human immunodeficiency virus (HIV) have a duty to tell potential subjects that they do not have the right to participate if they refuse to receive their HIV test results.^{1,2} Furthermore, promotion of the routine feedback of such test results has been based on the grounds that knowledge is power and information is liberation.³ However, other researchers argue that, although it is desirable to offer study participants post-test counselling, for practical and ethical reasons some study participants should be given the right to refuse such counselling.⁴ Although we support the right of participants to opt out of post-test counselling and thus not to receive their test results, we also propose that subjects who are – or may be – tested for HIV should be given information that may decrease their resistance to learning their test results. We draw on data, collected between 1998 and 2013, on rural Malawians' experience with – and perceptions of – HIV testing.

From the perspective of the organizations that promote HIV testing, it is axiomatic that people will benefit from knowing their HIV status. In Maher's view, such benefit justifies sanctioning those who refuse to receive their test results.² We disagree, for two reasons. First, the experience of many Malawians is that refusal to consent to testing may have serious consequences. For example, although the policy

for antenatal HIV testing in Malawi includes an opt-out provision, accounts from pregnant women attending antenatal clinics show that HIV testing is compulsory if the women are to receive antenatal care.⁵ Moreover, in population-based HIV surveys, fieldworkers are always under pressure to minimize the numbers of test refusals and may exert undue pressure on individuals who do not want to receive their test results. While exclusion from antenatal services is, presumably, much more serious than exclusion from survey participation, in both of these examples people are sanctioned for not giving consent – which is a clear ethical violation.

Second, our ethnographic data depict the anguish that many suffer as they anticipate the future receipt of their test results – an issue that has rarely been discussed in the public health and social science literature.⁶ Two common misperceptions among rural Malawian adults are that the result of an HIV test will almost always be positive and that a positive result will inevitably be followed by hastening psychological deterioration, suicidal thoughts and death. Yet survey data from people living in rural Malawi show that between 80% and 90% of respondents who believed that they were HIV-positive before they were tested learned that they were HIV-negative.^{7,8}

That so many are convinced, wrongly, that an HIV test will inevitably produce a positive diagnosis is the consequence of rural Malawians' incorrect understanding of the probabilities of HIV transmission. For example, most of our survey respondents believed that an uninfected individual was certainly or highly likely to be infected with HIV during a single act of unprotected intercourse with an infected person.⁸ Would it not be preferable to treat those living amidst the HIV epidemic as having an ethical right to accurate information on the probabilities of transmission? Efforts should be made to evaluate the potential benefits of disseminating accurate information on the probabilities of transmission, the approximate prevalence of HIV infection and the probability of a positive result in an HIV test – such that consent for HIV testing in surveys is fully, rather than incompletely, informed. We need to know whether such health education would be a liberation, lead to fewer test refusals in research studies and, importantly, increase the number of people who are willing to know their HIV status. ■

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