Knowledge is power; information is liberation

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In 1597 Francis Bacon stated that "knowledge itself is power"[1] and Nelson Mandela, in the same vein, said in 2003 that "education is the most powerful weapon we can use to change the world".[2] In this issue of the *Bulletin of the World Health Organization*, Dermot Maher discusses the ethics of conducting population-based surveys involving clinical tests for research and surveillance purposes without routinely giving participants their test results, if these are positive, so that they can seek access to lifesaving treatment. Maher argues specifically that because antiretroviral treatment is now widely available, even in low- and middle-income countries, it is no longer ethical to fail to inform research participants when the result of a test for the detection of human immunodeficiency virus (HIV) infection turns out to be positive.[3,4]

According to the Council for International Organizations of Medical Sciences, "individual subjects will be informed of any finding that relates to their particular health status".[5] In 2004 and 2013, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) issued ethical guidance for HIV surveillance that included a guiding principle particularly relevant to this discussion: in household or clinical surveys, "participants must be given the opportunity to be informed of their test results".[6] Currently, participants in many population-based surveys in which blood or other samples are collected for research purposes are "given the opportunity" to learn their test results, through testing services provided in the community or referral to local counselling and testing services, but are still allowed to "opt out" of learning their results.

Very little data exist on the percentage of survey respondents who ask to be informed of their HIV test results when given these options and most surveys lack methods for tracking this group. In the 2007 Kenya AIDS Indicator Survey (KAIS), participants were encouraged to go to a testing site to receive the results of their HIV, HSV-2 and syphilis tests and the methods used made it possible to determine the fraction that did so. Overall, 49% of the survey participants collected their results; of those who were infected with HIV but previously unaware of their infection and not enrolled in treatment, 36% collected their results.[7] During the KAIS conducted in 2012, procedures were modified to give participants the opportunity to learn the results of in-home testing immediately after the survey questions were completed. The proportion of survey participants that "opted in" was 72% – a much higher percentage than in the 2007 KAIS. Although this approach made it easier for people to access their test results, a significant proportion of people identified as having HIV still remained unaware and without access to treatment (Andrea Kim, National AIDS and STD Control Programme, Kenya, personal communication, October 2013).

Maher argues that the principle of informing all survey participants of findings relating to their health should be applied in all surveys in which HIV testing is conducted. Potential survey participants who decline to learn their test results – those who "opt-out" – should be considered ineligible for participation and should not be allowed to give a sample for testing. Maher also points out that routinely giving population-based survey participants feedback on their test results can help to reduce the stigma associated with an individual testing positive and to expand the uptake of HIV testing in general.

We commend Maher for his careful articulation of the arguments for and against the provision of HIV test results in the context of population-based surveys and we urge careful consideration of his arguments. Modifying the design of surveys to provide routine immediate feedback of HIV test results to all participants will increase the cost and complexity of these surveys, but when a treatment for HIV infection is available that can prolong or save life, prevent orphanhood and reduce HIV transmission, is anything less than giving patients full knowledge of their HIV test results acceptable or ethical? The time has come for WHO, UNAIDS, national governments and donors supporting surveys that include HIV testing to re-examine ethical guidelines and research procedures to ensure that survey participants are given the results of any tests performed on their samples. Anything less than routine feedback of such results is a missed opportunity to empower survey participants. ■

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