

The ethics of feedback of HIV test results in population-based surveys of HIV infection

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Abstract Population-based disease prevalence surveys raise ethical questions, including whether participants should be routinely told their test results. Ethical guidelines call for informing survey participants of any clinically relevant finding to enable appropriate management. However, in anonymous surveys of human immunodeficiency virus (HIV) infection, participants can “opt out” of being given their test results or are offered the chance to undergo voluntary HIV testing in local counselling and testing services. This is aimed at minimizing survey participation bias. Those who opt out of being given their HIV test results and who do not seek their results miss the opportunity to receive life-saving antiretroviral therapy.

The justification for HIV surveys without routine feedback of results to participants is based on a public health utility argument: that the benefits of more rigorous survey methods – reduced participation bias – outweigh the benefits to individuals of knowing their HIV status. However, people with HIV infection have a strong immediate interest in knowing their HIV status. In consideration of the ethical value of showing respect for people and thereby alleviating suffering, an argument based on public health utility is not an appropriate justification.

In anonymous HIV surveys as well as other prevalence surveys of treatable conditions in any setting, participation should be on the basis of routine individual feedback of results as an integral part of fully informed participation. Ensuring that surveys are ethically sound may stimulate participation, increase a broader uptake of HIV testing and reduce stigmatization of people who are HIV-positive.

Abstracts in **عربي**, **中文**, **Français**, **Русский** and **Español** at the end of each article.

Introduction

Population-based surveys raise important ethical issues, especially when participants provide biological samples for testing. In response to the question, “Should survey participants routinely be told their test results?” the guidance of an international group of ethicists is straightforward: “Individual subjects will be informed of any finding that relates to their particular health status.”¹ In population-based surveys in which reliable tests are used to detect clinically important, treatable conditions, participation is generally on the basis of routine feedback of test results to all participants so they can receive proper management. It might seem obvious that in surveys of highly treatable conditions such as hypertension and tuberculosis, for example, an inherent aspect of fully informed consent is feedback of test results to participants in light of the benefits of treatment. However, in surveys of human immunodeficiency virus (HIV) infection conducted in developing countries, HIV test results are often not routinely provided to participants.² For methodological reasons, in some surveys and settings participants can sometimes “opt out” of knowing their HIV status or are offered the chance to find it out through a local HIV counselling and testing service. This is surprising in light of the need for HIV-positive people to know their HIV status to protect their own health and that of others to whom they could transmit the virus.

Ethical issues have surrounded HIV testing ever since HIV was identified as the cause of acquired immunodeficiency syndrome (AIDS). From an ethical standpoint, population-based HIV surveys should benefit the individuals who take part in them as well as the populations surveyed. HIV testing is of unquestionable importance for both individual and population health: detecting HIV infection in individuals is the mainstay of effective clinical care,³ while the results of population-based HIV surveys underpin efforts to prevent and detect HIV infection and mitigate its consequences on a large scale.⁴

This paper focuses mainly on sub-Saharan Africa – where two thirds of the global burden of HIV infection is found – and it deals with surveys conducted as part of research or public health practice. Although a distinction is sometimes made in international ethical guidance between surveys in these two domains,¹ it has long been recognized that “the distinction between research and practice is blurred partly because both often occur together”.⁵ In either case, the key ethical issues – e.g. respect for the principle of informed consent⁸ – are similar^{6,7} and, from the individual standpoint, the consequences of undergoing HIV testing are the same. In this paper, a comparison is drawn between the basis for participation in HIV surveys, and other surveys in which a reliable test is used to detect a clinically important, treatable condition.

Ethical aspects of population-based surveys

In population-based health surveys, it is standard for participants to agree, as part of fully informed consent, to be confidentially informed of their test results and referred for appropriate management if required.¹ Ensuring voluntary participation based on informed consent to protect participants is a key feature of modern codes of ethics.^{9,10} In line with the ethical duty to show respect for human beings and thereby alleviate suffering, prospective health survey participants should receive all the information they need to decide, on a fully informed basis, whether they wish to participate and receive their test results. This approach is generally uncontroversial and regarded as obligatory in health surveys of noncommunicable conditions such as hypertension and diabetes, and of communicable diseases such as syphilis or tuberculosis, whose treatment benefits the individual and also the community through decreased disease transmission.

The confidentiality of the information collected about individuals’ health status for any purpose is an important

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ethical concern that the HIV epidemic has brought to the fore.¹¹ One way to ensure confidentiality in health surveys is to record data anonymously, with linked or unlinked testing (Box 1), both of which have been used in population-based HIV surveys.¹² An important ethical question with respect to linked HIV testing is whether participation should be based on participants being routinely told their HIV test results. The ethical question with regard to unlinked HIV testing, given that it is impossible to tell participants their test results, is whether the justification for the survey is appropriate.

Linked anonymous testing

Although linked anonymous HIV testing allows for feedback of results to survey participants, in population-based HIV surveys in developing countries participants are often given the opportunity to opt out of being told their HIV status or to undergo voluntary HIV testing through a local HIV counselling and testing service if they prefer. For those who want to know the result of the HIV test performed as part of the survey, arrangements are made to inform them. The investigators' aim in not routinely giving HIV test results to survey participants is to avoid discouraging participation, especially among people who suspect they are HIV-positive. Such discouragement could lower participation and increase the risk of bias, to the detriment of the public health value of survey results. There is some evidence that HIV-positive people are under-represented in HIV surveys because they are reluctant to participate out of fear of the consequences of having others know their HIV status.² However, those who opt out without knowing their HIV status miss the opportunity to find out if they are seropositive and to be referred, if HIV-positive, for appropriate management, including antiretroviral therapy (ART). Offering survey participants the choice of opting out of knowing their HIV status has been criticized as showing disregard for the ethical duty to protect them and their families.¹³

Box 2 contains two examples of population-based surveys using linked anonymous testing that highlight differences in the approach to routine feedback of HIV and other test results to participants.

Box 1. Anonymous data records in population-based surveys: linked and unlinked testing

Linked testing: Data are linked to individual participants, whose characteristics are therefore potentially known to the investigators. This enables a more detailed analysis of HIV epidemic dynamics through linking HIV status with social, behavioural and other biomedical information.¹²

Unlinked testing: Data are not linked to individual participants, whose characteristics are therefore not known to the investigators. Recent ethical guidance on HIV surveillance has mainly covered unlinked testing.⁸

HIV, human immunodeficiency virus.

Box 2. Linked anonymous population-based surveys in Uganda and Zimbabwe

In a long-standing population-based HIV study in Uganda, participants were asked to take part in a survey of the prevalence of cardiovascular disease risk factors and that of HIV infection. Those with an abnormal finding on measurement of indicators of cardiovascular disease risk were informed of the finding and advised to attend their nearest local health facility or the study clinic.¹⁴ In the same survey, the same participants were asked to provide a blood sample for HIV testing, accompanied by voluntary counselling and testing for those who wanted to know their results. Those who did not were given the option of opting out.¹⁴

In a tuberculosis prevalence survey in Zimbabwe, participants with a positive sputum smear had the test result reported back to their homes and were referred for tuberculosis treatment.¹⁵ Since tuberculosis and HIV infection often go hand in hand, participants were asked to provide a blood sample for HIV testing, accompanied by voluntary counselling and testing for those who wanted to know their results. Those who did not were given the option of opting out.¹⁵

In both studies, the researchers could know the identities of the HIV-infected survey participants, a proportion of whom never found out that they were HIV-infected because they opted out of knowing their HIV status. Such participants are likely to experience disease progression for lack of treatment and could transmit HIV to other people.

HIV, human immunodeficiency virus.

Unlinked anonymous testing

Anonymous surveillance with unlinked HIV testing was proposed in the 1980s as a way to obtain data on HIV prevalence and incidence in particular populations while minimizing participation and selection bias. It was endorsed by the World Health Organization (WHO), which concluded that it could be used "without endangering or compromising the broad principles of public health and human rights".¹⁶ However, evidence of the importance of knowledge of HIV status has dramatically increased since then. Before the mid-1990s, the prevailing ideal was that everyone should exercise universal precautions for HIV prevention, irrespective of HIV status. The benefits of knowing one's HIV status were broadly that HIV-positive individuals could modify risk behaviours and receive preventive treatment for HIV-related conditions and palliative care. The view that knowing one's HIV status was not important became increasingly untenable with increasing evidence of the importance of knowledge of HIV status for prevention and treatment.³ Demonstration in 1994 of the effectiveness of

zidovudine in reducing mother-to-child transmission of HIV marked a turning point. The United States of America had pioneered large-scale HIV surveillance based on unlinked testing,⁴ but dramatic arguments comparing unlinked anonymous HIV testing at antenatal clinics with the infamous Tuskegee syphilis trial led the Centers for Disease Control and Prevention to halt such testing in these antenatal clinic settings in 1995.¹¹ The immediate interest of pregnant women in knowing their HIV status outweighed any possible public health justification based on the value of epidemiological surveillance.

Social developments have been accompanied by increased receptivity towards HIV testing and advances in HIV diagnosis and treatment.¹⁷ The availability since 1996 of highly effective triple therapy against HIV infection, with significant scale-up in Africa since 2003, has incontrovertibly tilted the balance and made it important for those who are HIV-positive to know their HIV status. Knowledge of HIV status is associated with decreased sexual risk behaviour, particularly among those who learn they are HIV-positive and HIV-discordant couples.^{18,19} Identification

of HIV-infected individuals is essential to initiate ART,²⁰ which has radically improved the prognosis of people with HIV infection²¹ and the prospects for decreasing HIV transmission through decreased viral load and infectivity,²² as confirmed by the HPTN 052 study.²³

Although halted in the United States, unlinked anonymous testing continued in developing countries in Africa. In 2004, WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) recommended that those who participate in unlinked anonymous surveys have access to readily available HIV counselling and testing services in the study area to enable them to find out their HIV status.⁴ However, being given the result of an HIV test is very different from being told how and where to obtain it. Although by 2011 UNAIDS and WHO had recognized this distinction in their ethical guidance on HIV surveys and had acknowledged that referring participants elsewhere for testing “represented a failure to meet the central ethical responsibility to provide appropriate care for survey participants”,⁸ the recommendation to date is that “participants must be given the opportunity to be informed of their test results” (by the surveillance team or by referral to free local HIV testing and counselling).⁸ This is inconsistent with the wide recognition that it is essential for HIV-positive people to know their HIV status, and indeed with the claim on the part of WHO and UNAIDS that “the importance of ‘breaking the silence’ cannot be overstated”.⁸

Is no routine feedback justifiable?

The justification for conducting anonymous HIV surveys with unlinked testing – or with linked testing and the choice of opting out from receiving HIV test results – rests mainly on the grounds of public health utility.⁸ The argument is that the public health benefits arising from more valid survey results outweigh the benefits of participants knowing their HIV status. This raises questions regarding: (i) where the balance lies between public health and individual interests; (ii) whether utilitarian ethics are appropriate justification for surveys in which participants are not routinely given their HIV test results;

and (iii) whether special considerations apply in developing countries.

The balance between public health and individual interests has shifted considerably over the course of the HIV epidemic as the benefits of people knowing their HIV status have become evident: “As the prospects for intervention in HIV infection increased, the immediate interest of people with HIV infection to know that fact increased as well.”⁴ Since the evidence that people with HIV infection have a strong immediate interest in knowing if they are HIV-infected is now overwhelming, the benefits of participants in anonymous HIV surveys knowing their HIV status outweigh any possible public health justification for not telling them their test results and giving them the usual counselling, with fully informed consent. In view of the ethical value of showing respect for people and thereby alleviating suffering, HIV surveys should be conducted on the basis of routine feedback to participants of their HIV test results (with fully informed consent and the usual counselling).

The ethical value of showing respect for individuals must be borne in mind when considering whether utilitarian ethics serve to justify surveys conducted on the basis of not routinely giving participants their test results. The importance of this ethical principle is vividly illustrated by the infamous medical experiments that have been occasionally conducted “for the wider good” but to the detriment of subjects, including those in Nazi Germany and those conducted by United States agencies on United States citizens (e.g. the Tuskegee experiments of 1932 to 1972) and on foreign citizens (e.g. in Guatemala from 1946 to 1948). Consideration of respect for people would suggest that a public health utility argument is not appropriate justification for conducting HIV surveys in which HIV test results are not provided routinely, in view of the importance of participants knowing their HIV status. A case in point is that early in the HIV epidemic, the United States Public Health Service (PHS) considered and largely rejected the public health utility argument as a justification for linked anonymous surveys with the option of opting out. In 1988 the PHS established the policy that “when HIV testing is conducted or supported by PHS, individuals whose

test results are associated with personal identifiers must be informed of their own test results”.²⁴ This applied to all PHS activities, whether research- or service-related, domestic or foreign. However, the principle that “individuals may not be given the option ‘not to know’ the result” could be breached when “extremely valuable knowledge might be gained from research involving subjects who would be expected to refuse to learn their HIV antibody results”.²⁴ Furthermore, research “in foreign sites” should “be carefully evaluated to account for cultural norms, the health resource capabilities and official health policies of the host country”.²⁴ These two escape clauses were to be regarded as exceptions and subject to rigorous institutional review, along with “the risk/benefit evaluation of the research”.²⁴ In practice, however, the exception often proved the rule, with externally funded anonymous HIV surveys in developing countries, especially in sub-Saharan Africa, commonly conducted on the basis of participants not routinely receiving their test results.¹²

When an external funder uses an argument based on research utility (“the risk/benefit evaluation”)²⁴ to justify anonymous HIV surveys in developing countries, alarm bells should ring. Sponsors from developed countries fill much of the enormous gap in developing countries between the need for health research and the resources available.²⁵ However, the risk of exploitation posed by inequalities in resources between developed and developing countries⁹ has made obvious the need for ethical guidance of particular relevance to research in developing countries,²⁶ to epidemiological research,¹ and to the relationship between research sponsors in developed countries and study populations in developing countries.⁹

Some have also argued, in reference to special considerations applicable in developing countries, that the ethical underpinnings of unlinked anonymous HIV surveys should be context-specific and determined locally,²⁷ based on the value of such surveys in enabling advocacy for the provision of ART in settings where access to ART is limited.⁸ However, the importance of making ART widely available is already well recognized.¹⁷ Since people with HIV infection need to know their HIV status wherever they live, anonymous HIV

surveys should be conducted on the basis of routine individual feedback of results in both developed and developing countries.

Sound ethical basis for surveys

Because it is so important that HIV-positive people know of their condition, the basis for participation in population-based HIV surveys and in surveys of other treatable diseases should be the same, with routine individual feedback of test results being an integral part of voluntary survey participation with fully informed consent. This clearly has nothing to do with “mandatory testing”; it simply means that those who do not want to know their HIV status do not participate in the survey. In general, study participants do not have a “right” to take part in a study irrespective of whether they fulfil eligibility criteria, such as age or residence. In the same light, people do not have a “right” to take part in a population-based HIV survey, get tested and opt out of knowing the result of the test on their sample. Ensuring confidentiality and fully informed consent so that survey participants completely understand the implications of being tested for HIV is crucial in avoiding the problem of “incompletely informed consent”.²⁸

Ensuring a sound ethical basis for HIV surveys – by putting a stop to unlinked testing and to linked testing with the choice of opting out – may also have practical advantages which should be evaluated in the field. First, knowing the prevalence of HIV infec-

tion in a community and knowing HIV status in the case of an individual are important for the very same reasons: knowing how many people in the population have HIV infection is essential for planning ART programmes, and, for an individual, knowing that he or she has HIV infection is a requisite for starting ART. Informed consent enables participants to make the logical connection between the importance of establishing the prevalence of HIV infection in a community and that of knowing their own HIV status. If participants are allowed to opt out, they may interpret it as a sign that knowing their HIV status is not important and this may discourage survey participation. In addition, if people see the importance of knowing one's HIV status reflected in research and public health practice, it may lead to broader uptake of HIV testing. This is particularly important in sub-Saharan Africa, where most people do not know their HIV status.²⁹ Finally, health-care workers, researchers and public health practitioners have the enormous responsibility of actively countering the stigmatization of people with HIV infection or, at least, of avoiding attitudes and behaviours that perpetuate it. Treating participation in anonymous surveys of HIV infection on an equal footing with surveys of other treatable conditions may also help to counter stigma against people who are infected with HIV. Participation in HIV surveys on the basis of routine individual feedback of HIV test results is facilitated by the development of easy and inexpensive rapid tests with high sensitivity. High specificity can be obtained with a second confirmatory test in cases in which the first result is

positive.³⁰ The feasibility of “on the spot” HIV counselling and rapid testing for HIV survey participants is supported by the model of delivery of HIV testing to individuals in their communities, which is proving successful.³¹ High uptake, acceptability and delivery of results have been demonstrated in several sites in Africa. A recent systematic review of studies on home-based HIV testing showed its benefits and little evidence of harm.³²

Summary

Population-based HIV surveys have played a crucial role in our understanding of the epidemiological characteristics of HIV infection as part of the response to the HIV epidemic: “No effort to control the HIV epidemic and direct resources to those most at need can be effective without an accurate understanding of the incidence, prevalence and dynamics of HIV, and HIV-related risk behaviours.”⁸ In the era of widespread access to ART, population-based HIV surveys are of unquestionable importance in sub-Saharan Africa – as elsewhere – in assessing the impact of ART on the incidence, prevalence and dynamics of HIV infection and on HIV-related risk behaviour.³³ For the ethical reasons explained in this paper, in such surveys routine individual feedback of test results should be as an integral part of survey participation in any setting. ■

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ملخص

أخلاقيات التعليقات على نتائج اختبار فيروس العوز المناعي البشري (HIV) في مسوح عدوى فيروس العوز المناعي البشري المستندة على السكان

يختارون عدم الحصول على نتائج اختبار فيروس العوز المناعي البشري الخاص بهم ولا يطلبون نتائجهم الفرصة لتلقي العلاج المضاد للفيروسات القهقرية الذي ينقذ حياتهم.

يستند تبرير مسوح فيروس العوز المناعي البشري بدون التعليقات الروتينية لنتائج المشاركين على حجة تتعلق بجدوى الصحة العامة، هي: أن فوائد الوصول إلى طرق المسح الأكثر دقة وصرامة – انخفاض تحيز المشاركة – ترجح على فوائد معرفة الأفراد لحالة إصابتهم بفيروس العوز المناعي البشري. ومع ذلك، يمتلك الأشخاص المصابون بعدوى فيروس العوز المناعي البشري مصلحة مباشرة قوية في معرفة حالة إصابتهم بفيروس العوز

تثير مسوح انتشار المرض المستندة على السكان مسائل أخلاقية، بما في ذلك ما إذا كان من الواجب إبلاغ المشاركين بنتائج اختباراتهم على نحو روتيني. وتدعو المبادئ التوجيهية الأخلاقية إلى إبلاغ المشاركين في المسح بأية نتائج ذات صلة سريرية لتمكين التدبير العلاجي الملائم. ومع ذلك، يستطيع المشاركون في المسوح غير محددة الهوية حول عدوى فيروس العوز المناعي البشري (HIV) “اختيار عدم الحصول” على نتائج اختباراتهم أو منحهم الفرصة لإجراء اختبار طوعي لفيروس العوز المناعي البشري في مواقع خدمات الاستشارات أو الاختبارات المحلية. ويهدف ذلك إلى تقليل تحيز المشاركة في المسح إلى أدنى حد ممكن. ويضعف من

الروتينية للتائج كجزء لا يتجزأ من المشاركة عن استنارة كاملة. ومن الممكن أن يحفز التأكد من سلامة المسوح من الناحية الأخلاقية المشاركة، ويزيد من الإجراء الأوسع لاختبارات فيروس العوز المناعي البشري ويقلل من وصمة العار التي تلحق بالأشخاص المصابين بفيروس العوز المناعي البشري.

المناعي البشري. وعند مراعاة القيمة الأخلاقية لإظهار الاحترام للأشخاص و العلاج الذي يخفف من المعاناة، فإن الحجة المستندة إلى جدوى الصحة العامة ليست تبريراً سليماً. في المسوح غير محددة الهوية لفيروس العوز المناعي البشري وكذلك مسوح الانتشار الأخرى للحالات القابلة للعلاج في أي بيئة، ينبغي أن تكون المشاركة على أساس إبلاغ الأفراد بالتعليقات

摘要

基于人群的艾滋病病毒感染调查中艾滋病检测结果反馈的伦理

基于人群的疾病患病率调查会引发伦理问题，其中包括是否应该按常规向参与者告知其检测结果。为实现适当的管理，伦理学指导原则要求将所有临床相关结果通知给参与者。但是，在艾滋病病毒（HIV）感染的匿名调查中，参与者可以“选择拒绝”收到他们的检测结果，或者获得在当地咨询和检测服务部门接受自愿艾滋病病毒检测的机会。这样做旨在尽可能降低调查参与偏差。选择拒绝收到艾滋病病毒检测结果以及不寻求知晓结果的人也错过了接受挽救生命的抗逆转录病毒治疗的机会。

不按常规向参与者反馈结果的艾滋病病毒调查，其理由是基于这样的公共卫生效用论点：更严格的调查方

法所得到的好处（降低参与偏差）比个体知晓其艾滋病病情的好处更重要。但是，感染艾滋病毒的人如果知晓其艾滋病病情就会获得很大的直接利益。从显示对人的尊重以及因此缓解病痛的伦理价值方面考虑，基于公共卫生效用的论点就不是一个合适的理由。

在匿名艾滋病调查以及任何背景下其他可治疗病情的患病率调查中，参与的基础应该是将结果向个体的常规反馈作为完全知情参与的有机组成部分。确保调查在伦理上合理，可能会刺激参与，使艾滋病检测得到更广泛的接受，并减少艾滋病毒阳性人群所受到的羞辱。

Résumé

L'éthique de rétroaction des résultats du test VIH dans les enquêtes de population à infection de VIH

Les enquêtes de population sur la prévalence des maladies soulèvent des questions éthiques, notamment celle de savoir si les participants devraient être informés systématiquement des résultats de leurs tests. Les directives éthiques appellent à informer les participants de l'enquête de toute conclusion cliniquement pertinente pour permettre une gestion appropriée. Toutefois, dans les enquêtes anonymes de l'infection du virus de l'immunodéficience humaine (VIH), les participants ont la possibilité de « renoncer » à être informés des résultats de leurs tests ou de se voir proposer de subir volontairement un test VIH dans les services de conseil et de dépistage locaux. L'idée est de réduire au minimum le biais de participation à l'enquête. Ceux qui choisissent de ne pas être informés des résultats de leur test VIH et qui ne demandent pas leurs résultats ratent l'occasion de recevoir une thérapie antirétrovirale pouvant leur sauver la vie.

La justification d'enquêtes sur le VIH sans rétroaction systématique des résultats aux participants repose sur un argument d'utilité de santé

publique : les avantages des méthodes d'enquête plus rigoureuses – biais de participation réduit – l'emportent sur les avantages pour les individus de connaître leur statut sérologique. Toutefois, les personnes infectées par le VIH ont un fort intérêt immédiat à connaître leur statut sérologique. Par rapport à l'importance éthique de montrer du respect pour les personnes et de soulager ainsi leurs souffrances, un argument qui se fonde sur l'utilité de la santé publique n'est pas une justification appropriée.

Dans les enquêtes VIH anonymes ainsi que dans d'autres enquêtes sur la prévalence des maladies traitables dans n'importe quel milieu, la participation devrait être basée sur une rétroaction individuelle systématique des résultats en tant que partie intégrante d'une participation pleinement informée. Veiller à ce que les enquêtes soient conformes à l'éthique peut stimuler la participation, augmenter un recours plus large au dépistage du VIH et réduire la stigmatisation des personnes séropositives.

Резюме

Этические вопросы уведомления о результатах проверки на ВИЧ при проведении исследований ВИЧ-инфекции среди населения

Проведение исследований среди населения на предмет распространенности заболеваний поднимает ряд этических вопросов, включая вопрос о том, должно ли быть стандартной практикой уведомлять участников о результатах проверки. Этические принципы призывают информировать участников исследований о любых клинически значимых результатах, чтобы они могли начать надлежащее лечение. Тем не менее, при анонимном обследовании на вирус иммунодефицита человека (ВИЧ) участники могут «отказаться» от уведомления о результатах проверки или получить приглашение пройти добровольное тестирование на ВИЧ в местных службах консультирования и

тестирования. Целью этого является минимизация отклонений в выборке участников. Однако те люди, которые предпочитают не узнавать результаты проверки на ВИЧ и не обращаются за своими результатами, упускают возможность получить антиретровирусную терапию для спасения их жизни.

Для обоснования проведения исследований на ВИЧ без стандартной практики уведомления участников о результатах используется аргумент практической пользы такого подхода для системы здравоохранения: преимущества от более строгих методов исследования (снижение отклонений выборки) перевешивают преимущества от получения участниками

информации об их ВИЧ-статусе. Однако в интересах ВИЧ-инфицированных людей знать свой ВИЧ-статус. Принимая во внимание этическую ценность уважения к больным и облегчения их страданий, аргумент, основанный на полезности для системы здравоохранения, является необоснованным.

В анонимных исследованиях на ВИЧ, а также других исследованиях распространенности излечимых заболеваний в

любых условиях участие должно осуществляться с использованием стандартной практики уведомления о результатах в качестве неотъемлемого элемента участия, основанного на полной информированности. Обеспечение этической безупречности исследований может стимулировать участие и способствовать увеличению степени охвата тестирования на ВИЧ и меньшему общественному осуждению ВИЧ-инфицированных людей.

Resumen

La ética de informar sobre los resultados de las pruebas del VIH en encuestas de población sobre la infección por VIH

Las encuestas sobre la prevalencia de enfermedades basadas en la población plantean cuestiones éticas, como si se debería informar de forma rutinaria a los participantes acerca de los resultados. Las directrices éticas exigen que se informe a los participantes de cualquier hallazgo clínicamente relevante a fin de que sea gestionado de manera adecuada. Sin embargo, en las encuestas anónimas sobre el virus de la inmunodeficiencia humana (VIH) los participantes pudieron escoger no ser informados acerca de los resultados de sus pruebas o se les ofreció someterse voluntariamente a una prueba de VIH en los servicios locales de asesoramiento y análisis, opciones que tenían como objeto minimizar el sesgo en la participación en la encuesta. Aquellos que optan por no ser informados sobre los resultados de la prueba del VIH y los que no averiguan los resultados pierden la oportunidad de recibir una terapia antirretroviral que podría salvarles la vida.

La justificación de la ausencia de información rutinaria sobre los resultados en las encuestas sobre el VIH se basa en un argumento de los servicios de sanidad pública, que afirma que los beneficios de los

métodos de encuesta más rigurosos, con un sesgo de participación menor, superan los beneficios de que los participantes conozcan su estado serológico. Sin embargo, las personas infectadas por el VIH suelen demostrar un interés inmediato por conocer dicho estado. Teniendo en cuenta el valor ético de mostrar respeto por las personas y, en consecuencia, paliar su sufrimiento, no puede considerarse una justificación adecuada un argumento basado en los servicios de sanidad pública.

En las encuestas anónimas sobre el VIH, así como en otras encuestas sobre la prevalencia de enfermedades tratables en cualquier emplazamiento, la participación debería tener lugar en base a una información personal rutinaria de los resultados como parte fundamental de una participación plenamente informada. Garantizar la ética de dichas encuestas podría fomentar la participación, aumentar la adopción de las pruebas del VIH y reducir la estigmatización de las personas seropositivas.

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