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## CDC Recommendations for Opt-Out Testing and Reactions to Unanticipated HIV Diagnoses

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### Abstract

The U.S. Centers for Disease Control and Prevention (CDC) now recommends testing all health care patients for HIV—regardless of their reported risk behaviors—using an “opt-out” approach in which patients are informed that an HIV test will be conducted unless they explicitly decline to be tested. These new testing procedures will facilitate the identification of persons living with HIV who are unaware of their infection. However, some of these newly diagnosed persons may not previously have considered the possibility that they might have HIV and may be ill-equipped to cope with an HIV diagnosis. The present commentary reviews the potential reactions of persons who receive unanticipated HIV-positive diagnoses and suggests that additional research is needed to better understand these reactions and associated harms.

### INTRODUCTION

Approximately 250,000 persons in the United States are currently living with undiagnosed HIV infection.<sup>1</sup> HIV-infected persons who are unaware of their serostatus cannot avail themselves of effective antiretroviral therapies that can improve their long-term prognosis and enhance their quality of life. To increase HIV testing and thereby decrease the number of persons living with HIV who are unaware they are infected, the U.S. Centers for Disease Control and Prevention (CDC) recently recommended changes in the administration of HIV tests in health care settings.<sup>2</sup> According to the new testing guidelines, HIV tests should be performed routinely regardless of the risk behavior of the individual and without the requirement of prevention counseling or the execution of a separate, signed consent specifically authorizing an HIV test. The guidelines recommend that health care providers adopt an “opt-out” approach when informing patients about the test. Rather than asking a patient if he or she would like to be tested for HIV, which requires an affirmative response on the patient’s part, the CDC recommends that providers inform the patient that absent dissent, he or she will be tested.

Under the new guidelines, patients still must be informed either orally or in writing that they will be tested and that they may decline the test. Providers also are expected to explain the meanings of preliminary positive and negative test results and to give patients the opportunity to ask questions. Although the requirement of prevention counseling has been eliminated, the CDC remains cognizant of the importance of prevention education in settings where individuals are likely to be at increased risk for HIV infection and encourages providers to conduct prevention counseling when appropriate. Nevertheless, the CDC position is that prevention

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counseling should be eliminated if it poses a barrier to providers conducting routine HIV screening.

This streamlined approach to HIV testing is intended to facilitate identification of persons living with HIV who might not otherwise be tested, perhaps because they do not perceive themselves to be at risk of HIV infection. Under the existing, risk-based testing paradigm, individuals are tested either because they have sought out testing on their own accord, or because a health care provider has determined they are at risk of infection. Although few people expect to test positive for HIV, persons who are tested because their behaviors have placed them at risk of infection likely have contemplated the possibility of infection, and may have considered, at some level, the ramifications of an HIV-positive diagnosis and how they might respond. In contrast to risk-based testing, opt-out testing does not require the patient or provider to suspect that the patient may be infected. As such, opt-out testing is likely to identify HIV-infected persons who did not anticipate being tested for HIV—much less the possibility of testing positive—and whose test results therefore catch them unawares, before they have had the opportunity to prepare themselves for receiving an HIV-positive diagnosis.

## UNANTICIPATED DIAGNOSES

An HIV-positive diagnosis is unlikely to be welcomed at any time, but it may be that there are better times than others to discover one is infected. Under an opt-out protocol, individuals who do not believe they are at risk for HIV may agree to testing because they customarily defer to physicians and other health care professionals, because they are uncomfortable declining the test, or because they are preoccupied or distracted by the condition that prompted them to seek medical care in the first place. Consequently, they may assent to be tested during times in their lives when they would have resolutely rejected the notion of testing if they had anticipated the test result would be positive.

Little is known about the extent to which an individual's life circumstances impact his or her ability to assimilate an HIV-positive diagnosis and to respond effectively. An individual already attempting to cope with demanding life circumstances could find him or herself overwhelmed by the unexpected news that he or she has HIV.<sup>3</sup> For example, a newly diagnosed person might already be struggling with more immediate threats to health, safety, or livelihood, such as a recent or impending loss of a job or housing, a dangerous or abusive living environment, or threatening legal prospects such as a custody dispute or sentencing hearing. Perhaps an individual's time, energy, and other resources are consumed by raising children as a single parent, caring for an elder, or complying with requirements of parole or probation. Perhaps a recent divorce or the death of a loved one is already challenging an individual's emotional resilience. These and similar circumstances could impair an individual's ability to absorb the shock of an HIV-positive diagnosis.

HIV infection disproportionately affects individuals who occupy marginalized positions in society.<sup>4</sup> Lack of resources including regular access to health care and sound health information could result in these individuals underestimating their risk for HIV. In a recent U.S. study, women, persons over age 40, persons not born in the United States, and persons for whom English is not a first language were more likely than other individuals to refuse HIV testing in an urgent care setting.<sup>5</sup> When asked why they declined testing, individuals in these groups were also more likely to report (perhaps erroneously) that they were not at risk.<sup>5,6</sup>

In contrast to voluntary testers, who generally can control the timing and context of the testing experience, some persons who test positive under an opt-out protocol may be tested when they lack the emotional resources and social supports needed to cope effectively with an HIV-positive diagnosis. Yet adjustment to the diagnosis is imperative for a variety of reasons, including initiation and adherence to appropriate medical treatment, adoption of secondary

prevention behaviors, and utilization of social services, including participation in treatment for addictive or compulsive behaviors that otherwise could compromise treatment and secondary prevention efforts.<sup>7–10</sup>

## POTENTIAL REACTIONS

Immediate post-diagnosis reactions may include devastation, rage, and nearly over-whelming guilt.<sup>11–13</sup> Newly diagnosed persons may have difficulty modulating their emotions and may be inclined to act on impulse by harming themselves or others, especially if they are “blindsided” by an HIV-positive diagnosis. Risk of suicide likely would be greater among persons who have not had an opportunity to prepare themselves for an HIV-positive diagnosis, especially if they associate HIV infection with shame or believe that HIV disease is invariably fatal or untreatable.<sup>12</sup> Some newly diagnosed persons may experience an impulse to harm the individual believed to be responsible for transmitting the virus.<sup>13,14</sup> These impulses likely would be accentuated among persons who had no reason to suspect they were at risk of infection, such as those who believed themselves to be in a mutually monogamous relationship and discovered their partner’s infidelity only when they tested positive for HIV. Persons who suffer from mental illness are at increased risk of HIV infection.<sup>15,16</sup> Preexisting depression, limited distress tolerance skills, and/or difficulty with impulse control could increase risk of harm to self or others.

Many recently diagnosed persons resort to drugs and alcohol use as a means to “blunt” or “numb” the emotional pain of learning they have HIV.<sup>7,16,17</sup> For persons who are stunned by an unexpected HIV diagnosis and who consequently have had no time to explore healthier coping strategies, this impulse may be even stronger. Increased substance use, in turn, could inhibit the development of adaptive coping responses and lead to further numbing efforts and increased delay in seeking treatment and ceasing risk behavior.

Because they have had no opportunity (or reason) to rehearse cautious disclosure strategies, some persons who receive an unanticipated diagnosis may disclose their HIV status injudiciously. They may disclose to an unstable spouse or sexual partner before making a plan to ensure their own safety or to secure alternative housing, if necessary. Disclosure of seropositive HIV status to a partner could result in a violent response or in dissolution of the partnership, with serious emotional, psychological, and financial consequences for the newly diagnosed individual.<sup>14</sup> Newly-diagnosed persons may turn reflexively for support to a friend or family member without considering his or her reaction or the possibility that he or she might have difficulty maintaining a confidence. Impulsive disclosures to family and friends could cause irreparable rifts in these relationships and subsequent losses of social, instrumental, and financial support. This may be especially true for older persons whose contemporaries often hold discriminatory attitudes toward persons living with HIV.<sup>17</sup> Work-place disclosures could be especially problematic. Although anti-discrimination laws protect the rights of persons living with HIV, the law is not as effective at preventing discrimination as initial information management can be.

## SUMMARY AND CONCLUSION

The opt-out testing procedures advocated by the CDC will facilitate the identification of persons living with HIV who are unaware of their infection. This is a critically important public health objective. However, some of these newly diagnosed persons may not previously have considered the possibility that they might have HIV and—even more so than under a risk-based paradigm—may be ill-equipped to cope with an HIV diagnosis. A person who is stunned by an unanticipated HIV diagnosis may be more prone to act on initial impulses or to disclose his or her status to others injudiciously.

The CDC's revised HIV testing guidelines reflect pragmatic concerns that requiring extensive informed consent and prevention counseling discourages HIV testing in health care settings such as emergency departments, urgent care clinics, and physicians' offices.<sup>17,19</sup> These guidelines signal a progressive shift away from risk-based testing toward treating HIV as a routine medical condition.<sup>20,21</sup> However, despite more than two decades of public education campaigns by the CDC and others, HIV remains a highly stigmatized and feared disease.

The potential psychological and social harms associated with an HIV-positive diagnosis distinguish HIV from most other conditions covered by routine consent for medical care. Relatively little information is available on immediate, post-diagnosis experiences in adults and even less on the experiences of HIV-positive youth. The few studies that have explored the topic in depth drew exclusively from women's experiences.<sup>13,14</sup> Nevertheless, several studies confirm that HIV diagnosis can be traumatic for a variety of persons living in a variety of cultures. Post-traumatic stress disorder secondary to HIV diagnosis has been noted in HIV-positive women, men who have sex with men, and heterosexual men.<sup>22–25</sup>

A number of factors are likely to moderate reactions to unanticipated diagnosis including gender, relationship status, mode of infection, extent to which an individual is isolated, education level, and social status. Research is needed to identify potential harms, to assess the prevalence of these harms among recently diagnosed persons, and to examine the particular vulnerabilities of persons who did not anticipate testing HIV-positive, and who may differ in important respects from persons diagnosed as HIV-positive through self-initiated testing.

The CDC suggests that when the benefits of earlier initiation of antiretroviral therapy and the reduction in the risk of secondary transmission by persons who are aware versus unaware of their HIV status are taken into account, an informal risk-benefit analysis favors expanded HIV screening without the burdensome requirements of lengthy prevention counseling and explicit informed consent procedures.<sup>2</sup> The recommendations seem to presuppose that learning one's HIV status is always in the patient's best interests. Likely this will be true for the vast majority of persons who will test positive under an opt-out protocol. For the remaining few, the possibility of psychological or other harms entails an ethical imperative to understand the potential reactions of persons who test positive and to intervene, when necessary, to prevent or mitigate associated harms.

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