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## HIV Testing Scale-up: WHO/UNAIDS Guidance Launched to Promote Provider-Initiated Testing and Counselling in Health Facilities

### *What is civil society saying?*

#### **ICW**

The International Community of Women Living with HIV/AIDS (ICW) observes with alarm the global trend to dramatically scale up opt-out, service provider-initiated, testing. We believe that such a strategy will take the control from women and men to decide and prepare themselves for tests and for results and there are also many current concerns with testing that have not been addressed and will only be exacerbated with scale-up. Over all, we should not be calling for routine, provider-initiated, opt-out testing when 1) gender inequality and HIV-related stigma make disclosure a life threatening prospect; 2) women and men have limited access to care, treatment and support; 3) women and men are not in a position to decide for themselves whether or not they want to be tested; and 4) stigma and discrimination from healthcare providers, in the work place and elsewhere make asserting our rights impossible. We urge the UN to pay attention to their own guidelines: *Public health legislation should ensure that HIV testing of individuals should only be performed with the specific, informed consent of the individual.*

#### **Louise Binder**

Chair of the Canadian Treatment Action Council and a member of the Global Coalition on Women and AIDS Leadership Council, Louise Binder, herself HIV-positive, states, "We are disappointed that WHO and UNAIDS have moved away from the gold standard in HIV testing of voluntary (i.e. opt-in) testing with comprehensive pre- and post-test counseling. We are concerned also that in practice, efforts to rapidly scale up testing may well lead to a failure to protect people's human rights adequately, including rights to provide free and informed consent, confidentiality, and non – discrimination."

"It is likely that many health systems will not have enough counselors trained and available to provide prevention counseling to those who test negative. And, unfortunately, many of those who are tested will not have access to adequate care, treatment and support following a positive HIV diagnosis. Recent history shows that this leaves people, especially women and adolescents, in a very vulnerable position. Not only are they likely to be abused by their partners or others; they also face potential isolation and rejection in their community."

"Further, the number of people tested is not an adequate indicator of benefit. If people are unprepared for the results of testing and the disclosure of their status, and are inadequately counselled at the time of testing, adverse consequences of testing will rise along with the number of test results. These include abandonment by family members, violence, abuse, and psychological depression. Simply measuring the number of people tested does not capture the experience of testing or the number at risk for adverse outcomes. Inadequate, uneven counselling is a fact in every country."

"Policies on testing cannot be considered in isolation from factors including stigma and discrimination. There is absolutely no proof that testing more people leads to less discrimination as we have seen in North America. It is not legitimate to normalize HIV from a medical perspective until we face a level playing field in the areas of law and social policy, which we do not have yet."

#### **Joe Amon**

Director of the HIV/AIDS Program of Human Rights Watch, "Expanded HIV testing will have little impact on the AIDS epidemic unless there is a real commitment to universal access to prevention and treatment. WHO and UNAIDS are right to be worried that without an 'enabling environment' there are real risks in expanding testing. Human Rights Watch has extensively documented coercive testing, breaches of confidentiality, and violence against people living with HIV. WHO and UNAIDS must do more than offer specific guidelines about testing and vague calls for better policy and legal frameworks. Expanding access to HIV testing is important, but it will

only work alongside better prevention and treatment efforts, and an end to stigma against people living with HIV.”

Further, “it’s important that these guidelines move beyond the previous recommendation for 3 C’s - counseling, confidentiality and consent - to include broader issues such as ensuring access to prevention, referral to treatment and positive legal/policy frameworks, but at a minimum WHO and UNAIDS must make sure that governments that are adopting these guidelines conduct close monitoring to ensure that these basic elements are respected.”

### **Beri Hull**

As ICW’s Global Advocacy Officer: Access to Care, Treatment and Support, “I want to state again how important it is for people to be aware of their HIV status – when they are ready, willing and able. It is important in the response to the pandemics that at-risk communities and people be prepared to test HIV positive, which includes the access to care, treatment and support, and an environment that supports protection from stigma and discrimination.”

### **Lydia Mungherera**

As a leading global advocate and a woman living with HIV/AIDS, Dr. Lydia Mungherera from Uganda states “It should be very clear to anyone who has worked in the field that anyone who will be tested for HIV should have enough counseling pre- and post- testing to make certain that the person being tested will be able to cope with the result.” Further, HIV testing programs should include “home visits, discordant couple training, training and sensitization on disclosure, and means for addressing domestic violence, a common consequence of disclosure for women.” Lastly, “adequate treatment must be available to individuals who test positive.”

### **AIDS Legal Network (ALN), South Africa**

Notwithstanding the need to scale up HIV testing, and the advantages of people knowing their HIV status so as to access available services, it is essential to ensure that human rights principles of non-discrimination, informed choice, consent, autonomy, and confidentiality are adhered to. We do not believe that the public health 'need' to test for HIV may override and disregard people's fundamental human rights and freedoms.

Recognising prevailing inequalities, imbalances and injustices, as well as persistent discriminatory attitudes and behaviours based on a person's sex, gender, sexual orientation and/or HIV status raises serious concerns as to the extent to which the WHO document carries the potential to facilitate an uptake of HIV testing without further perpetuation of stigma, discrimination and the subsequent violation of fundamental rights and freedoms. Thus, the WHO document, does, arguably, fail to ensure the human rights framework in which HIV testing services are to be 'taken up'.

Our main concerns can be summarised as follows:

- Fears about 'provider-initiated' HIV testing becoming 'routine/mandatory' HIV testing -- The environment is not conducive for most people accessing healthcare facilities to 'opt-out'
- Gender bias -- Since women are the ones mostly accessing healthcare facilities, women will be the ones mostly testing for HIV and thus, women will be 'blamed', stigmatised and discriminated against
- Failure to take existing inequalities/power imbalances into account -- Since healthcare providers are perceived to be 'experts', 'powerful', and 'knowing what is best', individuals are less likely to 'disagree'/'opt-out'
- Failure to take existing HIV-related stigma and discrimination into account -- Existing HIV-related stigma and discrimination already deter access to HIV testing services
- Concerns that people will be discouraged from accessing healthcare facilities -- The fear of being tested for HIV (while unprepared and not ready) will deter people from accessing healthcare facilities
- Concerns about lack of counselling -- Providing pre-test information (individually or collectively) does not adhere to the principle of counselling and cannot ensure informed consent
- Concerns about 'informed consent' -- The basis principle of informed consent, based on factual, non-biased, non-directive information and the individual's right to freely decide, is threatened