



Testing and the Rights of HIV Positive Women

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ICW observes with alarm the UN's plan to dramatically scale up HIV testing. Not only is there a danger that such a strategy, particularly if tests are opt out, service provider initiated, will take the control from women and men to decide and prepare themselves for tests and for results, but there are also many current concerns with testing that have not been addressed and will only be exacerbated with scale-up. Although we recognise that knowing one's status can sometimes enable us to better protect our health and that of our partners we have a number of fears, described below, with planned and current testing practice.

Our main concerns centre around plans to offer service provider initiated, routine HIV tests, where the emphasis is on the service user to opt-out.

Limited access to care, treatment and support -

Embarking on routine testing is actually very dangerous considering that there is limited access to care, treatment and support for many women in many parts of the world on testing positive. Proponents of routine testing have argued that we cannot scale up treatment access if we don't scale up testing – but lets ensure that quality treatment and care are accessible first! We are diverting scarce resources to the scale up of testing when so many who are already tested or want testing need and cannot afford treatment.

Success of testing initiatives is often judged by the number of people tested – quite clearly this is not a measurement of success. Let's not get testing confused with prevention and treatment. The former does not automatically lead to either of the latter particularly when treatment is not even available.

The stigma and discrimination and related violence and loss of livelihood

that many women face on disclosure is also extremely worrying; a concern that is heightened when women are pushed to test with their partner or counselled to disclose before they are ready. In Kenya health care staff were horrified when a pregnant woman they encouraged to test was thrown out of her home (told to an ICW member working in Kenya). Such examples from members are all too common. A nod to gender inequalities in literature supporting routine testing is grossly inadequate, given that women make up 50% of people living with HIV and are often targeted for testing through ante-natal clinics.

Routine testing at health centres may also inadvertently have a negative impact on women where they access health services in greater numbers than men with the consequential blame heaped on her for testing and disclosing first.

Advocates for routine testing say that more testing will normalise HIV. We ask – show us the evidence!

Pre-test counselling, and to a certain degree **post-test counselling**, are casualties of routine testing and yet our members have reported that pre and post-test counselling are vital in helping them come to terms with a positive diagnosis. Sometimes group counselling has been used to get around the resource constraints of one-on-one counselling yet women in South Africa say they feel 'herded' through the process and are less likely to return for results (pers comms: Mags Beksinska, Reproductive Health Research Unit in South Africa).

Outreach testing services that do not offer appropriate counseling and community preparedness can also lead to violent responses by or towards those testing positive (Grace Sedio, ICW staff member from Botswana).

Informed, voluntary consent will also be lost - Do people really have the power to opt out of having a test at health centres, particularly as health care centres are seen as by most women as places of powerlessness? Routine testing assumes, that somehow a woman, who may have very limited ability to negotiate and who has been subjected to subordination all her life, who as a result of her circumstances may have very limited self esteem, is going to meaningfully participate and decide whether she should be tested or not. Literacy and language barriers and a lack of accessible, tailored information in local languages makes this possibility even more remote.

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Judgmental, discriminatory attitudes in health care settings - our members, from the UK, South Africa, Zimbabwe, Thailand and many other countries have repeatedly reported an inability to assert their will in health care settings, particularly after testing HIV positive. Rude behaviour on the part of health care workers, denial of services and treatments or indeed coercion regarding certain courses of actions are common. So what happens to informed, voluntary consent re testing under such conditions? Will women be denied services if they refuse to test or indeed if they do test and test positive?

Confidentiality – ICW’s research shows a worrying lack of concern on the part of health care workers for service users’ right to confidentiality. Unfortunately another causality of routine testing is likely to be training for health care workers regarding the rights of service users to respectful, confidentiality advice and care.

Marginalization and criminalisation – what happens to sex workers, migrants, drug users and men who have sex with men when they test positive or pregnant women who refuse treatment? In fact anyone who has limited access to health services and/or is already severely stigmatised and criminalised could be further disenfranchised and disempowered within a system that enforces HIV testing with limited counselling, care, treatment and support. We believe that a scale up of testing will also see a scale up in stigma, discrimination and criminalization when it comes down to country by country implementation, particularly if public officials interpret widespread knowledge of status to signify wide-spread personal control over transmission.

Testing in antenatal clinics - The current emphasis by the World Health Organisation on testing in ante-natal clinics (ANCs) for statistical purposes and to address mother to child transmission only serves to reinforce the view that women bring HIV into the family. Disturbingly the highest reported rates of disclosure-related violence are among women who test for HIV in the context of antenatal care **{1}**. Targeting ANCs also shifts the responsibility away from men to get tested. Furthermore, ICW is extremely concerned about the strong focus on testing women (and pressure on women to test) during pregnancy and during birth as pregnancy is an intensely emotional period of a woman's life and finding at this time about a diagnosis is extremely traumatic.

Preventing mother-to-child transmission is a priority. But we have noticed that the focus of PMTCT programmes is often on healthy babies; the importance of healthy mothers, fathers and in fact children (as the babies get older) gets neglected.

Already concerns have been expressed that the small percentage of women accessing ante-natal services, or indeed health services in general, is likely to dwindle if testing is presumed to be mandatory. Moreover, will women return for results or return to get their kids tested if they feel coerced into testing? Of course testing should be available during this time but we require more flexibility in the availability of testing facilities, greater respect for our right to choose whether to be tested and non-judgmental information and support so we can make more informed decisions about testing, child bearing and rearing. We support provider initiated opt-in testing which gives people the right to make personally informed choices.

Another approach is community-wide training workshops that encourage and support community members to go for VCT by, for example, giving members time to address prejudices and fears, their own and those of others in the community. Such an approach could relieve the pressure on pregnant women to test and disclose. ANC testing could then become a fall-back option rather than a first line of action.

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 they want to be tested, 4. stigma and discrimination from health care 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” **{2}**.

{1} Maman S and Medley A, 2004, Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes: A Review Paper. Geneva: World Health Organization.

{2} UN, 1998, The UN Guidelines on HIV/AIDS and Human Rights