



ISSUE PAPER FOR THE SESSION:

**Provider-Initiated Testing and Counselling in Health Facilities**

**Defining the Issue**

1. It is widely recognised – by policy makers, health practitioners, and human rights advocates alike – that the low uptake of HIV testing and counselling is a major challenge in the response to the epidemic that needs to be urgently addressed. It has also been observed that many people who present symptoms of HIV infection and those who might otherwise benefit from knowing their HIV status through contact with health facilities are often not offered an HIV test. Based on these concerns, WHO and UNAIDS has developed draft guidance on “Provider-Initiated Testing and Counselling in Health Facilities” in order to improve HIV-related diagnosis, treatment and care and to expand the availability and uptake of HIV testing and counselling in clinical settings. Once finalized, the guidance is intended to expand upon the 2004 UNAIDS/WHO Statement on HIV Testing.
2. The process of developing this guidance has sparked renewed debate on the role of and modalities for HIV testing and counselling, in health facilities and beyond. This debate underlines the urgency to clarify and articulate – in clear rights-based, operational terms – what is needed to ensure that people are able to obtain the full benefits from learning their HIV status for themselves and others; receive the best and most ethical care, diagnosis and treatment in health settings; and if positive, be supported to manage HIV infection, including prevention of transmission of HIV, and equipped to avoid, or seek redress for, stigma, discrimination and violence; and if negative, be supported through prevention strategies to stay negative.

**Development of WHO/UNAIDS guidance**

3. WHO and UNAIDS convened a two-day consultation in July 2006 to review a draft guidance document for countries on “Provider-Initiated Testing and Counselling in Health Facilities”. Though it was agreed that increasing the number of people who know their status is an important objective, many participants underlined that this in itself was insufficient: HIV testing and counselling has to be linked to prevention, treatment, care and support more broadly, and accompanied by intensified action to address social issues, such as stigma, discrimination, violence and other serious negative consequences related to disclosing one’s status to others. There were intense discussions during the meeting regarding the role of counselling, informed consent, and the ability to decline a test in situations where there are wide power differentials between patients and providers. At times, the discussion centred on the terminology employed in the draft – e.g. “routine offer of testing” vs. “routine testing”; “opt-in” vs. “opt-out”. Based on the discussions during the meeting and subsequent inputs by meeting participants, WHO posted a revised draft on the web at the end of November 2006 and invited comments by 5 January 2007 for the English version and 31 January for the French and Spanish versions.

**Concerns identified by civil society and the Reference Group**

4. Civil society has expressed several concerns about the content of the draft guidance. Fears have been expressed that the guidance could lead to *de facto*

mandatory or imposed testing in settings where health care workers either do not understand that patients should be able to opt out or do not supply sufficient information or opportunity for patients to decline. There are also concerns that fear of being subjected to an HIV test without consent will discourage people – particularly those most vulnerable to HIV – from seeking care for HIV and for other conditions. There are also concerns that the “counselling” component of HIV testing and counselling will be left out. Based on these and other concerns, a coalition of civil society organisations (many of which represent groups advocating for the rights of HIV positive women) distributed a “sign on letter” via HealthGap on 8 January 2007, addressed to WHO and UNAIDS and calling for the draft guidance to be withdrawn.

5. The Reference Group has provided its draft comments to WHO and UNAIDS which are circulated at this meeting. Concerns raised by members of the Reference Group in their comments included the following highlights urging WHO and UNAIDS to:
  - Clearly articulate that provider-initiated testing and counselling is only one component of making HIV testing and other prevention and care services more widely available
  - Acknowledge the limitations of provider-initiated testing and counselling and the barriers to uptake affecting all models of testing
  - Clarify use of opt-in and opt-out terminology
  - Elaborate guidance to ensure truly informed consent
  - Prepare a communications strategy for the new Guidelines
  - Remove references to “HIV screening”
  - Strengthen guidance to address risks faced by women and girls
  - Address training and support needs of health personnel
  - Include explicit support for community mobilisation, education and engagement
  - Go beyond “supportive policy and legal framework” and address related services, and
  - Monitor and evaluate implementation of the policy and guidance.

### **Rearticulating the “human rights position” on HIV testing and counselling in the era of Universal Access**

6. Since the beginning of the epidemic, the human rights community and others have put forward a convincing and necessary rights-based critique of mandatory HIV testing policies. Less often have human right advocates proposed concrete, operational responses by which to increase knowledge of HIV status through increased access to testing and counselling in order to increase access to prevention, treatment and care, and at the same time, protect people from the possible negative consequences of knowing and disclosing one’s status. In the current context, some have accused the human rights community of “blocking access to treatment and appropriate health care” by blocking access to HIV testing with “human rights concerns”. There appears to be a need for the human rights community to take the lead in rearticulating the human rights concerns and programmatic priorities in a world trying to reach universal access where an estimated ninety percent of people living in low and middle income countries do not know their HIV status, and infections and deaths continue to rise in an epidemic of mammoth proportions. What does the right to health mean, in terms of its actual content, for the infected and uninfected? How can it best be achieved programmatically? How to achieve many elements of the right to health at the same time: the right to knowledge of one’s health status; the right to be

provided the best prevention strategies as well as the best diagnostic modalities and treatment; the right to be protected from discrimination and violence based on health status; the right to be protected from infectious disease?

7. There are many programmatic responses that can provide the human rights protections that are part to the right to health and other human rights. But these are not guaranteed in terms of political support, funding or implementation capacity. These include the provision of training to health care workers on informed consent, counselling, confidentiality, and non-discrimination; support for the development of widespread community-based HIV testing and counselling, treatment and rights literacy; an adequate policy and legal framework and legal and social support for those who cannot access the legal system; and most importantly, a framework by which to monitor health and human rights outcomes, so that the expansion of HIV testing and counselling does indeed lead to the expansion of treatment and the reduction of discrimination and violence. Shaping the road towards universal access is going to require clear and pro-active leadership from the human rights community – and from the UNAIDS programme – about what it takes to protect and promote human rights to enable people to know their HIV status and disclose it if desired; access prevention, treatment, care and support; and avoid adverse consequences.

### Questions for discussion

- a) Is there a need to rearticulate the human rights concerns and recommendations around HIV testing and other issues in the context of the current epidemic and the scale-up toward universal access? If so, how can UNAIDS best play its own appropriate role and support the human rights community in that exercise? What would be the essential elements of such re-articulation?
- b) What technical support/programmatic actions are needed to ensure that human rights are protected and promoted as the guidance on provider-initiated testing and counselling is implemented? How should they be prioritized by the international community and by countries, keeping in mind resource constraints?
- c) How would the Reference Group advise WHO and UNAIDS to communicate the new guidelines – and the ongoing centrality of confidentiality, counselling and informed consent – given concerns that it may be perceived in some circles as a move towards imposed testing? How can the need for sustained/augmented support to voluntary testing and counselling also be communicated, especially as a means to serve those who do not use formal health services?
- d) What forms of monitoring should be recommended to countries as part of the rollout of provider-initiated testing and counselling with regards to human rights?

### Supporting documents

- Reference Group comments on the draft WHO/UNAIDS “Guidance on Provider-Initiated Testing and Counselling in Health Facilities”(15 January 2007)