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Understanding and respecting different levels of HIV disclosure

UN PLUS GUIDANCE FOR UN STAFF ENGAGED IN THE AIDS RESPONSE

All people living with HIV have the right to decide whether or not to disclose their HIV status. Their decisions to disclose their status must be respected, and the different levels of disclosure they may choose, and the context and setting in which such decisions are made, must be understood. In the light of our commitment to implementing the GIPA principle, I encourage all UNAIDS and UN staff who are engaged in the AIDS response to refer to this important guidance.

Michel Sidibé, UNAIDS Executive Director

UN personnel tell us that the most powerful UN Cares activities are those that include interventions by individuals living with HIV who generously agree to share their stories. As UN Cares team members—and UN system staff in general—we must understand that the decision to disclose one’s HIV status is individual, contextual and very sensitive. This guidance will help us approach conversations about disclosure with the necessary respect and care.

Laurie Newell, UN Cares Global Coordinator

Disclosure of one’s HIV status is an extremely sensitive issue. The extent to which people living with HIV decide to keep their HIV status private is a personal choice, and we need to respect that decision in any context or any setting. However, we often encounter situations where such sensitivity is taken lightly and one’s personal decision and choice is not fully respected. This is why UN Plus has developed this guidance to raise further awareness of disclosure of HIV status among those who are engaged in the AIDS response in the UN system. We hope that it will be of use to those who work with people living with HIV, and that it will increase their understanding of not only the right of people living with HIV to decide whether or not to disclose their HIV status, but the importance and sensitivity of that issue.

Yoshiyuki "John" Oshima, UN Plus Global Coordinator
Introduction

This document provides guidance for United Nations (UN) staff members on understanding and respecting personal decisions of people living with HIV about disclosing their HIV status. This is of particular importance to UN system staff who work on HIV-related issues and who collaborate with non-UN staff (including civil society and people living with HIV) during the implementation of UN programmes and events.

UN organizations involved in the AIDS response are committed to implementing the greater involvement of people living with HIV (GIPA) principle. They do this by striving to ensure that people living with HIV are actively engaged in research, policy-making, and technical and political issues, and that they participate meaningfully in any relevant advisory and decision-making bodies related to HIV. People living with HIV work with UN organizations as UN staff or consultants, are participants in meetings or large-scale public or media events, are members of working groups, or are staff of partner organizations (such as governments, civil society or networks of people living with HIV).

Implementing the GIPA principle often requires UN staff to request information about whether proposed participants are living with HIV, and if they are open about their HIV status. People living with HIV, however, can be at different stages in their disclosure process. For example, some people are open about their HIV-positive status, and some have only disclosed outside of their home region; still others may not have disclosed their HIV-positive status at all.

Given the great sensitivity around disclosure, it is critical that UN staff follow a human rights-based approach. Recognizing and respecting the Denver Principles will allow UN staff to handle situations confidentially and with respect, thus ensuring the meaningful participation of people living with HIV in the AIDS response.

Levels of disclosure

Disclosure is “the action of making new or secret information known.” It is important to note that with HIV, there are different levels of disclosure:

- Non-disclosure: a person does not reveal his or her HIV status to anyone.
- Partial disclosure: a person only tells certain people about his or her HIV status.

The greater involvement of people living with HIV (GIPA) principle and the Denver Principles (1983)

GIPA is a guiding principle that calls for the active and meaningful participation of people living with HIV in the inception, development, implementation, monitoring and evaluation of policies and programmes. To be successful, the involvement of people living with HIV should be mainstreamed across all aspects of the AIDS response, including prevention, treatment, care and support. This participatory way of working breaks down simplistic and false assumptions of “service providers” as those who are living without HIV, and “clients” as those who are living with HIV.

The GIPA principle originates from the Denver Principles (1983), which outline how people living with HIV desire to participate in anything that affects their lives. These key principles include:

- the refusal of people living with HIV to identify with or accept the labelling of “victim”; and
- a strong request to support people living with HIV in the struggle against stigma and discrimination.

The declaration also includes a call to all people living with HIV to:

- form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies;
- be involved at every level of decision-making, and specifically to serve on the boards of directors of provider organizations; and
- be included in all AIDS forums with equal credibility as other participants, and to share their own experiences and knowledge.
Full disclosure: a person talks openly in public about his or her HIV status.

Irrespective of the level of disclosure a person is at, disclosing a person’s status—even if that person lives openly with HIV—still remains a decision and action for the person living with HIV and no one else. It also may differ from context to context.

Addressing HIV status

Below are 10 guiding points that should inform the work of UN staff on how best to address issues around HIV status. Following the GIPA principle, these elements were developed in consultation with people living with HIV, and they include ways to introduce, refer to or enquire about a person's HIV status during (or related to) official UN work.

1. Get consent. Obtain permission from people living with HIV to address their HIV status before introducing them as living with HIV. This is essential to building a respectful dialogue and relationship with people living with HIV. Moreover, disclosure of one's HIV status is the decision of the person living with HIV, irrespective of the level of disclosure that person has adopted outside of the context in question. In other words, permission should be explicit for each introduction—permission that has been given in the past, particularly for another context or group, does not automatically apply to future introductions.

2. Assess someone's level of disclosure. Do not ask people about their HIV status in the form of a direct, closed question (yes or no). Instead, ask whether they are open to discussing their HIV status. Inquiring about someone's HIV status should never be done in public unless previously agreed. Be clear about why UN staff need to address the question of HIV status and how it is relevant to the task at hand.

3. Do no harm. Referring to people publicly or privately as individuals living with HIV should never put them in danger or constitute a threat. Stigma, discrimination, criminalization and sociocultural circumstances are serious issues that must be considered, because they could put people living with HIV at increased risk of human rights violations. UN staff must be sensitive to these issues and use their best judgement in this respect.

4. Determine options on a case-by-case basis. It should be clearly stated from the outset of any conversation about HIV status that everyone has a right to decide whether or not to disclose their HIV status. The right to choose when and how to disclose HIV status is a human right, and the willingness to disclose that status (along with the level of disclosure) should be respected without question. Since the level of disclosure and its consequences may vary depending on the context, each situation needs to be clarified on a case-by-case basis in order to determine when, if and how someone's name may be linked to an HIV-positive diagnosis. It is wrong to assume that permission to discuss someone's status in one context is transferable to another one without prior agreement.
5. Establish introductions beforehand. Clarify how people would like to be introduced and ask if they are comfortable having others refer to their HIV status. Under no circumstances should people living with HIV be introduced as such—even if they have agreed to participate as a people living with HIV—unless they have given their explicit authorization.

6. Clarify reasons for participation. Determine this internally first, and then explain to participants how their participation as people living with HIV is relevant to the purpose and outcomes of the activity. It is important to clearly communicate the significance of the meeting or forum to communities of people living with HIV. Always affirm the GIPA principle and how it is crucial for people living with HIV to be involved in the activity in a meaningful way.

7. Keep it professional. Remember that people living with HIV who have disclosed their HIV status still have the right to privacy. Conversations and questions, especially about HIV status, should remain professional; they should not be addressed in a personal manner. Questions about mode of transmission (i.e. how a person was infected with HIV) should not be asked or addressed unless they have been previously agreed upon and are relevant to the specific context. It is the right of people living with HIV to determine the extent to which they will provide any personal information that goes beyond their HIV status.

8. Be aware of the media. Ensure that people living with HIV understand the potential consequences—both positive and negative—that may result from speaking to the media. UN staff should ensure, especially if an introduction has been made, that consent forms have been signed and that the individual understands the implications of the activities to which they have agreed. The UN should work only with media representatives who have an ethical code and a good understanding of human rights related to disclosure. If the meeting with the media has been organized by the UN, the UN should seek to ensure that the person’s HIV status is communicated in a positive manner.

9. Follow up. Follow up appropriately to make sure that people living with HIV were comfortable with how their HIV status was addressed. Ask if they have any thoughts or opinions about the content or context of the meeting.

10. Ensure a safety net. UN offices should attempt to support people living with HIV through any personal crisis that results from a public disclosure at a UN meeting. Make sure to provide your contact details in case any stigma, discrimination, negative media or pressure (familial or official) results from the public disclosure. Also ensure that people disclosing their status at public events have the contact details for a national or local network of people living with HIV that could or would provide support following public disclosure.
Some scenarios to help you understand this guidance

Example 1

You are inviting an AIDS activist to a conference as one of the speakers. At the conference, you plan to introduce him as an “activist living with HIV.”

Consider … Did you ask him if he was comfortable being publicly introduced as a person living with HIV? Did you provide him with any information about the conference (such as the agenda, venue or audience)?

You should seek his permission and guidance on how he should be introduced before the conference. In particular, you need to ask him whether he would feel comfortable being introduced as a person living with HIV.

You also should consider the context of the conference and inform him about it. Relevant information might include whether the conference is political, academic or religious in nature, as well as its location and the expected audience. This is done to avoid accidentally exposing him to potential risk in certain contexts by introducing him as a person living with HIV. If he is introduced as a person living with HIV, you should follow up with him after the conference to make sure that he was comfortable with how his HIV status was addressed. (See guiding points 1, 3, 4, 5, 6 and 9.)

Example 2

You are facilitating a UN Cares session in which a UN Plus member is participating. You plan to ask her to speak about her experience living with HIV during your session.

Consider … Did you ask her if she was comfortable being introduced as a person living with HIV? Did you ask her if she was open to discussing her HIV status in front of her colleagues?

Before the session, you should privately ask her if she would be comfortable being introduced as a person living with HIV, and if she is open to discussing her HIV status in front of her colleagues. If you cannot—or do not—seek her permission before the session, you should not introduce her as a person living with HIV, nor should you refer to her in such a way during the session. You should not assume that she is open about her HIV status just because she is a UN Plus member. (See guiding points 1, 3 and 4.)

Example 3

You know that a colleague in your office has been active in UN Plus, and that she has been engaged in a number of UN Plus activities in Geneva. You have approached her and asked her to be in a video for an anti-stigma campaign, and to give a short message about HIV-related stigma as a UN Plus member.
Consider ... Did you ask her whether she would be comfortable being in a video and introduced as a person living with HIV? Did you inform her of how the video was going to be used in the campaign and disseminated to the public?

You should privately ask her if she is comfortable being in a video and introduced as a person living with HIV. You also should inform her about how the video will be used and disseminated (e.g. at the UN Cares sessions, through YouTube, on websites). This includes identifying the possible and intended audiences of the video (e.g. UN staff in Geneva or around the world, or anyone who accesses the website where the video would be made available). She needs to understand the implications before she agrees to appear in the video. (See guiding points 3, 4, 6 and 8.)

Example 4

You bumped into an old friend of yours at the International AIDS Conference (IAC). When a colleague who was attending the IAC with you asked about your friend, you told her that he was a friend from a support group for people living with HIV.

Consider ... Was it appropriate for you to imply your friend’s HIV status to your colleague? If you had mentioned how you knew your friend when he was not present, would it have been appropriate?

In this specific setting, you did not have the chance to talk to your friend beforehand to get his consent to being introduced as a person living with HIV. Therefore, it was not appropriate for you to disclose or imply his HIV status, even if he was not present. Disclosure of an individual’s HIV status is the decision of the person living with HIV, and no one should disclose or imply that status without prior agreement, even if the individual is absent. (See guiding points 1, 3, 4 and 5.)

Example 5

You know that your colleague is living with HIV and is open about his HIV status in the office. When his parents visited him in Geneva, you met them and mentioned that your colleague was doing fine despite his “health condition.”

Consider ... Was it appropriate for you to tell your colleague’s parents about their son’s health condition? Irrespective of the actual condition (HIV, diabetes, cardiovascular disease, cancer, etc.), is it appropriate to disclose or imply any health condition without consent?

It was inappropriate for you to imply to your colleague's parents that their son had specific health conditions. Health conditions are a personal matter, and it is inappropriate to disclose or imply those conditions to a third party. You also should not have assumed that he was open about his HIV status to anyone simply because he was open about it in his office. It is important to remember that someone's status in one context is not transferable to another one. (See guiding points 1 and 4.)
Example 6

You were participating in a UN Cares training session where a woman was giving a talk about her experience as a person living with HIV. After her talk, you raised your hand and asked how she “became infected with HIV.”

Consider … Was it appropriate for you to ask about how she became infected with HIV?

It was inappropriate for you to ask how she became infected with HIV. Questions about an individual’s mode of transmission should not be asked or addressed unless they have been previously agreed upon and they are relevant to the specific context. It is the right of people living with HIV to determine the extent to which they will speak about any other personal information that goes beyond their HIV status. (See guiding point 7.)

Example 7

You were organizing a World AIDS Day (WAD) event and you were looking for volunteers in your office to give a talk about their experience of living with HIV. You approached a colleague of yours, who was a UN Cares facilitator. Assuming that he was living with HIV because of his active involvement in UN Cares activities, you asked him if he was HIV-positive and, if so, if he would be willing to give a talk at the WAD event.

Consider … Was it appropriate for you to ask him about his HIV status using a direct, closed question (a yes-or-no question)? How should you have approached him in this context?

It was inappropriate for you not only to assume that he was HIV-positive because of his active involvement in UN Cares, but also to pose a question about his HIV status using a direct, closed question. Instead, he should have been asked whether he was open to discussing his HIV status or not. Also, inquiring about someone's HIV status should never be done in public unless they have previously agreed to it. (See guiding point 2.)

Example 8

You are considering who should be invited to a public, high-visibility panel on “The AIDS response in the post-2015 era.” The position is for a person living with HIV who can speak about living with HIV and participating in the AIDS response. Someone recommended that you invite a young woman living with HIV from a local network of people living with HIV. However, she is not openly living with HIV.

Consider … What are the measures that you need to take to ensure her right to decide whether or not to disclose her HIV status? What is the responsibility of the UN when people who are not openly living with HIV are put in a situation where they have to disclose—implicitly or explicitly—their HIV status?
Any situation where she would have to disclose her HIV status implicitly or explicitly must be avoided at all costs. She should be duly informed in advance that she is being invited as a person living with HIV, and that she would be addressed at the panel as a person living with HIV. You need to ensure that she understands this, as well as the implications and significance of her presence on the panel as a person living with HIV.

If she agrees to attend the panel as a person living with HIV, you should ask how she would like to be introduced. You also need to ask her about her level of disclosure. For example, she may agree to participate in the panel as a person living with HIV, but she may not want to appear in photographs or videos, and this must be respected.

After the panel, you should follow up with her to make sure that she was comfortable with how her HIV status was addressed and to ask about her reflections on the experience. She should contact you or a local network of people living with HIV in case any negative consequences—such as stigma and discrimination—result from her disclosure. (See guiding points 1, 3, 4, 5, 6, 8, 9 and 10.)

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1 In 1994, representatives of 42 governments met in Paris, France, for the AIDS Summit. Based on the participation of people living with HIV, the outcome of the Summit was the call for the greater involvement of people living with HIV/AIDS as a guiding principle for all HIV-related work. This is referred to as the GIPA principle. The Paris Declaration can be found at http://data.unaids.org/pub/externaldocument/2007/thesummitdeclaration_en.pdf (accessed 28 January 2015).


3 To ensure that any enquiry about HIV status is done in a confidential, appropriate and respectful manner, a brief questionnaire was prepared and circulated to key individuals living with HIV through the Global Network of People Living with HIV (GNP+). The purpose of this questionnaire was to provide guidance to the UN on when, why and how UN staff can address or refer to the HIV status of any given person. The results of that questionnaire have informed this guidance.

4 Questions around how people became infected with HIV are not only personal, but they could fuel stigma and lead to notions such as “some people living with HIV are victims while others deserve it.” Asking questions related to mode of transmission therefore should be avoided as much as possible.
**UN Plus** is a global group of United Nations staff who are living with HIV.

If you are working in the United Nations system, living with HIV and would like to join UN Plus, please send an e-mail to unplus@unaids.org or visit www.unplus.org. All communication will be treated confidentially.