



Treating All People Living with HIV: the WHO Guidelines

Policy Paper

Interagency
Coalition on AIDS
and Development



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GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV

1 WHAT IS THE ISSUE?

Based on new scientific studies, the World Health Organization (WHO) recommends that all people living with HIV start antiretroviral therapy (ART) as soon as they learn that they are diagnosed with HIV.¹ This position paper explains the new recommendations, why WHO has made them, how the new guidelines affect people living with HIV, and what this means for advocates and service providers from HIV-affected communities.

2 WHY THE NEW WHO GUIDELINES MATTER TO PEOPLE LIVING WITH HIV AND COMMUNITY GROUPS

- **Starting treatment must be a choice:** Starting treatment must always be a choice, not a requirement. Starting treatment should never be mandatory or coercive. Under the WHO guidelines, every person living with HIV should be offered treatment so they can decide if the time is right for them to start. As countries work to adopt the WHO guidelines, people living with HIV need to be involved in determining how treatment will be offered and make sure that no one is coerced ('forced') into starting treatment.
- **Treatment access must be available without discrimination:** People need to know that treatment is available regardless of where they live or who they are. All people living with HIV have the right to treatment: rich or poor, young or old, male or female, whether they are a sex worker, a drug user, a man who has sex with other men, a transgender person, a migrant, disabled or incarcerated.
- **Treatment must be based on informed decisions:** In order to make informed decisions, people need clear information about their options: when to start, what ARVs to start with, side effects and dosing, drug resistance and the importance of taking ART consistently and on schedule, and CD4 and viral load testing.
- **The supply of medicines and diagnostics must be consistent and secure:** Inconsistent access to medications

creates the risk of drug resistance. People need to know that the medicines will be consistently available to all who need and want them. If people live in places where their medication supplies run short, they may decide to not start treatment until a reliable supply is available and/or wait until their risk of serious illness increases. Consistent access to viral load testing is also essential so that people know whether the medicines are working in their bodies and if they need to switch to another treatment regimen.

- **Equitable and rational approaches to treatment access:** If a country does not have the resources to provide treatment consistently to all who want and need it, then policies need to be in place to ensure that (1) the sickest and most vulnerable people are the first ones to receive medicines, (2) treatment is equitably dispensed and not withheld from marginalized populations, such as people who use drugs, sex workers, transgender women, and gay and bisexual men and other men who have sex with men, and (3) medication supplies are consistently available to those on treatment to avoid the possible development of drug resistance.
- **Treatment also serves as prevention:** The primary purpose of starting ART is the treatment and the well-being of the individual. However, people living with HIV care deeply about HIV prevention and understand the value that ART provides in preventing HIV transmission. The engagement of people living with HIV as partners in prevention is a key to success of prevention programmes.
- **People living with HIV should be employed and compensated for service provision:** The WHO guidelines recognize that people living with HIV have an important role to play as service providers. The guidelines recommend peer-based services for HIV testing, linkage to care, treatment literacy and adherence support.

3 BACKGROUND INFORMATION AND RECENT DEVELOPMENTS

WHO now recommends that people living with HIV begin ART as soon as possible, before developing any signs or symptoms of illness and before their immune systems have weakened. This is a change in approach. **Before**

¹ The 2015 WHO recommended guidelines are available on the WHO website at www.who.int/hiv/pub/guidelines/earlyrelease-arv/en/ (accessed 3 December 2016).

2015, the WHO treatment guidelines recommended that people living with HIV begin treatment if:

- They were diagnosed with AIDS or had symptoms of HIV-related illness, such as severe weight loss, fatigue or thrush (a fungal infection that can leave white patches in a person's mouth).
- Their immune system was weak according to the results of blood tests measuring their CD4 cells, which are white blood cells that are important indicators about the health of one's immune system. The average CD4 cell count in a healthy adult is around 1,000. Prior to 2015, WHO recommended starting ART if the CD4 count fell below 500.

Also, all pregnant women and people living with other conditions such as tuberculosis (TB) were recommended to start treatment immediately.

The *new recommendations to start treatment as soon as possible* are based on the results of scientific studies that compared starting treatment at less than 500 CD4 cells against starting with more than 500 CD4 cells. All studies have shown that people who started treatment earlier had better results: they stayed healthy for a longer period of time. Because ART suppresses the ability of the virus to 'replicate' (copy itself) in the body, earlier treatment keeps HIV from attacking and weakening a person's immune system. Thousands of people living with HIV participated in these studies and people living with HIV were also involved in designing and implementing them. The studies were conducted at the highest standards and produced reliable results.

Newer and improved ARV medicines also have fewer side effects and require taking fewer pills each day. These ARVs are more accessible and more affordable. These factors make it easier for people living with HIV to start and stay on treatment. When the amount of HIV in the body is reduced to low levels (known as "viral suppression") and maintained over time, then people living with HIV are very unlikely to transmit HIV to others, making HIV treatment an important HIV prevention strategy. All these factors led to the change in WHO recommendations, but the most important factor is that earlier treatment keeps people living with HIV healthier.

The new guidelines also recommend that all people living with HIV have access to viral load testing, a simple blood test that measures the level of HIV virus in one's blood. An 'undetectable' viral load means that ART is working and that viral replication is being suppressed so low that the blood test cannot find any virus in the blood. If the virus

develops resistance to antiretroviral medicines, the viral load will increase. Viral load testing is essential to knowing whether treatment is working.

Most countries will adopt the new WHO guidelines and begin to recommend the immediate use of ART to everyone living with HIV. Millions more people will now be encouraged to start ART. This has important implications for how countries spend their HIV budgets, how people decide whether they want to start treatment, how treatment and support services will be provided, and how to make sure that key populations such as sex workers, people who use drugs, transgender people, and gay and bisexual men and other men who have sex with men are included in the scale up of treatment delivery.

ADHERENCE: A CORNERSTONE OF EFFECTIVE HIV TREATMENT

To be effective in preventing HIV from damaging a person's health, antiretroviral medications must be taken every day so they are constantly active in the body. Otherwise the virus can develop resistance to the medications and the medications might stop working. The term 'adherence' in HIV treatment refers to whether a person on ART is taking the medications as often as they are supposed to be taken. Adherence can be difficult, especially when people have complicated treatment regimens or when the medications have side effects. Fortunately, antiretroviral medications today have fewer side effects and ART regimens now include effective one-pill once-a-day options. Adherence can be even more challenging for other reasons, such as when a person cannot afford to pay for transport to pick up the medications or when they are not available because of shortages at a clinic.

Lack of adherence, for whatever reason, can lead to serious health problems because HIV is not being controlled effectively. An individual might also have fewer treatment options because HIV can become resistant to one or more drugs in an ART combination. If this happens, it can be difficult to find a different drug combination that works and is regularly available and affordable.

To be effective, ART programmes must provide more than pills: they also need to ensure that the pills are always available, that diagnostic tests to measure viral load are available, and that adherence support programmes are available as well.

4 THE GOOD AND THE BAD: OPPORTUNITIES AND CHALLENGES FOR PEOPLE LIVING WITH HIV AND COMMUNITIES

Overall, the changes in WHO and national treatment guidelines are positive news for people living with HIV. Some of the **reasons for optimism** include the following:

- The results of new research provide everyone with **more and better information about how to use ART effectively**. This is important to help keep people living with HIV healthy and living a normal life span as well as to protect others from becoming infected with the virus.
- People living with HIV have **more control over their own health** since they can decide if and when to start treatment instead of being forced to wait if their CD4 count is above a certain number.
- The knowledge that HIV treatment is immediately available could prompt **more people to be tested for HIV**. Some might have avoided this step because they thought that knowing their status made no difference if treatment is not possible. Now they have options if they test positive.
- The new WHO guidelines offer important opportunities for **using the experience of people living with HIV** as service providers—such as by offering testing and counselling, linkage to care, treatment literacy and adherence support.

The guidelines will only make a difference if they result in more people receiving high-quality HIV treatment on demand. That is not possible now in all or part of many countries. Some of the important **challenges** to this vision are listed below:

- People can only start treatment after they **know their HIV status**. More outreach and awareness is needed to encourage people to be tested. Testing also needs to be made easier and more convenient, which is why self-testing and home testing might be good options.

Community-based organisations and other civil society groups can have a big role in efforts to increase testing.²

- All antiretroviral drugs in a country's treatment protocol **must be available at all times, in all places**. This can be difficult to achieve because many countries already struggle to meet HIV treatment needs. Shortages ('stock-outs') of drugs put the health and lives of people living with HIV at great risk because they make adherence more difficult.
- **Quality HIV treatment is complex**. ART is a necessary part, but not the only one. For example, the new WHO guidelines recommend that, at a minimum, all people on ART should receive a viral load test six months after starting treatment and then once every year after. The results of these tests give people on ART and their caregivers information about whether the medicines are working. If they are not working, it might be necessary to provide support for better adherence or to change to a different combination of antiretroviral drugs. Quality HIV treatment also includes other kinds of support services that help people on ART to keep taking their medicines by making their lives easier and more comfortable. These services might include flexible clinic hours, more convenient and affordable transportation options, and more nutritious food.
- **Quality HIV treatment is expensive**: more money and experience are needed. The services mentioned above, from viral load tests to nutrition, all cost money. Many countries already find it difficult to provide quality HIV treatment. It will get even harder with the new guidelines and other efforts to get more people tested for HIV, which WHO, donors and national governments all want to do. Without more money, countries will not be able to train and hire enough health care workers to meet demand. They may not be able to afford to buy enough antiretroviral drugs, including new and different ones that individuals on treatment might need. Community and civil society groups already provide some of the necessary services, but they also need more funding to expand in most places.

² 'Civil society' is a term that usually refers to organisations and groups that are not part of government or in the for-profit (private) sector. Civil society includes nongovernmental organisations (NGOs), advocacy groups, faith-based organisations (FBOs), networks of key populations and people living with HIV, etc.

5 HOW TO BE INVOLVED: SUGGESTED ACTION AREAS FOR PEOPLE LIVING WITH HIV AND COMMUNITIES

People living with HIV, key population groups and community organisations can and should be involved in making sure that the new guidelines make a difference in their countries and globally. The following are examples of suggested activities and actions:

- **Treatment literacy and education.** ‘Treatment literacy’ refers to providing people living with HIV with important information about the virus and how they can make treatment work best for them. The WHO recommends the expansion of peer-based treatment literacy services.
- **HIV testing outreach.** Many people at greatest risk for HIV, including key populations, do not know their HIV status. Often they choose not to be tested because they are concerned about confidentiality or being identified as gay or someone who injects drugs, which could put them in legal trouble or make them victims of abuse or violence. People living with HIV, key population groups and community groups are likely to have the most success in encouraging people like them to be tested, and then helping direct them to care.
- **Monitoring HIV treatment.** New treatment guidelines and promises are useless unless they are put in place and enforced. Quality HIV treatment should be regularly available to all who want it, at all times. This might not happen without independent monitoring, which refers to collecting information and observations from people on treatment and their caregivers. Monitoring might include, for example, questions about whether viral load testing is available for everyone on treatment as often as it should be. Community and civil society groups can be involved in this vital monitoring role. They can make their findings public and hold people accountable for making changes.

OTHER AREAS WHERE ADVOCACY IS NEEDED:

- **Changing national guidelines** to reflect the new WHO recommended ones, if this has not yet been done. Particular attention should be given to viral load testing being mentioned as the ‘standard of care’ for all people on ART.
- **Making more antiretroviral drugs available**, especially for second- and third-line treatment. While most people living with HIV worldwide are on first-line drugs, these medications do not work against HIV for all people for a variety of reasons. Advocacy in this area might also need to focus on changing a country’s national treatment protocols to include more antiretroviral drugs as official, acceptable options.
- **Expanding the role and involvement of community-based organisations and other civil society groups.** In addition to more funding, this might require changing a country’s HIV treatment policies or laws that restrict the activities of non-government organisations (NGOs).