

LIVING 2008 Summit themes:

Access to treatment, care and support

“Doctors’ knowledge regarding access to treatment, care and support is often low. They are mostly not very helpful. We as PLHIV need to educate ourselves regarding access to treatment, care and support issues.”

(LIVING 2008 delegate from Eastern Europe)



1 What is the issue?

There is reliable evidence that access to treatment, care and support (ATCS) works. However, ATCS is often interpreted as meaning access to ARVs only. But ATCS is more than having access to ARVs. ATCS can only be a part of a holistic response to HIV and AIDS. HIV funding is often abundant at country level nowadays and targeted to PLHIV, but not under the control, supervision or accountability of PLHIV. Increased international funding is often leading to reduced government responsibilities. Even within the community of activists working on treatment access, there is a tacit understanding that different standards of medical and social standards of care and support are acceptable in different countries and

regions (vulnerable groups, women, children and ethnic groups). PLHIV need to know about and become experts on quality of standard, trade issues, patent laws, HIV research, procurement standards, treatment side effects, pediatric diagnosis, and ATCS. Greater involvement of PLHIV in matters of their health care is called for.

One of the major challenges is that there is no consensus on what standards of care there should be. Should there be one internationally agreed on, universal standard or can we have different ones for different regions or countries? Can the PLHIV community accept differing degrees of standard of care?

2 What are the key advocacy messages on Access to treatment, care and support?

a) Access to treatment is a fundamental human right and necessity of PLHIV. The current more favourable climate and overall greater access of PLHIV to treatment, however, allows a shift from an almost complete focus in earlier years on treatment to wider issues of access to treatment, care and support.

b) In spite of effective treatment literacy programmes, PLHIV and communities need more information with regard to treatment, such as what it means to be on treatment, issues of adherence, and myths and realities about generics. Other knowledge gaps exist in the areas of ARV registration procedures, the procurement and supply chain, the epidemiology of HIV and AIDS, and advocacy opportunities at country and regional levels.

c) The knowledge regarding access to treatment, care and support issues among health care providers, in particular medical doctors, is mostly not sufficient. There should be better training of health care providers.

d) There is a need for PLHIV to get more involved and knowledgeable on issues regarding their health care. PLHIV should become experts regarding their health care.

e) Regarding women and ATCS issues, there is a need to: Advocate for equitable access to treatment. Provide knowledge and information regarding access to treatment, care and support, with a focus on gender issues; and Initiate research on microbicides, and effects of new and existing ARVs and other drugs on the body, fertility and libido.



3 What are the envisaged next steps?

Train health care providers regarding the access to treatment, care and support needs of PLHIV.

Provide more information to PLHIV on access to treatment, care and support issues, for example by offering capacity building workshops or widely disseminating information resources in different languages.

Establish effective national legal frameworks with standards regarding access to treatment, care and support (national governments).

Ensure expeditious and reliable procurement and distribution chain of ARVS and commodities throughout the national health systems, including treatment and care of infectious and opportunistic diseases (national governments).

4 What is needed from the following audiences (in the next 12- 24 months) to address this issue and remove some of the 'barriers'?

International Donors

Support the establishment of effective national legal frameworks with standards regarding access to treatment, care and support.

Policy makers

Provide technical support in the establishment of effective national legal frameworks with standards regarding access to treatment, care and support.

National Programme managers

Provide information to PLHIV regarding treatment, for example what it means to be on treatment, issues of adherence, and myths and realities about generics.

PLHIV Community

Increased individual – and community - involvement on issues regarding PLHIV health care to become more knowledgeable regarding ATCS issues.

Researchers

Initiate research on microbicides, and effects of new and existing ARVs and other drugs on the body, fertility and libido.

5 Suggested additional reading/information on this issue:

HIV i-Base

<http://i-base.info>

International Treatment Preparedness Coalition / HIV Collaborative Fund

<http://www.hivcollaborativefund.org>

Access to Care, Treatment and Support (ATCS), by ICW:

http://www.icw.org/tiki-download_file.php?fileId=60

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