HIV and AIDS
Treatment Education
Technical Consultation Report
22-23 Nov 2005 - Paris, France
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This report was written by Justine Sass, Coordinator of UNAIDS Inter-Agency Task Team on Education and Programme Specialist in HIV and AIDS Education, in UNESCO’s Division for the Promotion of Quality Education, Section for an Improved Quality of Life. The author acknowledges Dr. Kevin Moody of the World Health Organization, and Chris Castle, Jud Cornell, and Chris Mallouris of UNESCO’s Section for an Improved Quality of Life, who made suggestions and comments and who reviewed various drafts. Kate Elder, a UNESCO consultant, also provided important input as a Rapporteur for the meeting, and as a reviewer.

Thanks are also due to the following participants, who offered useful comments on earlier drafts: Kristina Bolme of Médecins Sans Frontières; Sandrine Bonnet of UNESCO’s International Bureau of Education; Ana Filgueiras of Portugal’s National Coordination of HIV/AIDS Infection; Carolyn Green of the International HIV/AIDS Alliance; and Jeffrey Lazarus of WHO.

### Acronyms

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<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>ACER</td>
<td>ARV Community Education and Referral</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td>CBO</td>
<td>Community Based Organization</td>
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<tr>
<td>EDUCAIDS</td>
<td>Global Initiative on Education and HIV/AIDS</td>
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<td>FBO</td>
<td>Faith Based Organization</td>
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<td>GFATM</td>
<td>Global Fund to Fight AIDS, Tuberculosis and Malaria</td>
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<tr>
<td>GIPA</td>
<td>Greater Involvement of People Living with HIV and AIDS</td>
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<tr>
<td>GNP+</td>
<td>Global Network of People Living with HIV and AIDS</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IBE</td>
<td>International Bureau of Education</td>
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<tr>
<td>ICW</td>
<td>International Community of Women Living with HIV/AIDS</td>
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<td>IATT</td>
<td>Inter-Agency Task Team</td>
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<td>IEC</td>
<td>Information, Education and Communication</td>
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<td>IFRC</td>
<td>International Federation of the Red Cross/Red Crescent Societies</td>
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<td>ITPC</td>
<td>International Treatment Preparedness Coalition</td>
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<td>MoE</td>
<td>Ministry of Education</td>
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<td>MoH</td>
<td>Ministry of Health</td>
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<td>MSF</td>
<td>Médecins Sans Frontières</td>
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<tr>
<th>Acronym</th>
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<tr>
<td>NGO</td>
<td>Non-governmental Organization</td>
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<tr>
<td>PAFPI</td>
<td>Positive Action Foundation Philippines, Inc</td>
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<td>PEPFAR</td>
<td>President’s Emergency Plan for AIDS Relief</td>
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<td>PICT</td>
<td>Parent to Child Transmission</td>
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<tr>
<td>PPTCT</td>
<td>Prevention of Parent to Child Transmission</td>
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<td>SAfAIDS</td>
<td>Southern Africa HIV and AIDS Dissemination Service</td>
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<td>STEP</td>
<td>Strategic Treatment Education Programme</td>
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<td>STI</td>
<td>Sexually Transmitted Infection</td>
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<td>TAC</td>
<td>Treatment Action Campaign</td>
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<td>TASO</td>
<td>The AIDS Support Organization</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV and AIDS</td>
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<td>UNESCO</td>
<td>United Nations Educational, Scientific and Cultural Organisation</td>
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<td>UNGASS</td>
<td>United Nations General Assembly Special Session</td>
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<td>UNICEF</td>
<td>United Nations International Children’s Fund</td>
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<td>USAID</td>
<td>United States Agency for International Development</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
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<tr>
<td>WE-ACTx</td>
<td>Women’s Equity in Access to Care and Treatment</td>
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<td>WHO</td>
<td>World Health Organization</td>
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Executive Summary

This report presents the key points and recommendations that emerged over the course of a two day Technical Consultation on HIV and AIDS Treatment Education held in Paris, France, November 22-23, 2005. The Consultation was co-sponsored by the United Nations Educational, Scientific, and Cultural Organization (UNESCO) and the World Health Organization (WHO), and aimed to:

- Review the current status of treatment education at the global country and community levels and “take stock” of experiences, lessons learned, and good practices in treatment education;
- Identify needs in the realm of treatment education, with a focus at this Consultation on treatment literacy and community preparedness;
- Develop an action framework with key priorities for work in the near future for the various partners, including UN agencies, national authorities, and civil society, taking into consideration the value added of each and encouraging joint programming; and
- Identify how the UNESCO-led EDUCAIDS Initiative and the UNAIDS-led campaign on «Universal Access to Prevention, Treatment and Care» can contribute to treatment education.

The meeting brought together technical practitioners with experience in HIV and AIDS treatment education from Government agencies, international and local NGOs, UN agencies, and networks of people living with HIV. Presenters provided insight into programme experience and lessons learned from activities in settings as diverse as: Belarus, Brazil, Bulgaria, Burkina Faso, Estonia, India, Kazakhstan, Kenya, Kyrgyzstan, Lithuania, Moldova, Nepal, Poland, Russia, South Africa, Swaziland, Thailand, Ukraine, Uganda, Uzbekistan, and Zambia.

Treatment education was identified as forming the bridge between the provision of treatment and the preparation and involvement of people and communities in comprehensive responses to HIV and AIDS. Treatment education encourages people to know their HIV status, explains how to gain access to treatment, offers information on drug regimens, offers support and ideas for adhering to treatment and helping others to do so, emphasises the importance of maintaining protective behaviours and healthy living, and suggests strategies for overcoming stigma and discrimination and gender inequality.

An important consensus emerged during the Consultation that treatment education should not be seen as a separate component, a new initiative, or an additional burden to already often overstretched systems. Instead, treatment education is an integral part of comprehensive HIV and AIDS education and, as such, should be part of planning processes to move towards universal access to prevention, treatment, and care. Treatment education programmes have been found to contribute to the wider uptake of voluntary counselling and testing services, a greater belief in the effectiveness of Antiretroviral therapy, better adherence to ART, improved treatment outcomes, and improved quality of life.

UNESCO and WHO recognise that treatment preparedness interventions are required to develop and/or support the capabilities of communities and health care structures to deliver and sustain the use of ART. However, the Consultation did not explore this issue as it has been addressed widely in other fora. Instead, the Consultation focused on Treatment Literacy and Community Preparedness, two sub-components of treatment education, which work synergistically to empower individuals and communities to access and use ART, to address the negative effects of HIV-related stigma and discrimination, and to support improved health outcomes.

The Treatment Literacy sessions focused on content, methodology, and adaptation. Programme experience has demonstrated that the process of developing treatment literacy materials and programmes is important. A consensus emerged during the Consultation on the need to:

- Involve stakeholders—including people with HIV and those on treatment—in the development, review, and evaluation of materials;
- Include accurate and up-to-date information that is culturally relevant, gender sensitive, age appropriate, and available in users’ local languages;
- Facilitate the development of knowledge, skills, and attitudes;
- Field test, monitor, and evaluate activities to determine appropriateness and impact; and
- Document and disseminate programme experience to further learning and progress in the field.

Participants also noted that the growing number of treatment literacy materials and programmes are available for review and adaptation to local contexts. In addition to the issues presented above, participants agreed that adapted materials should include images and examples that are relevant to local contexts, and information that is clinically appropriate and accurate.

While individuals need to be prepared with accurate and appropriate education and problem-solving skills to adhere to treatment and to access support when needed,
treatment education will be ineffective without the engagement of a wide range of actors at the community level. The Community Preparedness parallel sessions looked at content, methodology, and how to scale up efforts and work in partnership with communities.

Participants’ programme experience demonstrated that community preparedness initiatives contribute to the development of solutions that are appropriate, feasible, and “owned” by communities. To be effective, initiatives need to build on and mobilise existing resources and relationships and avoid duplication. They should involve “gatekeepers” such as government and local leaders and respect local contexts and protocols. Community ownership of the programme is key, and mechanisms must be in place to support the long-term sustainability of activities. The education sector should also be involved, as it often the largest employer and component of the public service, and it has an established physical infrastructure and range of skills and resources.

Participants noted that while small scale community preparedness initiatives are in place in multiple contexts, efforts are required to bring programmes “to scale.” There was a consensus that the successful scale up of community preparedness initiatives includes multiple elements such as:

- Identifying relevant, feasible, and willing catalysts;
- Using existing legislation and public policies to advance rights and responsibilities;
- Stimulating dialogue with communities to disseminate information and to build skills;
- Involving key stakeholders in planning, managing, training, and evaluating;
- Investing in and effectively involving people living with HIV;
- Supporting advocates and grassroots activities; and
- Linking up with other community activities to ensure holistic, comprehensive support.

A number of common themes also emerged from both the Treatment Literacy and Community Preparedness parallel sessions including the need to:

- Engage clients and communities as active participants in treatment;
- Take advantage of multiple entry points and involve all relevant sectors;
- Fully involve people with HIV and those on treatment;
- Support continued protective behaviours and healthy living; and
- Tackle stigma and discrimination.

There are a number of lessons learned from the Consultation which can inform future activities in the field of treatment education. These include the need to:

- Employ person-centred approaches: HIV is a chronic disease which requires the development of problem-solving skills to manage symptoms and side effects, to effectively liaise with community- and facility-based services, and to strictly adhere to ARV regimens. People with HIV and their groups are key partners in the scale up of treatment and prevention.
- Provide further support to partnerships and inter-sectoral collaborations between civil society partners, Ministries (Education, Health, Labour, and others), and multilateral and bilateral agencies. In some settings this will require a major shift to recognise the role of other sectors and the community in treatment education.
- Integrate treatment education across the continuum of HIV and AIDS education. Treatment education does not need to be seen as a separate component, a new initiative, or an additional burden to already overstretched education and health systems but as an integral part of comprehensive HIV and AIDS education. Treatment education should be included as part of planning processes to move towards universal access to prevention, treatment, care and support.
- Employ a range of approaches for different settings and audiences. One size does not fit all. Interventions must be informed by awareness of the social and political contexts, and use multiple entry points to ensure that education around treatment is accessible and relevant for all. Messages need to be targeted for priority groups, including “vulnerable populations” that may not have been traditionally addressed through treatment education activities.
- Involve affected communities and individuals, who are properly supported with the necessary knowledge and skills, using pre-existing structures where they are available and capitalising on the expertise of each group.
- Document, monitor, and evaluate treatment education initiatives for process and impact, ensuring that lessons learned are communicated and disseminated. Future initiatives should build on this evidence base, while further developing or adapting approaches to fit the local context.
The “3 by 5” initiative led by the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), the US President’s Emergency Relief Plan for HIV/AIDS (PEPFAR), other global and national initiatives, as well as significant reductions in costs, have expanded access to antiretroviral therapy (ART). Over one million people in low- and middle-income countries are now living longer and better lives as a result.

ART is recognised to be an essential component of comprehensive responses to the epidemic, which include universal access to HIV prevention, treatment, and care for those who need it, and impact mitigation. The recent endorsement of universal access to ART by 2010 by the Group of 8 leading industrialised countries at the Gleneagles Summit in July 2005 is a major boost to these efforts.

The success of programmes to scale up and ensure universal access to treatment will require more than simply the reliable provision of antiretrovirals (ARVs) and related monitoring and laboratory tests by qualified clinical staff. HIV is a chronic disease, requiring lifelong adherence to sometimes complicated treatment regimens with significant side effects and psycho-social complications. Community and individual preparation and education are, therefore, required to enable people with HIV and their supporters to appropriately manage health care and social services to support good health outcomes. This will require a paradigm shift away from “traditional patient education” toward “self-management education.” Self-management education puts people on treatment at the centre of care, assisting them and their supporters to acquire the skills to manage their illness over their lifetime, including solving treatment-related problems (e.g., managing symptoms and side-effects).

In some cases this will also require a major shift in mindset to move education about treatment beyond the health sector into other sectors and into communities. Often the largest institutional system, the education sector can be a mass communication and distribution network for information around treatment and can build important problem-solving and negotiation skills among its members and among learners. Treatment education can be linked to the education sector’s pre-existing work on prevention, care and support; integrated into life-skills and health education; offered through adult, employee, and community education programmes; provided in citizenship and rights education; and as part of Ministry of Education (MoE) sectoral training for staff.

UNESCO’s 2004 HIV/AIDS prevention strategy recognises the connection between prevention, care and treatment and defines HIV and AIDS education as “offering learning opportunities for all to develop their knowledge, skills, competencies, values and attitudes that will limit the transmission and impact of the pandemic, including through access to care and counselling and education for treatment.” The forthcoming publication developed for the UNAIDS Inter-Agency Task Team (IATT) on Education, entitled “HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care,” signals ways that the education sector can engage with communities in treatment education. UNESCO has also developed a short information policies brief on treatment education for the Global Initiative on Education and HIV/AIDS – EDUCAIDS. Its collaboration with WHO on this Consultation is based on the recognition that partnerships between the health and education sectors, civil society, and other stakeholders are important to identify and link needs and resources in a way that helps people to help themselves.

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In addition to its efforts to support the scale up of ART, WHO has been working with community members, educators, health workers and others to become active partners in HIV prevention, care and treatment through numerous activities. These include a $1.5 million grant to the Collaborative Fund for HIV/AIDS Treatment Preparedness, support for a community-driven monitoring and evaluation programme to develop tools to measure progress and develop an evidence base, and the development of training modules for community health workers in collaboration with the International Federation of the Red Cross/Red Crescent Societies (IFRC) and the Southern Africa HIV and AIDS Dissemination Service (SAFAIDS). WHO plans to expand its collaboration with UNESCO beyond this Consultation to jointly develop normative guidance on treatment literacy and community preparedness for partners and collaborators.

In order to draw upon the experiences and lessons
learned at the country level to inform future work on
treatment education, UNESCO and WHO hosted a Technical
Consultation on HIV and AIDS Treatment Education
November 22-23, 2005 at UNESCO Headquarters in Paris,
France.

The Consultation brought together technical practitioners
with experience in treatment education from Government
agencies, international and local non-governmental
organizations (NGOs), UN agencies, and networks of
people living with HIV (see Appendix 1 for the list of
participants). Presenters provided insight into programme
experience and lessons learned from activities in settings
as diverse as: Belarus, Brazil, Bulgaria, Burkina Faso,
Estonia, India, Kazakhstan, Kenya, Kyrgyzstan, Lithuania,
Moldova, Nepal, Poland, Russia, South Africa, Swaziland,
Thailand, Ukraine, Uganda, Uzbekistan, and Zambia.

The objectives of the Consultation were to:
• Review the current status of treatment education at
  the global, country, and community levels and “take
  stock” of experiences, lessons learned, and good
  practices in treatment education;
• Identify needs in the realm of treatment education,
  with a focus at this Consultation on treatment
  literacy and community preparedness;
• Develop an action framework with key priorities for
  work in the near future for the various partners,
  including UN agencies, national authorities and civil
  society, taking into consideration the value added of
  each and encouraging joint programming, and;
• Identify how the UNESCO-led EDUCAIDS Initiative
  and the UNAIDS-led campaign on “Universal Access
to Prevention, Treatment and Care” can contribute to
treatment education.

To achieve these objectives, Consultation organizers
developed a programme that combined plenary sessions,
parallel working groups, presentations, exercises and
discussions (see Appendix 2 for Consultation agenda).

This report presents the salient points that emerged
over the course of the Consultation and provides
recommendations for future actions in the field of
treatment education.
The concept of “treatment education” grew out of the 2002 International AIDS Conference in Barcelona, when a group of over two dozen advocates gathered to discuss how to boost treatment advocacy and education efforts. The concept was further outlined at the International HIV Treatment Preparedness Summit held in Cape Town, South Africa in March 2003. At the Summit, 125 community-based AIDS treatment advocates and educators from 67 countries emphasised that “information is as important as medicine,” and that “without good treatment education, we cannot effectively manage side effects or expect good adherence to therapy.”

The Summit concluded that treatment education is essential not only for people with HIV, but for health care providers, educators, advocates, government officials, families, communities and the greater public.

Many organizations use different terminology when referring to activities related to educating and preparing communities and individuals to become active partners in addressing HIV prevention, care and treatment needs. A draft HIV and AIDS Treatment Education Glossary, providing a brief overview of the various terms employed by different groups when discussing treatment education (e.g., treatment education, treatment preparedness, treatment literacy, community preparedness, advocacy and capacity building) was circulated for comment. The presenter, Christoforos Mallouris of UNESCO, emphasised that the purpose of discussing the Glossary was not to impose uniform terminology during the meeting. At the same time, Consultation participants and organizers recognised that this area needs further exploration and perhaps warrants a wider consultation in the future.

An important consensus emerged during the Consultation that treatment education should not be seen as a separate component, a new initiative, or an additional burden to already often overstretched systems. Instead, treatment education is an integral part of comprehensive HIV education and, as such, should be part of planning processes to move towards universal access to prevention, treatment and care.

Lori Hieber-Girardet from WHO concluded from the Community Preparedness parallel sessions that “[treatment education] shouldn’t be seen as a separate campaign. HIV can be prevented, and when it is not prevented, it can be treated.”

One of the background papers for the meeting, “HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care,” provided a platform for discussion about the different components of treatment education (see Box 1).

There was general agreement that treatment education could be seen as forming the bridge between the provision of treatment (medication and physical support) and the preparation and involvement of people and communities in comprehensive responses to HIV and AIDS. It encourages people to know their HIV status, explains how to get access to treatment, adhering and supporting others to adhere to treatment and understanding the negative role of stigma and discrimination and gender inequality.

Box 1: What is treatment education?

Treatment education is a critical part of overall efforts to prepare people for treatment and to engage communities and individuals to learn about antiretroviral therapy so they understand the full range of issues involved with treatment. These include understanding the benefits of treatment, the importance of maintaining protective behaviours, knowing one’s HIV status, getting access to treatment, adhering and supporting others to adhere to treatment and understanding the negative role of stigma and discrimination and gender inequality. Treatment education complements the provision of drugs and medical care by preparing and involving people in comprehensive responses to HIV and AIDS, and places people on treatment at the centre of their own care.


“[treatment education] shouldn’t be seen as a separate campaign. HIV can be prevented, and when it is not prevented, it can be treated.”

In one village, almost 90% of people stopped taking the ARVs within a short period of time. The main reason is because of the way they distributed the drugs without any education. They just passed them out without any education. So some of the people had side effects and others watched them and stopped. So there is a lack of understanding and no treatment literacy and rumours start to come out of the village, ‘the government is trying to poison us.’ There is a lot of misunderstanding.”

Thomas Cai, China


Treatment education was also recognised by Consultation participants as a key component in efforts to move towards universal access to prevention, treatment, care and support. Treatment literacy and community preparedness were identified as sub-components of treatment education, which work synergistically to empower individuals and communities to access and use ART, to address the negative effects of HIV-related stigma and discrimination, and to support improved health outcomes (see Figure 1). UNESCO and WHO also recognised that treatment preparedness interventions are required to develop and/or support the capabilities of communities and health care structures (including public, private, NGO and others) to deliver and sustain the use of ART. However, the Consultation did not explore this issue as it has been addressed widely in other fora.

In a review of five treatment education programmes from a range of settings and contexts, Avina Sarna of the Population Council in the background paper “Current Research and Good Practice in HIV/AIDS Treatment Education” noted that treatment education had contributed to:

- Wider uptake of voluntary counselling and testing (VCT) services: For example, in Khayelitsha, South Africa there was a doubling of the number of persons tested in 2004 compared to 2003.
- Improved knowledge of ART: In northern Thailand, patients who received enhanced adherence counselling and treatment education prior to initiating ART showed significantly higher mean knowledge scores at baseline compared to patients in the control group receiving standard care.
- Greater belief in the effectiveness of ART: In northern Thailand, patients who received enhanced adherence counselling and treatment education by peers had the highest reported beliefs in ART effectiveness. Peer educators may serve as positive role models and examples of successful treatment outcomes, thereby fostering positive perceptions of treatment effectiveness.
- Better adherence to ART: In Mombasa, Kenya, treatment education in the form of counselling and adherence support from health workers through frequent contact during the initial months on treatment contributed to higher adherence levels. As one 33 year-old male patient explained, “It reduced my anxiety about drugs. I got used to taking drugs. Also the drug dose timing; I was able to follow the time strictly.”
- Better treatment outcomes: For example, in Khayelitsha, South Africa, 73 percent of patients have experienced viral load suppression, and the cumulative probability of survival at 36 months was reported at 81.5 percent.
- Improved quality of life: In northern Thailand, mental health and physical health scores were highest among patients receiving treatment education through enhanced adherence counselling when compared with those receiving adherence counselling and peer support and those receiving only standard care (see also the quote below from The AIDS Support Organization (TASO) in Uganda, page 12).

A representative of the Treatment Action Campaign (TAC), Vuyiseka Dubula, provided an example in the opening plenary session of treatment education in action. While TAC is known more widely for its advocacy work to expand access to ART and treatment for opportunistic infections, TAC’s treatment literacy programme has demonstrated good practices of putting people with HIV at the centre of care, equipping them and their care takers with the
knowledge and skills to manage the disease, and reducing the myths, fears and misconceptions that surround HIV.

TAC’s Project Ulwazi, was initiated in 2000 in the Western Cape province of South Africa. The project aims to build a cadre of trained treatment literacy practitioners capable of using their personal stories and experiences coupled with medical and scientific knowledge on HIV to increase treatment literacy among people with HIV and their supporters. Their activities take place in a range of venues, including clinics, workplaces, prisons, churches, schools and youth groups.

Peer education volunteers were initially recruited from 110 TAC branches in seven provinces of South Africa, but by 2004 the programme had been rolled out to other regions including the Gauteng, Mpumalanga, Eastern Cape and Limpopo provinces.

TAC has established three layers of treatment literacy volunteers: peer educators who are new volunteers; treatment literacy practitioners who have daily presence at treatment sites; and treatment literacy trainers who conduct trainings in each district. Treatment literacy practitioners are now given a stipend to support their work and to help avoid their loss to other organizations after they have been trained.

Community education and awareness campaigns are complemented by materials such as posters, videos, booklets and TAC’s signatory ‘HIV-Positive’ t-shirt (see page 22). Community mobilisation activities include health fora, marches and the expansion of TAC presence through the establishment of new community branches. In areas where TAC branches do not exist, volunteers do door-to-door campaigning and visit markets and taxi stands to spread their message and increase awareness.
TAC materials were one of many identified in the background paper “HIV/AIDS Treatment Education: An Overview of Materials and Communications Strategies,” prepared by Rachel Yassky, a Consultant to WHO. The paper concluded that treatment literacy practitioners have adopted a range of methodologies to enhance learning and skills development around treatment. These include: topical flyers; brochures or pamphlets; comprehensive booklets on specific themes/topics; curricula for health care providers or for persons on treatment; curricula for peer educators, support groups, networks of people living with HIV; teaching or behavioural modification aides such as health diaries and calendars, treatment side-effect charts, pill charts, pill containers; audio or video material for viewing by health care providers and/or clients; broadcast media programmes, radio or TV programmes or spots; posters; pictures, diagrams, or games; and instructional or participatory materials to guide discussions, role plays, and interactive exercises.

These plenary presentations provided participants with an excellent introduction to treatment literacy and community preparedness, the two parallel “working streams” of the meeting. Each “working stream” consisted of presentations, exercises, and discussions to promote learning and sharing of experiences.

“For the moment effectiveness can be assessed from the increasing number of requests for community education activities, from the large number of patients coming in for antiretroviral treatment, from a shift in counseling needs of clients towards issues such as wanting to get married, have children, going back to work, moving out of the area for employment and the dramatic improvements in the health status of patients”

Dr Etukoit Bernard Michael, TASO ART coordinator.

Treatment literacy materials and programmes support learning across a continuum from preparing people to learn about their HIV status, to pre- and post-test counselling, to support and care to those affected or infected by HIV. Treatment literacy can de-medicalise the terminology surrounding ART and make information on ARV regimens more accessible and understandable to those directly involved—people on treatment and those who support their care.

Consultation participants brought a number of materials to share and guide discussions. Their experience supported the findings of the commissioned paper, “HIV/AIDS Treatment Education: An Overview of Materials and Communications Strategies”; most incorporated different learning approaches, including didactic materials presenting basic information (e.g. TAC’s poster on opportunistic infections, ABIAIDS Bulletin on Brazilian production of ARVs), collaborative learning materials to encourage dialogue with health providers or peers (e.g., MSF’s pill diary), self-directed learning materials for both patients and health care providers (e.g. HIV i-Base’s guide to combination therapy, the International Federation of Red Cross and Red Crescent Societies’ (IFRC) ART toolkit), and other problem-based learning methodologies (see Figure 2. Appendices 3 and 4 also provide further information on treatment education practitioners and materials).

One treatment literacy programme presented in the parallel working session combines a range of adult learning and participatory methodologies to “build a pool of HIV treatment activists and peers in the [Eastern European and Central Asian] region who can assist in transferring knowledge and skills to others.” The Strategic Treatment Education Programme (STEP), presented by Alexandra Skonieczna, is comprised of:

- Homestudy to ensure everyone comes to the training with the same basic knowledge;
- Face-to-face sessions (4 days) to interact with experts and to practise solving problems using new knowledge and skills. Two sessions have been held to date: in Kiev for participants from Belarus, Estonia, Kazakhstan, Lithuania, Moldova, Russia, and Ukraine, and in Bishkek for participants from Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan;
- On-line problem-solving course (4 units, 4 months) (1st edition was held from March to July 2005 (11 graduates), while the second edition was ongoing at the time of the Consultation); and
- Small grants to provide resources for trainers to arrange sessions in their own communities.
Programme experience has demonstrated that the process of developing treatment literacy materials and programmes is important. A consensus emerged during the course of the Consultation on the need to:

- Involve stakeholders—including people with HIV and those on treatment—in the development, review, and evaluation of materials;
- “Know the learner” to ensure that materials fully meet the users’ needs. HIV i-Base, for example, has a treatment phone line to respond to queries and concerns which is also used to provide “market research” on information needs;
- Include accurate and up-to-date information that is culturally relevant, gender sensitive, and age appropriate;
- Facilitate knowledge, skills and attitudes, and problem-solving through treatment literacy materials and programmes that are reinforcing and synergistic.

Irene Malambo from the MoE in Zambia provided the example of the National HIV/AIDS Council’s working group on ART. The working group holds ART message harmonisation meetings to ensure consistent and synergistic information by the range of actors involved in treatment education;

- Translate materials into the local languages of the users. For example, TAC’s materials have been translated into 11 of the local languages in South Africa, and HIV i-Base’s materials have been translated into 28 languages (see also Box 2);
- Integrate activities wherever possible into pre-existing prevention, care, and support efforts;
- Field test, monitor, and evaluate activities to determine appropriateness and impact; and
- Document and disseminate programme experience to further learning and progress in the field.

Participants also noted that the growing number of treatment literacy materials and programmes are available for review and adaptation to local contexts. Many of the same issues relevant for the development of materials apply for adaptation. For example, when adapting materials, it is important to know the needs of the intended audiences, to involve stakeholders in the adaptation process, and to include accurate, up-to-date information that is culturally relevant, gender sensitive, age appropriate, and context specific. In addition to the issues presented above, participants agreed on the following issues to consider when adapting:

- Use images (see Figure 3) and examples that are relevant to local contexts. For example, in an HIV i-Base publication “peppermint tea” was suggested to calm the side effect of nausea caused by ART. In Bulgaria, this was changed to “dill tea,” a more commonly found and consumed product;
- Ensure that information is clinically appropriate and accurate. For example, when discussing drug regimens, adapt to national protocols, which dictate the availability of ARVs and monitoring tests (e.g., viral loads);
- Be aware of the challenge of copyrights and protected material.

Box 2: The importance of language

“The challenges of language must be highlighted. In Indonesia, few doctors are competent in English, and none of the other ‘world’ languages are spoken. Clearly, treatment literacy materials must be presented in the local language.”

Chris Green, Spiritia Foundation


Figure 3: Adaptation of treatment guide in Namibia—Not just the words...

Original

Adapted

While individuals need to be prepared with accurate and appropriate education and problem-solving skills to adhere to treatment and to access support when needed, treatment education will be ineffective without the engagement of a wide range of actors at the community level (see Box 3, page 16).

Carolyn Green of the International HIV/AIDS Alliance highlighted the importance of community preparedness in a presentation in the parallel session. In her experience, community preparedness is essential because: people seek support and information about HIV and ART from a wide range of sources; fear and stigma and lack of understanding inhibit people from accessing VCT and treatment; and increased knowledge and understanding of HIV and ART can increase support for people on treatment, reduce stigma and encourage protective behaviours. She cited a Zambian workshop participant who explained that, “HIV/AIDS is seen in the clinics, but it lives in our communities.”

Participants concluded that communities can play a key role by:

- Mobilising political will and commitment to improve/demand access to ART and reductions in cost of treatment;
- Conducting advocacy, including raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments;
- Promoting a safer environment where people will feel more comfortable being tested for HIV and aware of their status;
- Supporting individuals and groups to lobby health services for free and equitable access to treatment, and quality of care;
- Providing care and support to those on treatment;
- Establishing and supporting links to services;
- Supporting the meaningful involvement of people with HIV, including those on treatment, in the develop-

Figure 4: The treatment journey

Source: Community Preparedness Parallel Working Group Session.

“HIV/AIDS is seen in the clinics, but it lives in our communities.”
Box 3: Community preparedness engages a wide range of actors

These include:
- People living with HIV (men, women, and young people)
- Vulnerable and marginalised groups (e.g., men who have sex with men, sex workers, drug users, persons with disabilities)
- Educators
- Health workers
- The media (print, television, radio, and online)
- Private sector
- Community and religious leaders
- Traditional healers
- Trade, teacher, or other unions
- Other members of civil society

Source: Community Preparedness Parallel Working Group Session.

- Need to build on and mobilise existing resources and relationships and avoid duplication;
- Take time, effort and respect for local contexts and protocols;
- Are important to improving the uptake of VCT and prevention of mother to child transmission of HIV (PMTCT) services, which are important entry points for ART;
- Contribute to the development of solutions that are appropriate, feasible, and “owned” by local communities;
- Require the involvement and commitment of “gatekeepers” such as government and local leaders;
- Need to not include individuals as “tokens” but as programme stakeholders, with access to opportunities for personal and professional growth, networking, and learning;
- Should include mechanisms to support community ownership of the programme and long-term sustainability of activities; and
- Should incorporate the education sector, as it often the largest employer and component of the public service, and it has an established physical infrastructure and range of skills and resources.

The example of a Médecins Sans Frontières (MSF) project in Kibera, a slum in the Kenyan capital of Nairobi, demonstrated the importance of community preparedness in scaling up ART. As Kristina Bolme explained, in 2003, MSF recognised that although their project included well trained staff, treatment guidelines and data collection, those on treatment were simply recipients of care rather than drivers of their own treatment.

MSF decided to empower those on treatment, involve the community to the fullest extent and promote community ownership of the programme. The initial information, education and communication (IEC) team of five MSF staff was expanded to include 45 people living with HIV who were trained and supported to conduct support groups, health talks, workshops with key groups and advocacy activities.

The active involvement of the community contributed to a massive scale up: by April, 2005, over 2,000 patients were enrolled in the programme, over 400 patients were on ART, more than 400 people were seeking VCT services per month, and use of out-patient and maternal and child health services also increased. Due to the success of
this community-owned project, MSF plans to completely ‘hand over’ the project to the Ministry of Health and phase out in the near future.

Participants noted that while small scale community preparedness initiatives are in place in multiple contexts, efforts are required to bring programmes “to scale.” There was a consensus that the successful scale up of community preparedness initiatives includes multiple elements such as:

- Identifying relevant, feasible, and willing catalysts;
- Engaging partners to collaborate at different levels;
- Using existing legislation and public policies to advance rights and responsibilities;
- Employing social mobilisation to monitor the legal policy framework;
- Stimulating dialogue with communities to disseminate information and to build skills;
- Developing managerial capacity;
- Employing innovative participatory methods and strategies;
- Involving health and education workers from the outset;
- Bringing people together for planning, managing, training, and evaluating;
- Investing in and effectively involving people living with HIV;
- Supporting advocates and grassroots activities; and
- Linking up with other community activities to ensure holistic, comprehensive support (e.g., income-generating or micro-credit activities, social services).
A number of common themes emerged from both the treatment literacy and community preparedness parallel sessions including the need to:

1. Engage clients and communities as active participants in treatment

Many treatment education efforts to date have been some combination of HIV 101 (the basics of HIV, the immune system, common opportunistic infections and co-infections, transmission, etc.) and ARV 101 (what are they, how do they work, how to take them, what are the likely side effects, changing medications, etc.) While basic information is required to help people make the decision to initiate treatment, people on treatment also need appropriate skills in problem solving around their social and health situations in order to remain adherent to treatment and to access support when needed (see Box 4, page 23).

Preparing communities is also more than just providing information—it is igniting the call to action. Participants’ experience demonstrated that communities can help to create a demand for services, and to support people with HIV to initiate and adhere to treatment. This has been most effective when communities have been supported to identify the structural and attitudinal barriers to treatment and care, and to develop solutions to overcome these barriers. Cristina Pimenta of ABIAIDS also provided the example of rights-based approaches used by communities to demand access to treatment. As she explained, “Health in the US is viewed as a consumer right, in South Africa as a human right and in Brazil as a citizenship right.” At the same time, participants recognised that community engagement was a special challenge in environments where a culture of activism does not exist (see section on Challenges, page 23).

The creation of “expert patients” or “smart clients” was seen to be a critical component for promoting change within healthcare systems to expand access to treatment and improve quality of care. “Beat It! Your Guide to Better Living with HIV/AIDS”, a weekly television series in South Africa, aims to combat fear and denial of HIV and AIDS by promoting accurate knowledge and information on a variety of HIV-related subjects, in turn empowering people to “take charge of their own health.” Episodes cover a variety of subjects, including topics such as dealing with death and loss, HIV and disability, tuberculosis (TB) and HIV, prisons, and HIV and gender and HIV, among others. Vuyani Jacobs of Siyayinqoba Beat It! explained that the series “is about making good decisions and creating environments in which those decisions can be made in a safe space.”
2. Take advantage of multiple entry points and involve all relevant sectors

To date, information on ART has largely been considered the domain of the health care system. Yet providers in many health care settings are often overstretched with their existing responsibilities to provide HIV testing and counseling, as well as treatment and prevention services. While treatment education is certainly needed in clinical settings to ensure that patients understand how the drugs must be taken and adhered to, the benefits and side effects of treatment, and the importance of continued protective behaviours and healthy living, treatment education needs to reach beyond health facilities into other institutions and into communities.

Often the largest institutional system, the education sector can be a mass communication and distribution network. As Jonathan Godden from the Mobile Task Team AIDS Response Trust explained, it is often the largest employer and component of the public service, and it has an established physical infrastructure and range of skills and resources (see Box 5). Young people who attend school or other educational settings may also be the easiest group to reach as they are a ‘captive audience’. Treatment education can be linked to the education sector’s pre-existing work on prevention, care and support; integrated into life-skills and health education; offered through adult, employee, and community education programmes; provided in citizenship and rights education; and as part of MoE sectoral training for staff. Zambia’s MoE has also demonstrated the importance of including not only information on ART, but wider access to treatment for staff.

Youth group performing for traditional healers, Zambia

Treatment education can also be conducted in nonformal settings. For example, the participant from the International HIV/AIDS Alliance reported that Projet Orange in Burkina Faso conducts community education through roadside coffee shops, internet cafés, and micro-finance activities. The background paper “Current Research and Good Practice in HIV/AIDS Treatment Education” provided the example of the ARV Community Education and Referral (ACER) project in Zambia which reaches into communities through church programmes, traditional healers, and support groups. Multi-media can also be effective, as demonstrated by radio and television programmes (e.g., Botswana’s “Talk Back” interactive teacher capacity building TV show, and the Beat It! series in South Africa).

Programmes also need to determine how they can work synergistically to ensure linkages, for example, from ART programmes to health and social services, income-generating opportunities, and support groups. The ACER Project in Zambia was reportedly successful in developing a two-way referral system between the health system and other sources of assistance for people on treatment. The background paper commissioned by the UNAIDS IATT on Education, “HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care” also provides the example of the Narimebe Diocese in Uganda, which invites people with HIV to post-test clubs where they can speak with a trained counsellor, meet with other people with HIV and access other support, including micro-credit programmes.

Box 5: Key messages for engaging the education sector

- Treatment education is not a new campaign making additional demands on an over-stretched sector;
- Treatment education is an essential enhancement of prevention, care, and support work;
- Treatment education messages need to be context specific and age appropriate; and
- The education sector has an important contribution to make.

3. Fully involve people with HIV and those on treatment

People with HIV and those on treatment have a crucial role to play at every level of treatment education, as active and informed participants in treatment, as treatment service providers, as treatment educators and counsellors, as programme managers, planners and evaluators, and as treatment advocates.

Participants were in agreement that the involvement of people with HIV and those on treatment in the development, review, and evaluation of treatment literacy materials was key to ensuring their relevance, acceptability and usefulness. In Rwanda, the Women’s Equity in Access to Care and Treatment (We-ACTx) convenes a local treatment literacy working group comprised of key stakeholders who review and discuss the curriculum. In the Philippines, the Positive Action Foundation Philippines, Inc. (PAFPI), funded by the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria (GFATM), has conducted guided group discussions to solicit suggestions and comments from people living with HIV, medical health professionals, academics and NGO/CBO staff.

Participants also agreed that people with HIV need to be involved at all levels of institutions—not only as volunteers or unpaid support staff. Two examples were provided by the International HIV/AIDS Alliance: at Projet Orange in Burkina Faso, people with HIV serve key functions from providing client support to making management decisions while at the ACER project, people with HIV are employed as treatment supporters. Beat It! is also working on the principle that the involvement of people living with HIV is essential to controlling the epidemic. One participant emphasised the importance of having people living with HIV at the centre of all activities, including in the evaluation of strategic plans, in leadership positions, and in evaluating application of the Greater Involvement of People Living with HIV and AIDS (GIPA) principles.

The Collaborative Fund, a fund to support community treatment preparedness initiatives, was created by the International Treatment Preparedness Coalition (ITPC) and the TIDES Foundation and receives financial support from WHO and other donors. Kate Thomson from UNAIDS explained that small grants worth a total of $200,000 per region will be distributed by the Fund to each of the ten regions by the end of 2005. Collaborative Fund grants fully integrate people living with HIV not only as recipients but as donors, and ensure that there is ownership by networks of people living with HIV at each level of the grant making and implementing process.

Beri Hull of the International Community of Women living with HIV and AIDS (ICW) noted that ICW is coordinating the African Collaborative Fund for Women and Families. The Fund will prioritise treatment literacy and preparedness needs and review grants for activities which are gender sensitive and address specific issues relating to women living with HIV.

Developing capacities is essential and ensuring that people with HIV have a key leadership role at every level of the intervention is important (see Box 6). One participant from MSF noted that the organization provides training and other tools to people living with HIV who participate in their programme, including basic computer knowledge, free access to the Internet, access to decision-making opportunities, and a meeting space to encourage dialogue and psychosocial support. The participant from TAC described a similar situation where the branches were seen as “spaces for shared learning” and stipends were provided to treatment literacy practitioners to support their work and to help avoid losing them to other organizations after they have been trained.

Box 6: Ensuring adequate support for involvement

Not all people with HIV have the proper skills or knowledge to advocate on their own behalf. To support the meaningful involvement of people with HIV in treatment education, programmes should provide:
- Training and other educational opportunities to develop HIV and AIDS knowledge, communication, organisation and management skills.
- Psychosocial and material support to people with HIV and AIDS with few resources (through, for example, peer counselling, financial compensation, food, drugs, medical care, travel reimbursement, child care and education programmes).
- Links to referral services for medical care, counselling, training, support groups and positive living skills.

4. Support continued protective behaviours and healthy living

Treatment education can support people with HIV to protect their sexual and overall health; avoid practices that put them at risk of contracting new STIs, other opportunistic infections, such as TB, or super-infection with other strains of HIV; delay the weakening of the immune system and the onset of AIDS-related illnesses; and prevent further transmission of HIV.

Tailoring prevention and treatment education efforts to meet the needs of people with HIV reflects an emerging area of interest for HIV prevention, and forms part of a comprehensive HIV prevention strategy. Prevention focusing on people with HIV, often referred to as “positive prevention,” has recently emerged as a programmatic strategy of the US Centers for Disease Control and Prevention (CDC) and is part of the WHO/UNAIDS’ list of key interventions to move toward universal access to prevention, treatment and care.

Participants concluded that community preparedness was key to successfully addressing the needs of people with HIV and to creating environments where people living with HIV can be comfortable practising safe behaviours. In the words of one participant, “It is the responsibility of the communities to ensure that positive prevention can happen, and there must be a social contract so that communities also disclose and break the silence.”

Special efforts may be needed for women living with HIV who require support for issues such as getting their partners to practice safer sex and disclosing their HIV status to their partners and children. ICW has conducted advocacy training in sexual and reproductive health and rights and access to care, treatment and support to build the capacity of women living with HIV in South Africa and Swaziland to influence policy and advocate for improved services, including health education. Participants of ICW’s training developed advocacy action plans which included training and educating women with HIV on available health services, and recommendations for the Ministry of Health on desired services.

Through the Beat It! series, people with HIV are encouraged to seek early treatment for opportunistic infections, enrol in ART and promote universal access, practice safer sex and serve as role models for accepting ones status. A policy brief from UNESCO’s EDUCAIDS initiative on positive prevention (Prevention with and for People Living with HIV) supports learning on this issue among Ministers of Education and senior decision-makers.

Treatment education often includes the importance of healthy food and hygienic food preparation, an important part of supporting the overall health and well-being of people with HIV. For example, many participating agencies including ABIAIDS, HIV i-Base, NAM, and TAC, mentioned treatment education materials addressing the importance of nutrition. In the commissioned paper, “HIV/AIDS Treatment Education: An Overview of Materials and Communications Strategies,” a treatment educator from PAFPI in the Philippines emphasised the importance of the “localisation” of nutrition guidelines. Mention was made of recommendations from a focus group with community stakeholders which reinforced that “the pre-nutrition information particularly on the item of ‘healthy food’ should be Filipinized; that is, choosing what is appropriate for the Philippines.”

Source: TAC. Nutrition Fact Sheet. Muizenberg, TAC, no date.
5. Support continued protective behaviours and healthy living

Increased knowledge and understanding of HIV and ART can increase support for people on treatment, reduce stigma, and support protective behaviours. The background paper commissioned by the UNAIDS IATT on Education, “HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care” described treatment education as “the foundation that strengthens and reinforces” the relationship between reduced stigma, VCT and ART. It improves the quality of life of people with HIV and AIDS and promotes a safer environment where people will feel more comfortable being tested for HIV and aware of their status. It improves health-seeking behaviour, including VCT, diagnosis and treatment of STIs), treatment of opportunistic infections, and other elements of HIV prevention and care (see Figure 5 below).

Community preparation can also change people’s attitudes about the disease. Reporting on the Community Preparedness parallel sessions, one participant concluded, “HIV was once considered a disease that was linked to death, but treatment education can make the community aware that HIV-related illnesses are treatable, and that people can live long and fulfilling lives on ART.” This can shift perceptions of people living with HIV from being “burdens” to “productive members” of their society.

TAC has encouraged its members living with HIV to wear “HIV-positive” t-shirts to assist them in disclosing their status, create an environment for discussion, and empower individuals by putting an identity to an HIV status. MSF in Kibera encouraged its community educators to wear TAC’s t-shirt for similar reasons. Nelson Mandela has also been seen wearing the TAC t-shirt as a sign of solidarity with the organization’s call for expanded ART in South Africa.

Attitudes, rumours, and misconceptions take time to change—interventions need to be committed and engaged over the long-term. The involvement of individuals, including people with HIV, in treatment education programmes must be must be carried out in a planned, sensitive and responsible manner to avoid being tokenistic, or exposing them to further stigma or discrimination.

TAC’s HIV Positive T-shirt: Stimulating dialogue, stimulating action

© Treatment Action Campaign

Figure 5: Relationship between Stigma, VCT, ARVs and Treatment Education

- If stigma is decreased, more people will test to know their status
- If more people test and are open about their status, stigma will be reduced
- To access ARVs, a person must know his/her status
- If ARVs are available, more people are likely to seek VCT
- If more people are on ARV treatment, stigma will be reduced
- If stigma is reduced, more people are likely to seek and adhere to treatment

Source: Adapted from the International HIV/AIDS Alliance 2002c: 34
Consultation participants represented different countries, agencies, and a diversity of settings. Yet it became clear that they faced many common challenges, including:

- **Mobilising communities and conducting treatment education among “vulnerable groups”:** A number of participants suggested that activism around treatment education may be more difficult in the case of concentrated epidemics among groups which are difficult to access and whose behaviour is often stigmatised. The International HIV/AIDS Alliance provided the example of their work in the Ukraine where the HIV epidemic is fuelled largely by injecting drug use and unprotected sex, including commercial sex. Community preparedness was reported to be a challenge in this country; the Alliance representative emphasised that there is a great need for comprehensive community responses that include adequate nutrition, counselling and prevention services and a reduction of social isolation. Mobilising communities that don’t have a traditional activist voice was also reported by many participants to be a challenge, as was ensuring that treatment literacy materials are available in both rural and urban areas, and for men and women equally.

- **Promoting rewarded engagement as opposed to volunteerism:** There is a need for community members to be more fully integrated into treatment education activities, and appropriate compensation provided through training and other educational opportunities, psychosocial and material support and links to services for medical care, counselling, training, among others. One suggestion provided by Francesca Celleti from WHO during the parallel session on treatment literacy was that health structures establish “emergency” policy decisions that would enable the creation of new posts for community support, education, and preparedness activities. Other participants emphasised the creation of links and referral systems that would promote synergies across programmes and wider access to care.

- **Involving people with HIV in treatment education:** The same challenges that have hampered the involvement of people with HIV in other areas also impact their involvement in treatment education. These include: loss of leaders and, therefore, institutional memory; lack of political will to ensure their meaningful and sustainable involvement (e.g., “lip service” provided to GIPA principles); lack of appropriate skills and training; lack of resources—both financial and human; and stigma, discrimination and violations of human rights. The representative from UNAIDS shared with participants the recently developed “Algiers Declaration of HIV” which urges governments, international partners and other institutions to address these challenges by: providing people with HIV with technical and financial support and resources required to play a meaningful role in the response to AIDS (e.g., skills, organisational and project development); working in partnership with people with HIV to achieve universal and free access to comprehensive health and prevention services; and ensuring free and uninterrupted supplies of ARVs at the lowest cost and with the widest range of options (e.g., second and third line treatments).

- **Engaging people who test positive for HIV but who do not immediately initiate treatment with ongoing information and links to services:** Treatment education must make it clear that not all people living with HIV will benefit immediately from ART as treatment eligibility depends on a range of factors such as the amount of HIV in the blood (viral load), the level of immune suppression (based on CD4 cell counts), evidence of HIV-related disease (based on WHO disease stage criteria), or some combination of these factors. Treatment literacy for people who test positive but who may not yet need ART is extremely important, as they require regular clinical check ups to avoid any delay in seeking health care and ART when the need arises. Robust referral links are essential. An example can be found in the background paper “Current Research and Good Practice in HIV/AIDS Treatment Education.” The TASO PMTCT site supported by CDC and WHO in Uganda provides screening for HIV-positive pregnant women for ART eligibility. Those found eligible initiate ART and those who do not need ART are offered treatment education and enrolled into the ART waiting list register.
**Widening reach and going to scale:** Many treatment education activities cover select communities on select topics at select points in time. Greater coordination and collaboration is required across sectors and agencies to widen reach and go to scale. This is particularly needed to provide information and services to the “vulnerable groups” (see the first point above), to those in rural and remote areas, and to those in areas where activism may be lacking to scale up and prepare for access to treatment. Efforts are also required to ensure treatment literacy materials are available in local languages—which is a challenge in countries such as Uganda, where there are more than fifty different indigenous languages—and available for all age-ranges. Many participants noted, for example that there are limited materials available for youth or for parents of young children on ART.

**Documenting, researching, and disseminating:** Finally, there is a continuous challenge of properly documenting, monitoring and evaluating interventions, as well as continuing to sustain research on these topics. Developing the evidence base requires a firm commitment to monitoring and evaluation and to communicating success through documentation and evidence-based results.
The Consultation concluded with a session in which participants reflected on how they planned to move treatment education forward individually and within their organizations. Future activities in the field of treatment education included, for example:

- **Advocating for treatment education:** Some participants expressed finding the Consultation to be a useful opportunity to gather lessons and materials that could be used to advocate for the wider expansion of treatment education in their own settings. For example, the participant from the MoE in Zambia said that she would share the materials from the Consultation with her directors within the Ministry and discuss their adaptation for learners in pre-school, high school, and tertiary institutions.

- **Producing guidance on developing treatment literacy materials:** Participants from both the WHO and UNESCO voiced an interest in developing guidance to assist in the development of treatment literacy materials. For example, the participant from UNESCO’s International Bureau of Education (IBE) said that IBE could potentially develop a set of appraisal criteria to evaluate treatment education materials for in-school teachers and learners. One participant from WHO also voiced an interest in working with UNESCO to put forward a series of guidelines on content, methodology, and adaptation of treatment literacy materials for use at the country level.

- **Developing, disseminating, and promoting the use of treatment literacy materials:** Many participants stated that they would continue to support the development, dissemination, and promotion of the use of treatment literacy materials. For example, IFRC is currently field testing a tool that they will share shortly with Consultation participants and organizers. Participants from HIV i-Base, NAM, and Portugal’s National Coordination of HIV/AIDS Infection also mentioned the ongoing development and support for adaptation of treatment literacy materials. The participant from UNESCO’s IBE also mentioned that IBE could make treatment literacy materials available online on their “Global Curriculum Bank for HIV/AIDS Preventive Education.”

- **Promoting GIPA in treatment education:** Other participants said that they would encourage the dissemination and use of existing strategies and materials to promote the involvement of people with HIV and those on treatment in treatment education activities. These materials included, for example, ICW’s “Participation Tree” which demonstrates the different levels of participation of people living with HIV in interventions from tokenism to cherry picking to research and project management. The International HIV/AIDS Alliance has also developed a set of stories entitled “A day in the life of a treatment support worker” which illustrate the effects of involvement and the challenges faced by treatment education practitioners. UNAIDS is also supporting the Eastern Europe Network to develop guidelines on how people with HIV can work with the United Nations; this resource will be available for regional adaptation.

- **Mainstreaming treatment education in the education sector:** Some participants also mentioned an interest in working with Ministries of Education, their civil society counterparts, and development partners to mainstream treatment education in the education sector. For example, one participant said that he would try to connect the MTT with DFID to see how they could support education sector responses. One participant from UNESCO’s Culture Sector mentioned the possibility of using existing guidelines that they had developed on adaptation to the socio-cultural context to also address treatment education.

- **Monitoring, documenting, and disseminating results:** Many participants mentioned the ongoing need to monitor, document, and disseminate results of their treatment education activities. The participant from TAC said that she was interested in working with universities in South Africa to document the impact of their activities and to learn from the experiences of other countries.
RECOMMENDATIONS
FOR FUTURE ACTIVITIES IN TREATMENT EDUCATION

There are a number of lessons learned from the Consultation which can inform future activities in the field of treatment education. These include the need to:

**Employ person-centred approaches:** HIV is a chronic disease which requires knowledge and skills to manage symptoms and side-effects, to effectively liaise with community- and facility-based services, and to strictly adhere to ARV regimens. As such, treatment education should strive to use methodologies that support the development of problem-solving skills. People with HIV and those on treatment are key partners in the scale up of treatment and prevention.

**Provide further support to inter-sectoral collaborations:** The Consultation demonstrated that partnerships and inter-sectoral collaborations between civil society partners, ministries (Education, Health, Labour, and others), multilateral and bilateral agencies can be fruitful and should be supported. In some settings this will require a major shift in mindset to recognise the role of other sectors and the community in treatment. As most successes are a composite of multiple interventions, attribution will be difficult; however, participants emphasised that that should only serve to reinforce the importance of partnerships and encourage programmes to take advantage of the specific expertise of everyone at the table.

**Integrate treatment education across the continuum of HIV education:** Treatment education does not need to be seen as a separate component, a new initiative, or an additional burden to already overstretched educational and health systems but as an integral part of comprehensive HIV education. As one participant explained, “It shouldn’t be seen as a separate campaign. HIV can be prevented, and when it is not prevented, it can be treated.” Treatment education should be included as part of planning processes to move towards universal access to prevention, treatment and care.

**Employ a range of approaches for different settings and audiences:** Treatment education does not need to be seen as a separate component, a new initiative, or an additional burden to already overstretched educational and health systems but as an integral part of comprehensive HIV education. As one participant explained, “It shouldn’t be seen as a separate campaign. HIV can be prevented, and when it is not prevented, it can be treated.” Treatment education should be included as part of planning processes to move towards universal access to prevention, treatment and care.

**Involve affected communities and individuals:** There are many players involved in preparing communities and individuals for treatment—each with different expertise and needs. Treatment education programmes should capitalise on individuals’ and communities’ strengths while at the same time, strengthen capacities to ensure sustainability and coordination.

**Document process and impact:** There is a great need to document, monitor and evaluate treatment education programmes, policies, materials, and strategies so that they can be adapted and replicated in other areas. Future initiatives should build on this evidence-base, while further developing or adapting approaches to fit the local context on the ground.
Appendix 1: Consultation Participant List

Keith Alcorn
NAM
Lincoln House
1 Brixton Road
London SW9 6DE
United Kingdom
E-mail: keith@nam.org.uk

Kristina Bolme
 Médecins Sans Frontières/LÄKARE UTAN GRÄNSER
Högbergsgatan 59B, Box 4262
10266 Stockholm
Sweden
E-mail: kristinabolme@yahoo.se

Sandrine Bonnet
HIV/AIDS Prevention Education Programme
International Bureau of Education
UNESCO
15 Route des Morillons
1218 Le Grane-Sconnex
Geneva,
Switzerland
E-mail: s.bonnet@ibe.unesco.org

Christopher Castle
Focal point for HIV and AIDS
Division for the Promotion of Quality Education
UNESCO
7, place de Fontenoy
75007 Paris
France
E-mail: c.castle@unesco.org

Francesca Celletti
HIV Department
WHO
Avenue Appia 20
1211 Geneva 27
Switzerland
E-mail: celletti@who.int

Emmanuelle Chazal
MSF Paris
8, rue Saint Sabin
75011 Paris
France
E-mail: echazal@paris.msf.org

Carolyn Green
International HIV/AIDS Alliance
Queensberry House,
104-106 Queens Road
Brighton BN1 3XF
United Kingdom
E-mail: cgreen@aidssalliance.org

Getachew Gizaw
Focal point for HIV
International Federation of Red Cross and Red Crescent Societies
PO Box 372
CH-1211 Geneva 19
Switzerland
E-mail: getachew.gizaw@ifrc.org

Margherita Licata
Associate Expert
ILO Global Programme on HIV/AIDS & the World of Work
International Labour Organization
4 route des Morillons
1211 Geneva 22
Switzerland
E-mail: licata@ilo.org

Irene Malambo
Ministry of Education
PO Box 50093
Lusaka
Zambia
E-mail: imalambo@moe.gov.zm
Christoforos Mallouris  
Division for the Promotion of Quality Education  
UNESCO  
7, place de Fontenoy  
75007 Paris  
France  
E-mail: c.mallouris@unesco.org

Kevin Moody  
Technical Officer, Treatment and Advocacy  
HIV Department  
World Health Organization  
Avenue Appia 20  
1211 Geneva 27  
Switzerland  
E-mail: moodyk@who.int

Mora Oommen  
Health and Human Development Programs  
Education Development Center  
55 Chapel Street  
Newton, MA 02458-1060  
USA  
E-mail: MOommen@edc.org

Mary Joy Pigozzi  
Global coordinator for HIV/AIDS and Director of the Division for the Promotion of Quality Education  
UNESCO  
7, place de Fontenoy  
75007 Paris  
France  
E-mail: mj.pigozzi@unesco.org

Cristina Pimenta  
ABIAIDS  
Rua da Candelária, 79/10o andar – Centro  
Rio de Janeiro/RJ - Cep: 20091-020  
Brasil  
E-mail: cpimenta@abiaids.org.br

Avina Sarna  
Program Associate  
Horizons, Population Council  
53 Lodi Estate  
New Delhi 110003  
India  
E-mail: asarna@pcindia.org

Justine Sass  
1, pl. Edouard Herriot  
94270 Le Kremlin-Bicêtre  
France  
E-mail: jsass@online.fr

Aleksandra Skonieczna  
STEP  
ul. Mickiewicza 65/55  
01-625 Warszawa  
POLAND  
E-mail: aleksandra_skonieczna@wp.pl, aleksandra.skonieczna@aster.pl

Kate Thomson  
Partnership Adviser  
UNAIDS  
20 avenue Appia  
1211 Geneva 27  
Switzerland  
E-mail: thomsonk@unaids.org

Rachel Yassky  
20 Plaza Street East, C11  
Brooklyn, NY 11238  
USA  
E-mail: ryassky@optonline.net
## Appendix 2: consultation agenda

### Day 1: Tuesday – 22 November 2005

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Session</th>
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</thead>
<tbody>
<tr>
<td>8:30</td>
<td>Registration</td>
<td>Distribution of meeting agenda and information packages</td>
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<tr>
<td>9:00</td>
<td>Opening Session</td>
<td>Welcome remarks</td>
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<tr>
<td>9:30</td>
<td>Plenary Session 1</td>
<td>Treatment Education in Action</td>
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<td>Introduction to the session</td>
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<td>What does Treatment Education mean at the country level: Lessons from the field</td>
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<td>Treatment Education terminology: Using a common language</td>
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<td>Discussion</td>
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<td>How the meeting will work</td>
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<td>10:30</td>
<td>Coffee Break</td>
<td>Pre-coffee break ice-breaker</td>
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<tr>
<td>11:00</td>
<td>Plenary Session 2</td>
<td>Current efforts and evidence</td>
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<td>Introduction to the session</td>
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<td>Draft Paper I: Inventory of past and current efforts in Treatment Education</td>
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<td>Draft Paper II: Evidence, gaps, needs, ways forward</td>
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<td>Discussion</td>
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<td>Explaining Parallel working group sessions</td>
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<td>12:30</td>
<td>Lunch</td>
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<tr>
<td>14:00</td>
<td>Parallel Working Session 1</td>
<td>Treatment Literacy: Content</td>
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<td>Introduction</td>
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<td>ARV provision to teachers and their families</td>
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<td>Developing the ART Toolkit</td>
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<td>Group work, reporting, and discussion</td>
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<td>14:00</td>
<td>Parallel Working Session 1</td>
<td>Community Preparedness: Content</td>
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<td>What is Community Preparedness? Key elements</td>
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<td>Introduction</td>
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<td>What is community preparedness? Experiences from Zambia, Burkina Faso and Ukraine</td>
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<td>Group work, reporting, and discussion</td>
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<td>15:30</td>
<td>Coffee Break</td>
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<td>Time</td>
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<tr>
<td>16:00</td>
<td>Parallel Working Session 2</td>
<td>Treatment Literacy: Methodology</td>
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<td>Introduction</td>
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<td>Treatment Education among HIV-positive women and girls</td>
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<td>Treatment literacy in Eastern Europe and the former Soviet Union</td>
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<td>The importance of linking the facility and the community</td>
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<td>Group work, reporting, and discussion</td>
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<td>16:00</td>
<td>Parallel Working Session 2</td>
<td>Community Preparedness: Methodology</td>
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<td>Introduction</td>
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<td>Reaching out to learners using radio</td>
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<td>Community Mobilization</td>
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<td>Group work, reporting, and discussion</td>
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<td>17:30</td>
<td>Plenary Session 3</td>
<td>Discussion on the day</td>
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<tr>
<td>18:15</td>
<td>Prep session for facilitators, group leaders and rapporteurs</td>
<td>Preparing for day 2: prepare summary powerpoint slides on the parallel sessions in day 1 and define key points to report back on day 2</td>
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<td>19:30</td>
<td>Dinner</td>
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<td>Opportunity to network and continue discussion in an informal setting</td>
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<td>9:00</td>
<td>Plenary Session 4</td>
<td>Applying GIPA to Treatment Education</td>
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<td>Introduction</td>
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<td>Involvement of PLHIV in treatment</td>
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<td>Discussion</td>
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<td>How the day will work</td>
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<tr>
<td>10:00</td>
<td>Parallel Working Session III</td>
<td>Treatment Literacy: Adaptation</td>
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<td>Introduction</td>
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<td>Adapting materials, four case studies:</td>
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<td>Nepal, Namibia, South Africa and</td>
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<td>Bulgaria</td>
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<td>11:00</td>
<td>Coffee Break</td>
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<td>11:30</td>
<td>Parallel Working Session III (cont)</td>
<td>Treatment Literacy: Adaptation</td>
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<td>Reporting, and discussion</td>
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<td>10:00</td>
<td>Parallel Working Session III</td>
<td>Community Preparedness: Partnerships</td>
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<td>Introduction</td>
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<td>Government and partnerships, working</td>
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<td>at scale: the Brazil experience</td>
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<td>Civil society and partnerships, working</td>
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<td>The role of the education sector</td>
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<td>11:00</td>
<td>Coffee Break</td>
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<td>11:30</td>
<td>Parallel Working Session III (cont)</td>
<td>Community Preparedness:</td>
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<td>Group work, reporting, and discussion</td>
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<td>12:30</td>
<td>Lunch</td>
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<td>14:00</td>
<td>Plenary Session</td>
<td>Reports from the parallel working</td>
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<td>Introduction to the session</td>
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<td>Brief overview and highlights of parallel</td>
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<td>Discussion and questions</td>
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<td>15.00</td>
<td>Coffee Break</td>
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<tr>
<td>15.30–17.30</td>
<td>Plenary Session</td>
<td>Next steps</td>
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<td>Evaluation</td>
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<td>Conclusion</td>
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</tbody>
</table>
Appendix 3: Selected List and Contact Information for Treatment Education Practitioners

AIDS Foundation East West (AFEW)
15/5, Chayanova Street
Moscow, 125047, Russia
Email: info@afew.org
Tel.: +7 095 2506377
Fax.: +7 095 2506387
Website: www.afew.org

AIDS Infonet
Website: www.thebody.com/nmai/nmai.html

AIDS Law Unit, Namibia Legal Assistance Centre
P.O. Box 604, Windhoek, Namibia
Tel: (264) (61) 223-356
Fax: (264) (61) 227-675
Email: arasa@lac.org.na
Website: www.lac.org.na/alu/aluover.htm

ActionAID International
PostNet suite #248
Private bag X31
Saxonwold 2132
Johannesburg, South Africa
Tel: +27 11 880 0008
Fax: +27 11 880 8082
Email: mail.jhb@actionaid.org
Website: www.actionaid.org

Canadian AIDS Treatment Action Exchange (CATIE)
555 Richmond Street West, Suite 505
Box 1104
Toronto, Ontario M5V 3B1 Canada
Tel: +1 416 203 7122 Fax: +1 416 203-8284
Email: info@catie.ca
Website: www.catie.ca

Centre for Right to Health, Nigeria
3, Obanle-Aro Avenue
Ilupeju, P.O. Box 6383
Shomolu, Lagos, Nigeria.
Tel: +234 1 7743816
Tel/Fax: +234 1 4979467
Email: crhaid@yahoo.com
Website: www.crhonline.org

EngenderHealth
440 Ninth Avenue
New York, NY 10001, USA
Tel: +1 212-561-8000
Fax: +1 212-561-8067
Email: info@engenderhealth.org
Website: www.engenderhealth.org

Family Health International (FHI)
P.O. Box 13950
Research Triangle Park
NC 27709 USA
Tel: +1 919 544 7040
Fax: +1 919 544 7261
Email: services@fhi.org
Website: www.fhi.org

Gay Men’s Health Crisis (GMHC)
The Tisch Building
119 West 24 Street
NY, NY 10011, USA
Tel: +1 212 367 1000
Website: www.gmhc.org

Global Network of People Living with HIV/AIDS (GNP+)
Central Secretariat:
P.O. Box 11726
1001 GS Amsterdam
The Netherlands
Tel: +31.20.423.4114
Fax: +31.20.423.4224
E-mail: infognp@gnpplus.net
Website: http://www.gnpplus.net

HIV i-base, England
3rd Floor East
Thrale House
44-46 Southwark Street
London, SE1 1UN, UK
Tel: +44 20 7407 8488.
Fax: +44 20 7407 8489
Email: admin@i-base.org.uk.
Website: http://www.i-base.org.uk

International Community of Women living with HIV/AIDS (ICW)
Unit 6, Building 1
Canonbury Yard
190a New North Road
London N1 7BJ, UK
Tel: +44 20 7704 0600
Fax: +44 20 7704 8070
Email: info@icw.org
Website: www.icw.org

International Federation of Red Cross and Red Crescent Societies
PO Box 372
CH-1211 Geneva 19, Switzerland
Tel: +41 22 730 42 22
Fax: +41 22 733 03 95
Email: secretariat@ifrc.org
Website: www.ifrc.org

International HIV/AIDS Alliance
Queensberry House
104–106 Queens Road
Brighton, BN1 3XF UK
Tel: +44 1273 718 900
Website: www.aidsalliance.org

Joint United Nations Programme on HIV/AIDS (UNAIDS)
20, avenue Appia
CH-1211 Geneva 27, Switzerland
Tel: +41 22 791 3666
Fax: +41 22 791 418
Email: unaid@unaid.org.uk
Website: www.unaids.org

NAM
Lincoln House
1 Brixton Road
London, SW9 6DE, UK
Tel: +44 20 7840 0050
Fax: +44 20 7735 5351
Email: info@nam.org.uk
Website: www.aidsmap.com

Network of African People living with HIV/AIDS (NAP+)
PO Box 30218
Nairobi, Kenya.
Tel: +254 222-8776/231-2888/231-2886
Fax: +254 281-1353
Email: nap@africaonline.co.ke
Website: www.gnpplus.net

Pan-African Treatment Access Movement (PATAM)
Email: info@patam.org
Website: www.patam.org

Population Council
Headquarters
One Dag Hammarskjold Plaza
New York, New York 10017 USA
Tel: +1 212 339 0500
Fax: +1 212 755 6052
Email: pubinfo@popcouncil.org
Website: www.popcouncil.org

Southern Africa HIV and AIDS Information Dissemination Service (SaF AIDS)
17 Beveridge Road,
Avondale, Harare, Zimbabwe
Tel: +263 4 336 193/4; 307 898
Fax: +263 4 336 195
Website: http://www.safaids.org.zw/viewpublications.cfm?linkid=39
Spiritia Foundation, Indonesia
J1. Radio IV No.10
Kebayoran Baru
Jakarta 12130, Indonesia
Tel: +62 21 7279 7007
Fax: +62 21 721 9521
Email: yayasan_spiritia@yahoo.com

Siyayinqoba-Beat It!
Email: info@beatit.co.za
Website: www.beatit.co.za

The AIDS Support Organization (TASO)
Old Mulago Complex
P. O. Box 10443, Kampala
Tel: +256-41-532580/1,
Fax: +256-41-541288
Email: mail@tasouganda.org
Website: www.tasouganda.org

Treatment Action Campaign (TAC)
34 Main Road
Muizenberg 7945, South Africa
www.tac.org.za
Tel. +27 (21) 788 3507
Fax: +27 (21) 788 3726
E-mail: info@tac.org.za
Website: www.tac.org.za

United Nations Educational, Scientific and Cultural Organization (UNESCO)
7, place de Fontenoy
75352 Paris 07 SP
France
Tel: +33 (0)1 45 68 10 00
Fax: +33 (0)1 45 67 16 90
Email: bpi@unesco.org
Website: www.unesco.org

United Nations Population Fund (UNFPA)
220 East 42nd St.
New York, NY 10017, USA
Tel: +1 212-297-5000
Website: www.unfpa.org

United Nations Children’s Fund (UNICEF)
UNICEF House
3 United Nations Plaza
New York, New York 10017, USA.
Tel: +1 212 326 7000
Fax: +1 887.7465/887.7454
Website: www.unicef.org

World Health Organization (WHO)
Avenue Appia 20
1211 Geneva 27, Switzerland
Tel: +41 22 791 21 11
Fax: +41 22 791 3111
Email: info@who.int
Website: www.who.int
Women’s Equity in Access to Care and Treatment (We-ACTx)
3345 22nd Street
San Francisco, CA 94110
Tel. 415 648 1728 office
Website: www.we-actx.org
Appendix 4: Selected List of Treatment Education Materials


AIDS Infonet. Factsheets on a range of topic areas including: Background information on HIV/AIDS; Laboratory tests; Preventing HIV infection; Living with HIV: Medications to fight HIV. Opportunistic infections and related diseases, and their treatment; Patient populations: Alternative and complementary therapies. Available online at www.thebody.com/nmai/nmaiix.html

Some examples include:

AIDS Law Unit (ALU). Treatment access posters. Windhoek, ALU, no date. Available online at www.lac.org.na/alu/poster1.jpg
www.lac.org.na/alu/poster2.jpg
www.lac.org.na/alu/poster3.jpg


Canadian AIDS Treatment Action Exchange (CATIE). “In depth fact sheets” on: AIDS-related complications, bacterial infections, AIDS-related complications, viral infections; Anti-HIV agents, non-nukes, Anti-HIV agents, nucleoside analogues (nukes), Anti-HIV agents, nucleotide analogues; Anti-HIV agents, nuke enhancers; Anti-HIV agents, protease inhibitors; Cancers; Complications in women; Drugs to help increase weight; Fungal infections; Hormones; Immune boosters; Infection fighters, anti-CMV drugs; Infection fighters, anti-fungals; Infection fighters, anti-hepatitis drugs; Infection fighters, anti-PCP/toxoplasmosis drugs; Life saving drugs; Lab tests; Medications to fight HIV. Opportunistic infections; Side effects; Weight loss [in English and French]. Toronto, CATIE, no date. Available online at www.catie.ca/e/pubs/index.html


Gay Men’s Health Crisis (GMHC). Treatment fact sheets: AIDS-related non-hodgkins lymphoma (NHL); Anemia; Cervical cancers; Cervical dysplasia; Cytomegalovirus (CMV); Hepatitis A; Hepatitis B; Hepatitis C; Herpes; Kaposi’s Sarcoma (KS); Mycobacterium Avium Complex (MAC); Pneumocystis Carinii Pneumonia (PCP); Toxoplasmosis; Tuberculosis (TB); Vaginal thrush. NY, NY, GMHC, 2003. Available online at www.gmhc.org/health/treatment/factsheets.html


NAM. Factsheets on a range of topics including: Anti-HIV therapy; Immune system; Opportunistic infections/health problems; Side effects; Healthy living. London, NAM, no date. Available online at www.aidsmap.com/en/docs/64321FC4-42BF-41E7-AEA6-4659F4D5A980.asp

NAM. Guides on a range of topics including: Adherence; Changing treatment; Children and HIV; Lipodystrophy; Palliative care; Resistance; Salvage treatment; Side effects, Starting treatment, Treatment access; Treatment interruptions; Tuberculosis; Women and HIV. London, NAM, no date. Available online at www.aidsmap.com/en/cats/ux/default.asp


Southern Africa HIV and AIDS Information Dissemination Service (SafAIDS). Women’s treatment literacy toolkit. Forthcoming

Siyayinqoba-Beat It! Beat It TV magazine programme. Available online at www.beatit.co.za


The meeting brought together technical practitioners with experience in HIV and AIDS treatment education from Government agencies, international and local NGOs, UN agencies, and networks of people living with HIV. Presenters provided insight into programme experience and lessons learned from activities in settings as diverse as: Belarus, Brazil, Bulgaria, Burkina Faso, Estonia, India, Kazakhstan, Kenya, Kyrgyzstan, Lithuania, Moldova, Nepal, Poland, Russia, South Africa, Swaziland, Thailand, Ukraine, Uganda, Uzbekistan, and Zambia.