

HIV and AIDS

Treatment Education Technical Consultation Report

22-23 Nov 2005 - PARIS, FRANCE



World Health
Organization

HIV and AIDS

Treatment Education

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Table of contents

Acknowledgements	4
Acronyms	4
Executive Summary	5
Background	7
Treatment Education: The Basics	9
Treatment Literacy: Content, Methodology, and Adaptation	13
Community Preparedness: Content, Methodology, Partnerships and Scaling Up	15
Common Themes	18
1. Engage clients and communities as active participants in treatment	18
2. Take advantage of multiple entry points and involve all relevant sectors	19
3. Fully involve people with HIV and those on treatment	20
4. Support continued protective behaviours and healthy living	21
5. Tackle stigma and discrimination	22
Challenges	23
Looking Forward: Future Activities in the Field of Treatment Education	25
Recommendations for Future Activities in Treatment Education	26
Appendix 1: Consultation Participant List	28
Appendix 2: Consultation Agenda	30
Appendix 3: Selected List and Contact Information for Treatment Education Practitioners	33
Appendix 4: Selected List of Treatment Education Materials	35

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Acronyms

ACER	ARV Community Education and Referral
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CDC	Centers for Disease Control and Prevention
CBO	Community Based Organization
EDUCAIDS	Global Initiative on Education and HIV/AIDS
FBO	Faith Based Organization
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV and AIDS
HIV	Human Immunodeficiency Virus
IBE	International Bureau of Education
ICW	International Community of Women Living with HIV/AIDS
IATT	Inter-Agency Task Team
IEC	Information, Education and Communication
IFRC	International Federation of the Red Cross/Red Crescent Societies
ITPC	International Treatment Preparedness Coalition
MoE	Ministry of Education
MoH	Ministry of Health
MSF	Médecins Sans Frontières

NGO	Non-governmental Organization
PAFPI	Positive Action Foundation Philippines, Inc
PEPFAR	President's Emergency Plan for AIDS Relief
PTCT	Parent to Child Transmission
PPTCT	Prevention of Parent to Child Transmission
SaFAIDS	Southern Africa HIV and AIDS Dissemination Service
STEP	Strategic Treatment Education Programme
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TASO	The AIDS Support Organization
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations International Children's Fund
US	United States
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WE-ACTx	Women's Equity in Access to Care and Treatment
WHO	World Health Organization

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.

B a c k g r o u n d

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 impor-

tant to identify and link needs and resources in a way that helps people to help themselves.

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.

Treatment education: the basics

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

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.

Source: UNAIDS IATT on Education. HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care. Paris, UNESCO, forthcoming 2006. Background paper for the Treatment Education Consultation.

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

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.*” Treatment education was also found to enhance prevention, care and support activities and generate more effective local responses.

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, 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 draws attention to the harmful effects of stigma and discrimination and gender inequality.

* Funders Concerned about AIDS (FCAA). 2003. International HIV Treatment Preparedness Summit. March 13-16, 2003. Cape Town, South Africa. Accessed online February 2006 at <http://www.fcaaid.org/publications/documents/FINALCAPETOWNREPORT.pdf>

“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

Source: Polly Clayden. Adapting materials, four case studies: Nepal, Namibia, South Africa and Bulgaria. Presentation at the Treatment Education Consultation, November 23, 2005.

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.

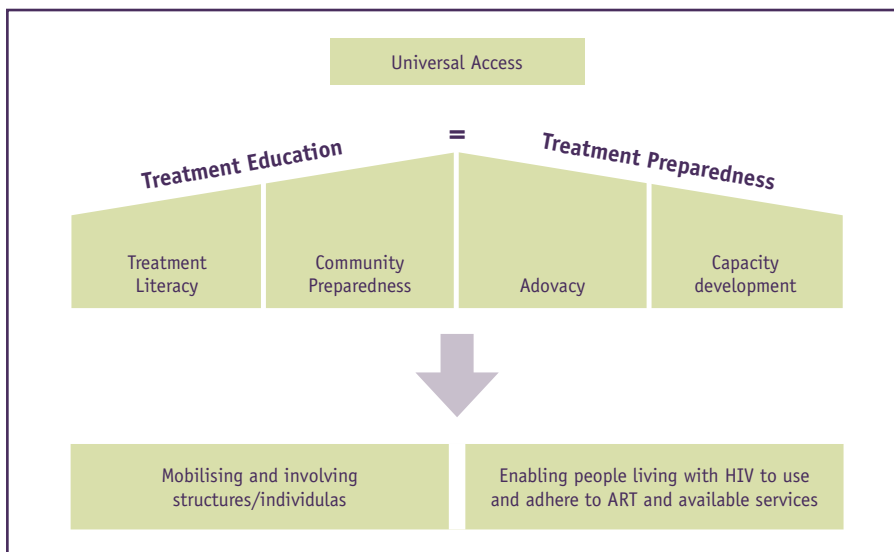
In a review of five treatment education programmes from a range of settings and contexts, Avina Sarna of the Population Council in the background paper “Current Research and Good Practice in HIV/AIDS Treatment Education” noted that treatment education had contributed to:

- 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

Figure 1: Treatment education in the context of universal access



Source: UNESCO. *Glossary of main terms on HIV Treatment Education*. Draft background paper for the Treatment Education Consultation. Presented November 22, 2005.

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.

Treatment Education in Action, South Africa



© Treatment Action Campaign

“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.

Source: Avina Sarna, Sajini Shayj. Current Research and Good Practice in HIV/AIDS Education. Draft background paper for the Treatment Education Consultation. Presented November 22, 2005.

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.



Figure 2: Examples of treatment literacy materials displayed during the Consultation

IFRC ART toolkit for community health workers

TAC poster for community health centres

ABIAIDS Bulletin on Brazilian production of ARVs

TREATMENT LITERACY: CONTENT, METHODOLOGY, AND ADAPTATION

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, in 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

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

Source: HIV/AIDS Treatment Education: An Overview of Materials and Communications Strategies. Draft background paper for the Treatment Education Consultation. Presented November 22, 2005.

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

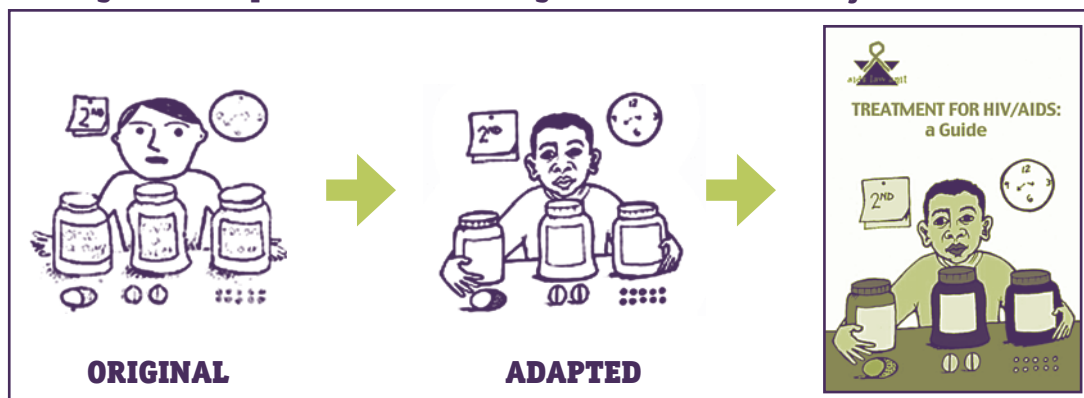
harmonisation meetings to ensure consistent and synergistic information by the range of actors involved in treatment education;

- 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.

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



Source: Polly Clayden. Adapting materials, four case studies: Nepal, Namibia, South Africa and Bulgaria. Presentation at the Treatment Education Consultation, November 23, 2005.

COMMUNITY PREPAREDNESS:

CONTENT, METHODOLOGY, PARTNERSHIPS AND SCALING UP

“HIV/AIDS is seen in the clinics, but it lives in our communities.”

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 devel-

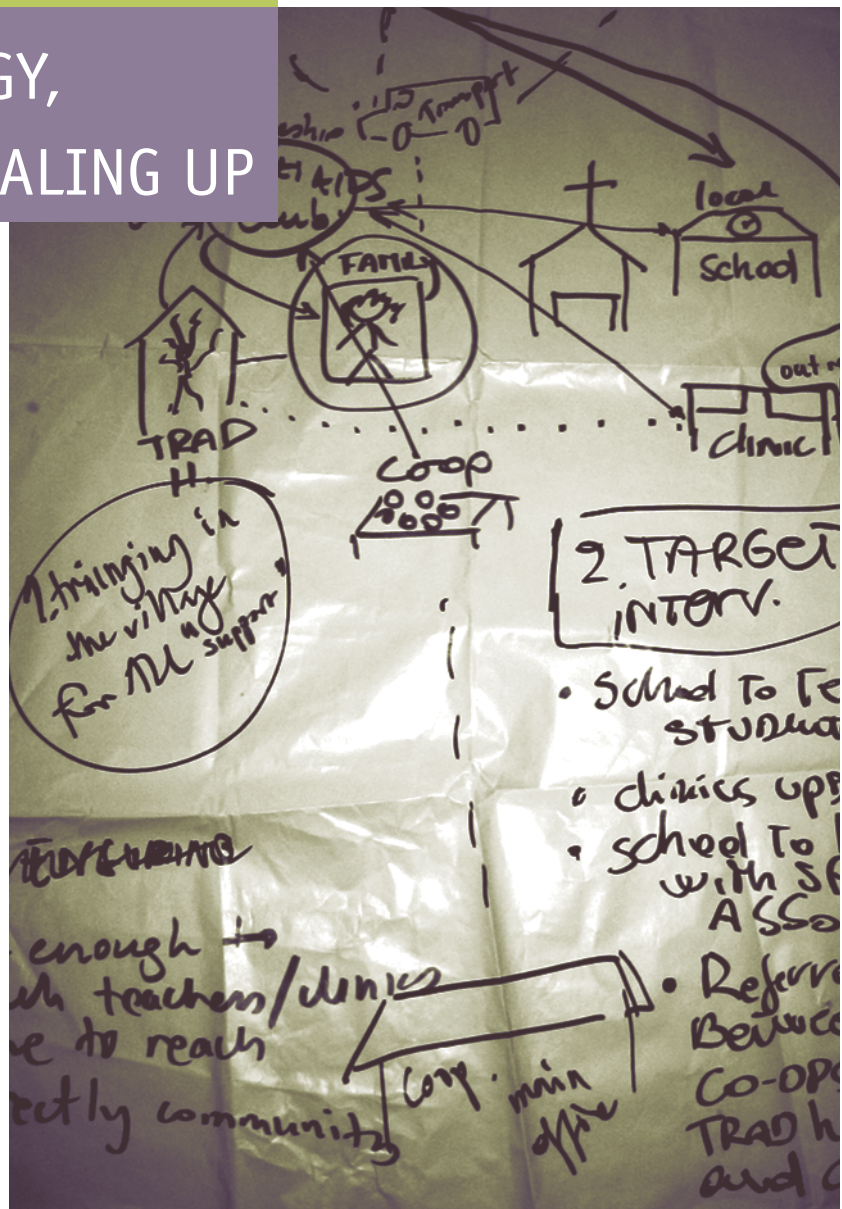


Figure 4: The treatment journey

Source: Community Preparedness Parallel Working Group Session.

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.

opment, implementation, and monitoring and evaluation of treatment programmes;

- Training local community members to be peer educators, treatment practitioners; and
- Providing resources—both human and material/financial—through local knowledge and experience, community-derived funding mechanisms, and structures.

Community mapping was identified as one useful tool to understand how to plan services, design referral networks, develop linkages between community and service providers, and to understand important factors such as the effects of stigma and discrimination on prevention and treatment. In an exercise, participants were presented with three scenarios and asked to visually depict structures and partners that could support behavioural and attitudinal changes to build an enabling environment for community preparedness (see example in Figure 4, page 15). Participants agreed that mapping out the “treatment journey” that a person with HIV undertakes would be useful at the local level in understanding the barriers to treatment and care; identifying important people, structures, and facilities that can support improved health outcomes; and reinforcing the importance of keeping the “client” at the centre of care.

Participants’ programme experience demonstrated that community preparedness initiatives:

- 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

MSF treatment educators in Kibera, a Nairobi slum in Kenya



© Kristina Bolme Kuhn/MSF Sweden, 2005

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).



Common themes

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

Box 4: Skills and competencies to be developed through treatment education

- Handling peer pressure
- Respecting diversity
- Demonstrating empathy and providing emotional support
- Contextualising risk, care, and support
- Asking questions and negotiating
- Overcoming internalised stigma
- Overcoming stigma and discrimination
- Advocating (both at the personal and community levels)
- Mentoring and providing peer support
- Improving health-seeking behaviour
- Supporting family members to adhere to ART
- Expressing needs
- Being aware of, and demanding, your rights

Source: Treatment Literacy Parallel Working Group Session

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 counselling, 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



© Carolyn Green/International HIV/AIDS Alliance, 2005

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.

Source: Jonathan Godden. The role of the education sector. Presentation at the Treatment Education Consultation, November 23, 2005.

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.

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

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.

Source: UNAIDS IATT on Education. HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care. Paris, UNESCO, forthcoming 2006. Background paper for the Treatment Education Consultation.

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.

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.”

FACT SHEET: Nutrition

HIV also needs food as treatment
 Before doctors in the USA recognized AIDS as a disease, ordinary people had already identified it in Uganda. They called it “slimming disease”. In fact, it is called **Wasting Syndrome**. This means your body gets smaller and smaller like a piece of wood that is being chipped into small pieces. Many symptoms come with HIV. Losing weight is a central part of the disease process of HIV infection. HIV already steals the body long before you start losing weight. The treatment is anti-retroviral medicines and good nutrition. Eating healthy is important with all diseases. With HIV this is even more so.

Make eating an enjoyable event
 Many people living with HIV are badly affected about eating. They have been told, “Oh eat or die or don’t eat too much of that”. So consider the whole issue whether you are eating the right thing is not good. You can get insurance, get diabetes or even feelings of guilt. Eating should be an enjoyable relaxed event.

Prevent losing important muscle weight
 People living with HIV usually lose muscle weight. The shrinking of the muscles is not noticed for a long time, because the fat around the muscles is not lost. This hides the loss of the muscle weight. Muscles

are made up of a chemical called protein. This is important that you eat protein foods such as meat.

Eat lots of energy foods to prevent wasting
 Since your body has to fight the HIV virus as well as other infections, it needs more energy. It is cheaper to eat lots of staple foods like pap than to eat lots of meat, which is expensive. Food-eating people eat every day like pap, beans, rice, porridge and vegetables contain lots of energy. These foods and fats and oils provide chemicals called complex sugars. Complex sugars provide energy to the body. When your body runs out of these energy rich foods it will use energy stored in your body. Before you were infected with HIV your body would use up stored fat when it needed extra energy. The HIV virus changes this. Your body will now use up protein (meat) in order to get extra energy. If you do not eat enough, you will soon lose muscle and not fat. This is called wasting. Provided you eat enough energy foods regularly this will not happen. You will prevent your body from losing protein, which is more than having to top up.

HIV causes poor nutrition. Poor nutrition makes HIV worse. A vicious circle.
 HIV lives in your immune system and weakens it. HIV also reduces absorption of food, which weakens the body’s ability to reuse all kinds of vitamins. Poorly nourished people are much more likely to get severe diarrhea, TB and other infections. Good food helps prevent disease, and also helps the body to fight disease and recover. Don’t stop eating when you get sick. Women

who are pregnant or breastfeeding should eat more food.

Eat lots of fruit and vegetables
 The white blood cells of the immune system are made up of protein. They also need vitamins to function well. Your body gets vitamins from fruit, vegetables and meat.

What matters most is that you eat enough
 You can eat more if you eat the food you like. Eat the foods you love always eat. Expensive foods are not better than cheap foods. Often expensive food has been processed a lot in factories, which makes it less nutritional value. You cannot always believe advertising that says a product is very nutritious. For instance, a plate of soft porridge with a teaspoon of cooking oil is much more nutritious than a plate of cereals.

Eat at least three meals a day
 Eat five or more if you eat the food you like. Eat at least one meal includes some protein (meat, beans, lentils, eggs, fish, chicken, meat, liver, oil, etc.) Try to eat some meals like fish, meat, some milk, oranges or banana food in between.

Drinking alcohol and smoking should be discouraged
 Alcohol like beer, wine and spirits provide some sugars, but no real nutrition. It also makes you eat less. Alcohol weakens the immune system. Alcohol speeds up reproduction of the HIV virus. This alcohol is bad for the health of people living with HIV. Smoking get more about infections and would often make a cigarette instead of taking a snack.

Source: TAC. Nutrition Fact Sheet. Muizenberg, TAC, no date.



© Siya Yingola, Beat it! 2002

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 infec-



tion. It improves health-seeking behaviour, including VCT, diagnosis and treatment of STIs), treatment of opportunistic infec-

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

© Treatment Action Campaign

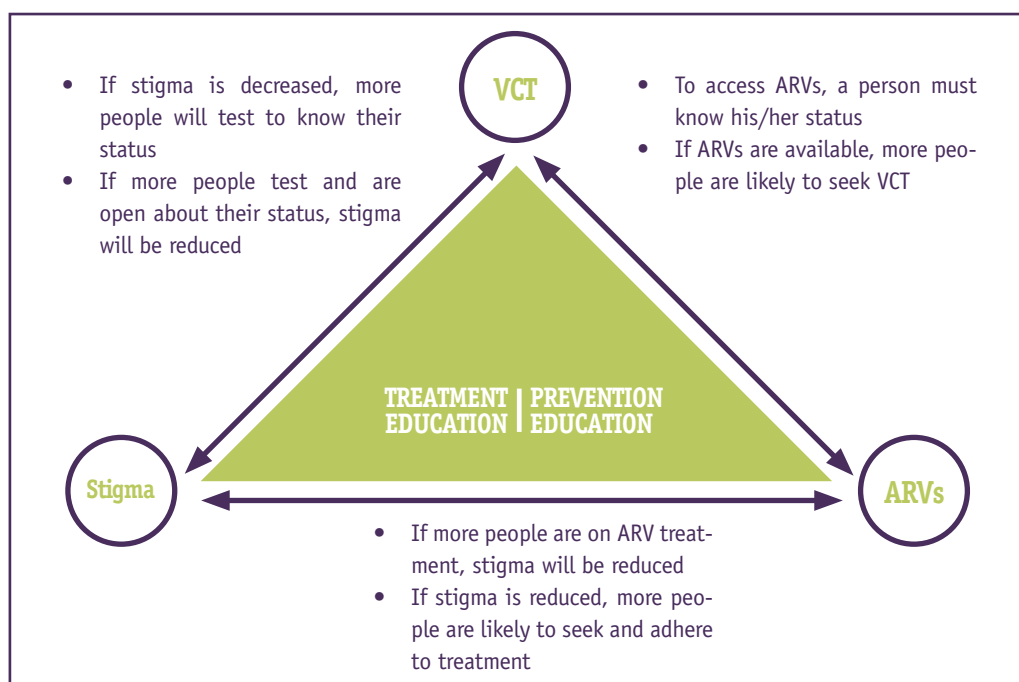
tions, and other elements of HIV prevention and care (see Figure 5 below).

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 carried out in a planned, sensitive and responsible manner to avoid being tokenistic, or exposing them to further stigma or discrimination.

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



Source: Adapted from the International HIV/AIDS Alliance 2002c: 34

Challenges

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 Celletti 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.

LOOKING FORWARD:

FUTURE ACTIVITIES IN THE FIELD OF TREATMENT EDUCATION

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

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Appendix 2: consultation agenda

Day 1: Tuesday – 22 November 2005

Time	Session		
8:30	Registration	Distribution of meeting agenda and information packages	
9:00	Opening Session	Welcome remarks	Mary Joy Pigozzi, UNESCO Kevin Moody, WHO
9:30	Plenary Session 1	Treatment Education in Action	
		Introduction to the session	Chair: Judith Cornell, UNESCO
		What does Treatment Education mean at the country level: Lessons from the field	Vuyiseka Dubula, TAC
		Treatment Education terminology: Using a common language	Christoforos Mallouris, UNESCO
		Discussion	
		How the meeting will work	Judith Cornell, UNESCO
		Pre-coffee break ice-breaker	
10:30	Coffee Break		
11:00	Plenary Session 2	Current efforts and evidence	
		Introduction to the session	Chair: Francesca Celletti, WHO
		Draft Paper I: Inventory of past and current efforts in Treatment Education	Rachel Yassky
		Draft Paper II: Evidence, gaps, needs, ways forward	Avina Sarna, Horizons - Population Council Inc., New Delhi, India
		Discussion	
		Explaining Parallel working group sessions	Judith Cornell, UNESCO
12:30	Lunch		
14:00	Parallel Working Session 1	Treatment Literacy: Content	
		Introduction	Kevin Moody, WHO
		ARV provision to teachers and their families	Mrs Irene Malambo, Ministry of Education, Zambia
		Developing the ART Toolkit	Getachew Gizaw, IFRC
		Group work, reporting, and discussion	
14:00	Parallel Working Session 1	Community Preparedness: Content What is Community Preparedness? Key elements	
		Introduction	Christopher Castle, UNESCO
		What is community preparedness? Experiences from Zambia, Burkina Faso and Ukraine	Carolyn Green, International HIV/AIDS Alliance
		Group work, reporting, and discussion	
15:30	Coffee Break		

Time	Session		
16:00	Parallel Working Session 2	Treatment Literacy: Methodology	
		Introduction	Kevin Moody, WHO
		Treatment Education among HIV-positive women and girls	Beri Hull, ICW
		Treatment literacy in Eastern Europe and the former Soviet Union	Aleksandra Skonieczna, STEP, Poland
		The importance of linking the facility and the community	Francesca Celletti, WHO
		Group work, reporting, and discussion	
16:00	Parallel Working Session 2	Community Preparedness: Methodology	
		Introduction	Christopher Castle, UNESCO
		Reaching out to learners using radio	Vuyani Jacobs, Beat It!, South Africa
		Community Mobilization	Kristina Bolme, MSF, Sweden
		Group work, reporting, and discussion	
17:30	Plenary Session 3	Discussion on the day	Chair: Christopher Castle, UNESCO
18:15	Prep session for facilitators, group leaders and rapporteurs	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	
19:30	Dinner		
	Opportunity to network and continue discussion in an informal setting		

Day 2: Wednesday– 23 November 2005

Time	Session		
9:00	Plenary Session 4	Applying GIPA to Treatment Education	
		Introduction	Chair: Keith Alcorn, NAM
		Involvement of PLHIV in treatment education	Kate Thomson, UNAIDS
		Discussion	
		How the day will work	Jud Cornell, UNESCO
10:00	Parallel Working Session III	Treatment Literacy: Adaptation	
		Introduction	Kevin Moody, WHO
		Adapting materials, four case studies: Nepal, Namibia, South Africa and Bulgaria	Polly Clayden, HIV i-base
		Group work	
11:00	Coffee Break		
11:30	Parallel Working Session III (cont)	Treatment Literacy: Adaptation	
		Reporting, and discussion	
10:00	Parallel Working Session III	Community Preparedness: Partnerships and scale	
		Introduction	Christopher Castle, UNESCO
		Government and partnerships, working at scale: the Brazil experience	Cristina Pimenta, ABIAIDS
		Civil society and partnerships, working with government: the South African experience	Vuyiseka Dubula, TAC
		The role of the education sector	Jonathan Godden, HEARD
11:00	Coffee Break		
11:30	Parallel Working Session III (cont)	Community Preparedness:	
		Group work, reporting, and discussion	
12.30	Lunch		
14:00	Plenary Session	Reports from the parallel working sessions	Chair: Jonathan Godden, MTT
		Introduction to the session	
		Brief overview and highlights of parallel sessions	
		Discussion and questions	
15.00	Coffee Break		
15.30 – 17.30	Plenary Session	Next steps	Chair: Judith Cornell, UNESCO
		Evaluation	
		Conclusion	

Appendix 3: Selected List and Contact Information for Treatment Education Practitioners

AIDS Foundation East West (AFEW)

15/5, Chayanova Street
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Email: info@afew.org
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AIDS Infonet

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

AIDS Law Unit, Namibia Legal Assistance Centre

P.O. Box 604, Windhoek, Namibia
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Fax: (264) (61) 227-675
Email: arasa@lac.org.na
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Website: http://www.safaid.org.
zw/viewpublications.cfm?linkid=39

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Appendix 4: Selected List of Treatment Education Materials

AIDS Foundation East West (AFEW). HIV and pregnancy [in Russian]. Moscow, AFEW, 2005.

Available online at

<http://afew.org/english/publications/pmtct.php>

AIDS Foundation East West (AFEW). Antiretroviral therapy for prevention of mother-to-child transmission of HIV [in Russian]. Moscow, AFEW, 2003.

Available online at

<http://afew.org/english/publications/pmtct.php>

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/nmaix.html

Some examples include:

- Adherence. Fact Sheet 405. NY, NY, AIDS Infonet, 2005. Available online at www.thebody.com/nmai/adherence.html
- Drug interactions. Fact Sheet 407. NY, NY, AIDS Infonet, 2005. Available online at www.thebody.com/nmai/interactions.html
- Taking current antiretroviral drugs. Fact Sheet 401. NY, NY, AIDS Infonet, 2005. Available online at www.thebody.com/nmai/antivirals.html
- Treatment interruptions. Fact Sheet 406. NY, NY, AIDS Infonet, 2005. Available online at www.thebody.com/nmai/treatment_interruptions.html
- What is antiretroviral therapy (ART)? Fact Sheet 403. NY, NY, AIDS Infonet, 2005. Available online at www.thebody.com/nmai/therapy.html

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

ActionAID International. HIV/AIDS factsheet. Johannesburg, ActionAID International, 2004.

Available online at

www.actionaid.org/wps/content/documents/HIVFactsheet2004.pdf

Canadian AIDS Treatment Action Exchange (CATIE).

“Plain and simple fact sheets” on: An introduction to HIV; Complementary therapies; Drug treatment strategies; Nutrition; Opportunistic infections; Women [in English and French]. Toronto, CATIE.

Available online at www.catie.ca/e/pubs/index.html

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; ; Infection fighters, antibiotics; Lab tests; Parasitic infections; Side effects; Weight loss [in English and French]. Toronto, CATIE, no date.

Available online at www.catie.ca/e/pubs/index.html

Canadian AIDS Treatment Action Exchange (CATIE).

“Supplement sheets” on: Antioxidants; Complementary therapy systems; Helping nerves; Herbs; Infection fighters; Managing cholesterol and triglycerides; Proteins and amino acids; Vitamins [in English and French]. Toronto, CATIE, no date.

Available online at www.catie.ca/e/pubs/index.html

Canadian AIDS Treatment Action Exchange (CATIE).

Frequently asked questions on: Adherence; Diseases and conditions; Living with HIV; Medication; Newly diagnosed; Side effects; Street/recreational drugs; Test and lab results; Transmission; Understanding HIV: The basics; Women [in English and French]. Toronto, CATIE, no date.

Available online at www.catie.ca/e/pubs/index.html

Canadian AIDS Treatment Action Exchange (CATIE).

The positive side: Holistic health, information, and views for PHA. Toronto, CATIE, published annually. Available online at www.catie.ca/e/pubs/index.html

Canadian AIDS Treatment Action Exchange (CATIE).

“Practical guides” on: HAART (Highly Active Anti-retroviral therapy); HIV drug side effects; Complementary therapies for people living with HIV and AIDS; Herbal therapies for people living with HIV and AIDS; Nutrition for people living with HIV and AIDS [in English and French]. Toronto, CATIE, no date.

Available online at www.catie.ca/e/pubs/index.html

Centre for Right to Health (CHR). HIV/AIDS and human rights: Your rights in clinical trials. Lagos, CHR, 2002.

Available online at

www.crhonline.org/pubdetail.php?pubid=1

EngenderHealth. Online mini-course on HIV/AIDS and STIs. NY, NY, EngenderHealth, no date.

Available online at www.engenderhealth.org/res/onc/index.html, and on CD-ROM

Family Health International (FHI). Fact sheet: Safe and effective introduction of antiretroviral drugs.

Research Triangle Park, FHI, 2005. Available online at www.fhi.org/en/HIVAIDS/pub/fact/introarv.htm

Family Health International (FHI). Fact sheet: Nutrition in comprehensive HIV care, treatment and support programs. Research Triangle Park, FHI, 2005.

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Family Health International (FHI). HIV/AIDS care and treatment: A clinical course for people caring for persons with HIV/AIDS [in English and French]. Research Triangle Park, FHI, 2004.

Available online at www.fhi.org/en/HIVAIDS/pub/guide/careandtreatmentclinicalcourse.htm

Food and Agricultural Organization. Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS [in English, French, and Spanish]. Rome, FAO, 2002.

Available online at <ftp://ftp.fao.org/docrep/fao/005/y4168E/y4168E00.pdf>

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

Global Network of People Living with HIV/AIDS (GNP+). Positive development: Setting up self-help groups and advocating for change [in Arabic, Chinese, English, French, Hindi, Indonesian, Khmer, Portuguese, Russian, Spanish, and Vietnamese]. Amsterdam, GNP+, 2002.

Available online at www.gnpplus.net/cms/article.php/Positive_Development

HIV i-Base. Avoiding and managing side effects.

London, HIV i-Base, 2005.
Available online at www.i-base.org.uk/pdf/guides/2005/side_feb05.pdf

HIV i-Base. Changing treatment...if treatment fails: Second-line therapy and drug resistance. London, HIV i-Base, 2005.

Available online at www.i-base.org.uk/pdf/guides/2005/changing-apr05.pdf

HIV i-Base. HIV, pregnancy, and women's health. London, HIV i-Base, 2005.

Available online at www.i-base.org.uk/pdf/guides/2005/pregnancy-apr05.pdf

HIV i-Base. Introduction to combination therapy. London, HIV i-Base, 2005.

Available online at www.i-base.org.uk/pdf/guides/2005/starting-jun05.FINAL.pdf

Homan, R, Searle, C. «Exploring the role of family caregivers and home-based care programs in meeting the needs of people living with HIV/AIDS,» Horizons Research Update. Washington, DC, Population Council, 2005.

Available online at www.popcouncil.org/pdfs/horizons/hbccrqvrsa.pdf

International Community of Women living with HIV/AIDS (ICW). Positive women measuring change. London, ICW, 2005.

Available online at www.icw.org/tiki-index.php?page=Publications

International Community of Women living with HIV/AIDS (ICW). Access to care, treatment and support (ACTS) [in English, French, and Spanish]. London, ICW, 2004.

Available online at www.icw.org/tiki-index.php?page=Publications

International Community of Women living with HIV/AIDS (ICW). A positive woman's survival kit [in English and Spanish]. London, ICW, 1999.

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International Community of Women living with HIV/AIDS (ICW). Treatment literacy and advocacy workshop-South Africa. Workshop report. London, ICW, 2004.

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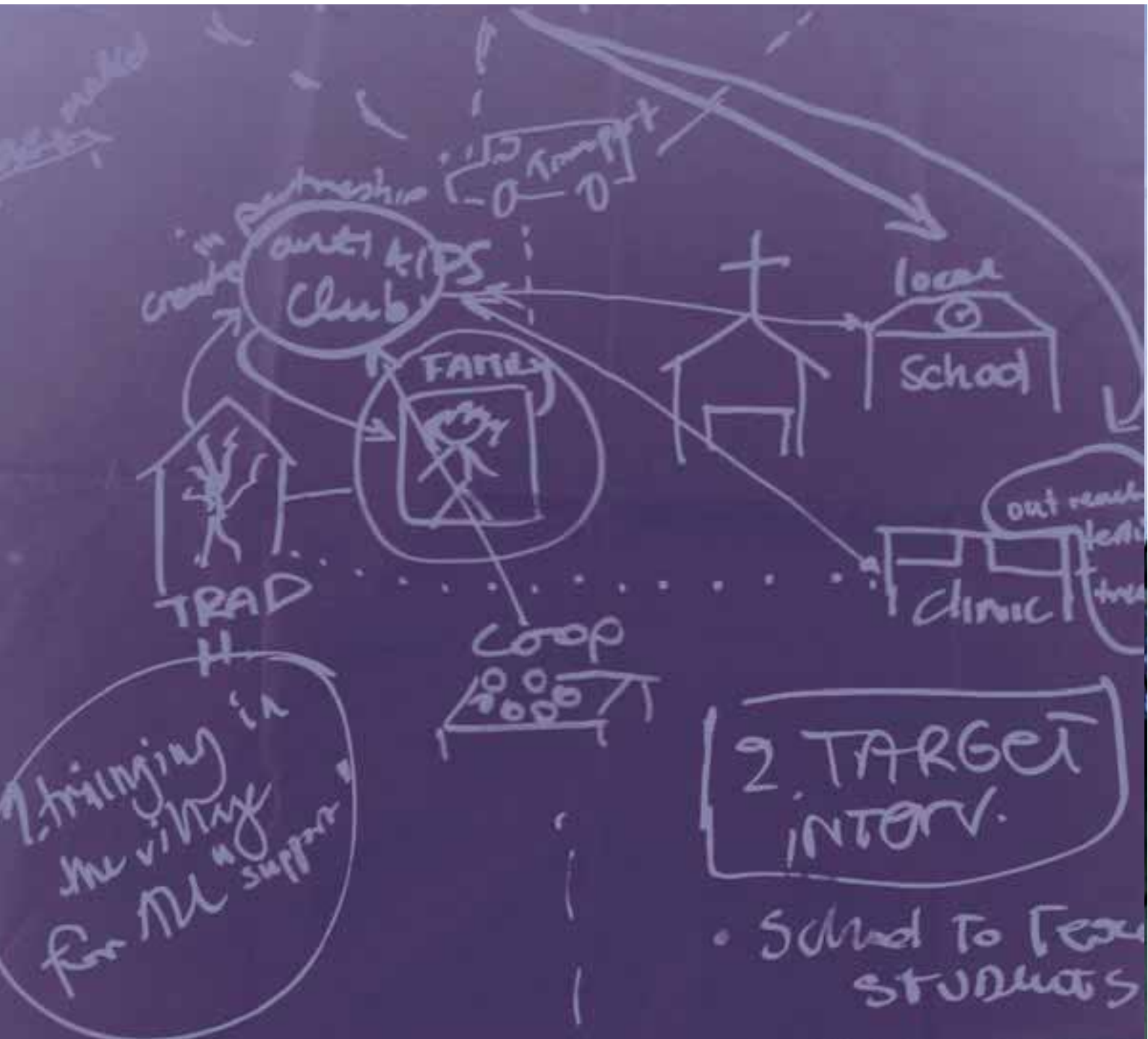
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The meeting brought together technical practitioners with experience in HIV and AIDS treatment education from Government agencies, international and local NGOs, UN agencies, and networks of people living with HIV. Presenters provided insight into programme 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.