

## Treatment literacy: empowering communities to access AIDS treatment

### Information and communication are essential to universal access to treatment and adherence to anti-retroviral therapy

#### INTRODUCTION

As treatment to AIDS is being scaled up, people living in resource poor countries have an increased and urgent need for information and communication around HIV, AIDS and treatment. Before and after anti-retroviral therapy (ART) is introduced into communities, people living with HIV, their supporters and the general population need to understand new and complex ideas around ART, side effects, nutrition, and positive living. Individuals and communities also need to be part of an empowering process to develop problem solving skills around social and health problems and be able to mobilise to provide support and care.

Currently, many communities lack the capacity and resources to understand and support ART. Research shows that communities need more and better information and communication about HIV and ART, as well as informed and trained health providers (International HIV/AIDS Alliance, 2003). Information and communication are essential elements of achieving universal access to ART. Indeed, the UNGASS Political Declaration on HIV/AIDS 2006 (UNGASS, 2006) stresses, in several instances that the effective provision of information, education and communication will lead to positive outcomes. Engaging with individuals and communities effectively around ART can improve health outcomes, contribute to greater uptake of voluntary counselling and testing services, facilitate better adherence and lead to a greater belief in the effectiveness of ART. This paper considers the role of treatment literacy, effective communication and preparing communities to understand and support ART.

#### ACCESS TO ANTI-RETROVIRAL THERAPY

Many global initiatives – such as the “3 by 5” initiative from the World Health Organization (WHO) and UNAIDS, and the US President’s Emergency Relief Plan for HIV/AIDS Relief (PEPFAR) – along with national government and bi-lateral

#### KEY POINTS

- ▶ Communication around anti-retroviral therapy is required for an effective and comprehensive response to HIV and AIDS that includes and makes linkages between prevention, treatment, care and support.
- ▶ Treatment literacy leads to improved health outcomes, better adherence to drug regimens and higher uptake of voluntary counselling and testing services.
- ▶ The process of developing treatment literacy materials is important and should include people living with HIV and AIDS and those taking ART and their guardians and supporters who can either enable or obstruct adherence.
- ▶ Communities need to be prepared to support their members taking ART. This means reducing stigma and discrimination and dispelling myths.
- ▶ Community care and treatment responses should be recognised as an important component of greater access to treatment.

efforts, have helped expand access to ART for people in developing countries. Although still short of targets set by WHO in 2003, at the end of June 2005, over one million people in developing countries were taking ART (WHO, 2005a). In July 2005, at the Gleneagles summit, the Group of 8 leading industrialised countries endorsed universal access to ART by 2010 (G8 Communiqué, 2005).

However, in communities affected by HIV and AIDS people are confronting significant challenges to accessing treatment. These include widespread stigma and discrimination, misinformation, lack of information on ART and insufficient resources to meet basic nutrition needs or travel costs to health clinics for care (IPTC, 2005; International HIV/AIDS Alliance, 2004). Improving communication is just one of

many different elements in efforts to increase access and adherence to ART. Global funding mechanisms need to collaborate speedily and efficiently to unblock bottle-necks and release resources, ensuring sustainability and reliability of access to medication (ITPC, 2005), including availability of fixed dose combinations (Theobald et al, 2006). Health systems and infrastructures need to be greatly improved to support the diagnosis of HIV through voluntary counselling and testing (VCT), the associated delivery of ART (Chopra, 2005) and the linking of ART with prevention and care efforts (WHO, 2005b). This needs to be balanced with strengthening health systems more broadly so that HIV and AIDS do not divert funding away from other health needs (Chopra, 2005; Makwiza et al, 2005; id21, 2002). Indeed, it is important to ask how ART delivery strengthens rather than undermines the broader public health system (Theobald et al, 2006). Technical issues around procurement of drugs, regular supplies to health facilities, and how adherence and drug resistance can be monitored need consideration (Ritzenhaler, 2005). Engaging the public sector through community based organisations and the private sector through the workplace are also critical to expand the coverage and impact of community based treatment (UNAIDS, 2005). The private sector has an increasingly large role to play with the Global Business Coalition and the policies of more prominent businesses that are now providing anti-retroviral drugs.

## Challenges include stigma and discrimination, misinformation, lack of information on ART and insufficient resources to meet basic nutrition and health care needs

The landscape is complex, and it is easy to overlook the vital role of information and communication as components of achieving universal access and adherence to ART. This paper focuses on treatment literacy. Communication, however, is vital at all stages of HIV and AIDS prevention, treatment and care. A recent paper provides a comprehensive overview of the broader communication issues (Vincent, 2006).

### WHAT IS TREATMENT LITERACY?

Organisations use different terminology to refer to treatment literacy, education and communication around ART and HIV and AIDS. At a UNESCO/WHO technical consultation on HIV treatment education held in Paris, in November 2005, participants agreed that “treatment education could be seen 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” (UNESCO/WHO, 2005). Treatment literacy and community

preparedness are seen by UNESCO and WHO as sub-components of broader treatment education: “Treatment education 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 suggests strategies for overcoming stigma and discrimination and gender inequality” (UNESCO/WHO, 2005). Treatment education is not only the responsibility of the health sector, and should also include other sectors such as education, as education institutions often can reach further into communities around the world (UNAIDS Inter Agency Task Team on Education, 2006).

Treatment literacy means people, both individually and in communities understand what anti-retroviral drugs are, why they are needed and what they can and cannot do. Treatment literacy translates medical information about ART into languages and formats that are accessible to everyone. The Treatment Action Campaign (TAC) emphasises the importance of treatment literacy: “We must know our medicines by name, how they were found to be effective, and how and where in the body they work; their side effects and how they can be managed; how to monitor the safety of medicine; what food to take and not to take with them. That way we can feel we have some control over our health. We must also follow new scientific research that sheds light on how best to use the drugs we take. All these things are part of what we call ‘treatment literacy’.” (TAC on HIV i-Base website, 2005). Prevention is also a part of treatment literacy including prevention from infection and re-infection, prevention of infecting others and prevention of the progression from HIV to AIDS (Kujinga, 2006).

### EFFECTS OF LACK OF TREATMENT LITERACY

Organisations at the forefront of advocacy and campaigning to ensure universal access to ART, such as the Treatment Action Campaign, International Treatment Preparedness Coalition (ITPC), and UNAIDS know treatment literacy programming is inadequate and advocate for increased resources. In a recent report of a six country survey, ITPC said, “ART awareness campaigns are often passive, uncoordinated, inappropriate, irregular and ineffective... and appear to have little effect on eliminating misinformation among both HIV positive and HIV negative people about the disease or ART” (ITPC, 2005).

The impact of misinformation and myths on the success of ART programmes can be devastating as one striking case in China demonstrates. Thomas Cai, an HIV and AIDS worker said, “In one village, almost 90 per cent of people stopped taking the ARVs within a short period of time. The main reason is because of the way they distributed the drugs... 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 started to come out of the village, 'the government is trying to poison us'. There is a lot of misunderstanding" (cited in UNESCO/WHO, 2006). This is an extreme example, but there are many cases where people observe side effects of drugs in friends, family members and colleagues and are fearful of ART. The effects of lack of communication and information can lead to increased stigma and discrimination, and contribute to a lack of adherence to ART. The need to adhere to ART is critical and should be central in treatment literacy efforts.

## ADHERENCE

When people start ART they must continue for an entire lifetime. This can be challenging at the best of times in developing countries, when travelling to the treatment centre may prove too expensive, where stigma and discrimination can prevent people from finding out or disclosing their status and from taking their tablets, where meeting nutritional requirements is sometimes impossible, and where it is more difficult to cope with side effects. Concerns about adherence are understandable. Adherence to anti-retroviral drugs should ideally be over 95 per cent. When people miss doses of their medication, the HIV virus develops resistance to the medication, people's conditions worsen and they are likely to die. Drug resistant HIV is also likely to develop in communities (Muyoti, 2006).

Adherence can be described as, "an engagement and accurate participation of an informed patient in a plan of care" (Rabkin et al, 2003). Evidence from a few early (and limited) studies in South Africa, Senegal and Uganda demonstrates that so far people in developing countries have levels of adherence consistent with those in industrialised countries. This shows that patients in developing countries are able to follow a treatment plan as well as those in the developed world (Machtinger et al, 2005). The main reason cited in the three countries (South Africa, Senegal and Uganda) for not adhering to drugs was financial barriers (Machtinger et al, 2005).

## Information and communication are essential elements of universal access and adherence to ART

Communication between providers and users is essential to negotiate the nexus of deprivations and responsibilities facing any household. Adherence is complex and multi-dimensional approaches are needed to tackle the challenges that exist. In Tanzania, a study to identify potential barriers to adherence found that reasons for non-adherence were given as poor knowledge, information, lack of treatment guidelines and a negative perception of treatment (Irunde et al, 2005). Patients who were knowledgeable about ART had received information through leaflets, seminars, adherence counselling, verbal counselling, television and radio. In Botswana, research found that adherence to treatment was related to the availability of information, material and emotional support from family members (Kgatlwane K et al, 2005). Researchers developed a number of recommendations to improve adherence these focus on introducing collaborative approaches with the patient, the community, health care workers and policy makers. Namely, providing healthcare workers with practical guidelines for implementing adherence management strategies including on-going counselling; assisting patients who cannot afford with transport costs to collect their treatment with transport vouchers; and support communities in mobilising to reduce stigma and discrimination to create an environment where people can take their drugs without fear (Kgatlwane J et al, 2005).

Information and communication are among the most important elements of universal access and adherence to ARVs, yet the challenges to communicating effectively around ARVs are considerable.

## INFORMATION GAPS FOR COMMUNITIES AND HEALTH WORKERS

In a recent study of people on ART and health care workers in Zambia in 2003, information needs about HIV, AIDS and ART came out strongly. People on treatment said they needed information on what clinical and support services were available and how to access them; the costs for treatment and tests; how to take anti-retroviral drugs and possible side effects; how the medication works; how to store the medication; the effects of treatment on daily life including sexual and reproductive health; strategies for adherence to ART and positive living including nutrition. In Zambia, there are very few information materials on ART and what it means for daily living. Communication is often restricted to verbal communication between health care workers and patients, during time restricted consultations. Similarly health care workers did not have enough knowledge about ART and needed information and training (International HIV/AIDS Alliance, 2004).

It is however unreasonable to expect health care workers to respond to individual and community communication needs about ART when they are already overstretched. So what can be done to meet the information needs of people living in HIV and AIDS affected communities? Efforts within and outside of the health system must be strengthened so that ART can reach its full potential to improve health outcomes. (UNESCO/WHO, 2006).

### TREATMENT LITERACY PROGRAMMES

There many local initiatives introducing treatment literacy programmes into communities. The Treatment Action Campaign is widely known and is worth learning from for the range of activities it carries out. TAC's treatment literacy programme puts people with HIV at the centre of care. This gives individuals and their care-givers knowledge and skills to manage their health and reduces myths, fears and misconceptions about HIV and AIDS. Trained treatment literacy practitioners use personal stories and experiences combined with medical and scientific knowledge to increase treatment literacy among people with HIV and their supporters.

#### COMPONENTS OF TAC'S TREATMENT LITERACY PROGRAMME

Education and awareness raising in the community have been critical in preparing communities to accept treatment. TAC's range of treatment literacy activities include:

- ▶ community education and awareness campaigns using posters, videos, booklets, brochures or pamphlets and t-shirts
- ▶ curricula for health care providers, for people on treatment and for peer educators; support groups and networks of people living with HIV
- ▶ teaching aids such as health diaries and calendars, treatment side effects charts; broadcast media programmes, radio or TV programmes
- ▶ instructional or participatory materials to guide discussions, role plays and interactive exercises
- ▶ marches and new community branches of TAC.

(TAC in UNESCO/WHO, 2006)

Growing numbers of national and international non-governmental organisations (NGOs) recognise the need to communicate effectively around ART. Many local organisations are already providing effective treatment literacy services and introducing innovative approaches to communicating around ART. Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS) has a good and useful guide on women and ART (SAfAIDS, 2005). Another interesting approach is 'body mapping' which has been used in South Africa and helps people to understand how HIV and treatment affects the body. The challenges for local organisations involved in treatment literacy is that people need to have a basic understanding of HIV before they can understand ART and that information about HIV and ART changes fast.

### Putting people living with HIV at the centre of care gives individuals and their care-givers knowledge and skills to manage their health

Programme experience demonstrates that the process of developing treatment literacy materials is important. People living with HIV and AIDS and those taking treatment should participate in the development, review and evaluation of materials to ensure they are appropriate, relevant and meet people's real needs (UNESCO/WHO, 2006). Guardians and supporters also have an important role to play here. There are factsheets and other participatory treatment literacy materials that can be reviewed and adapted for local use (International HIV/AIDS Alliance, 2005; ITPC, 2005; AIDS Law Unit, no date; Treatment Action Campaign, 2006; HIV i-Base, 2006) When adapting materials, there are some general rules to follow. It is important to use images and examples that are relevant to local contexts, ensure information is clinically appropriate and also be aware of the challenges of copyright and protected materials.

More generally the landscape of HIV and AIDS has changed with the expansion of access to ART and it is now necessary to revisit and update much of the old HIV and AIDS material in light of new treatment issues. Without being overly optimistic about how many people will benefit from ART, issues around 'positive living' rather than 'preparing for death' need to be addressed and there has to be a new shift in thinking (Green, 2006). Children have particular needs around ART and communication (International HIV/AIDS Alliance, 2005; Children's Institute 2004). Children need easy-to-take medication, child friendly material to help them understand their medication and support to accept increasing responsibility for their own treatment as they grow up (Sherr 2005). All community members including minority groups and non-literate people need communication approaches which they can engage with and relate to.

## EMPOWERED CITIZENS

It is not just a matter of providing information in appropriate formats and using the right communication channels. People on treatment also need skills in problem solving around their social and health situations in order to adhere to their treatment and access support when it is needed (UNESCO/WHO, 2006). Supporting people to develop these skills is critical. TAC and Médecins sans Frontières activists argue that not only do people have to understand medical treatment, they must also be 'empowered citizens' who understand the connection between biomedicine and the wider social world and political economy of health. This will demand a different kind of public engagement with HIV and AIDS and treatment where rights and responsibilities are a key feature (Robins S, 2005).

Debates about rights and responsibilities are also connected with the fact that poor individual adherence to treatment can lead to multi-drug resistant strains of HIV which could have a serious impact on the rest of the population. Evidence from pilot projects in South Africa show that high levels of adherence to ART stem from a new relationship between health care providers and patients. Responsibility for adherence is given to the patient with a clear framework of empowerment and support and is different to the "traditional paternalistic and passive relationship between healthcare workers and patients – changing this represents the key innovation challenge of an ART programme" (Coetzee and Schnieder, 2004). This can be broadened out to community levels too. In Khayelitsha, South Africa "the link between education and treatment can best be described as a new social contract: the clinics provide effective HIV/AIDS care and life-saving treatment, and the community breaks the silence, fights stigma and discrimination, and through education, promotes understanding and prevention" (WHO, 2003).

Introducing ART into communities, means more than ensuring individuals and families are able to support and care for people taking anti-retroviral drugs. Entire communities with diverse members, some of whom are marginalised or minority groups, should be able to understand HIV and AIDS and what it means to start and adhere to ART.

## COMMUNITY PREPAREDNESS

Communities play a vital role in supporting and coping with all aspects of HIV and AIDS including access and adherence to treatment. However a supportive community cannot be assumed: "Often the environment in which people have to take their medicine is quite hostile" (Green, 2006). Community consultations in Zambia in both rural and urban settings, showed that for communities to realise their potential as a valuable resource for ART, people need information and education as well as effective clinical care

and support (International HIV/AIDS Alliance, 2003). This is important particularly considering the stigma often attached to HIV and AIDS. Introducing ART into a community which will not accept it is likely to lead to failure: "Where stigma and discrimination are pervasive, people living with HIV and AIDS who are clinically eligible to participate in ART programmes may find it difficult to meet social criteria, such as willingness to visit a health facility regularly, be contacted at home, or disclose positive HIV status to a relative or friend who can support adherence to medicines" (Ritzenthaler, 2005). Overcoming stigma and discrimination and ensuring that people on treatment receive the family and community support they need, means working closely with community members at all levels to communicate around treatment issues and to dispel myths and rumours. Taking into account the different experiences of stigma and different challenges to adherence by men and women is also important and needs to be factored into community preparedness (Theobald et al, 2006).

An important consideration is that treatment preparation has to be done with and by community members (Green, 2005). Family Health International used a variety of interactive approaches to prepare communities for the introduction of ART in Ghana, Kenya and Rwanda including working with local leaders and people living with HIV. This fostered a spirit of collaboration and gave community groups a sense of ownership. Programmes in each country developed local language materials to enhance interaction between patients and health care providers, improving interpersonal relationships (Ritzenthaler, 2005).

A range of communication tools and channels can be used to engage and prepare communities. Project Orange in Burkina Faso conducts community education through roadside coffee shops, internet cafés and micro-finance activities (International HIV/AIDS Alliance, 2006). The ARV Community Education and Referral (ACER) project in Zambia reaches communities through church programmes, traditional healers and support groups. The ACER project is also effective in developing a two-way referral system between the health system and other sources of help for people on treatment (UNESCO/WHO, 2006). In Nigeria, the Mothers' Welfare Group used drama activities with adolescent groups to encourage community members to attend voluntary counselling and testing clinics (Healthlink Worldwide, 2006). Community driven 'post-test' clubs such as Liverpool VCT in Kenya can provide valuable support to people regardless of the result and create spaces where issues on HIV and AIDS and treatment can be discussed openly (HIV/AIDS STI Knowledge Programme, 2003). Mass media is also a powerful tool and 'Beat it! Your guide to better living with HIV/AIDS' is a weekly television series in South Africa aiming to combat fear and denial of HIV and AIDS by promoting accurate knowledge and information and empowering people to take control of their health.

“Preparing communities is also more than just providing information – it is igniting the sparks to action” (UNESCO/WHO, 2006). Many communities are already rising to the challenge of supporting ART. In 2004, Sidaction, a Paris based treatment rights group, in association with UNAIDS and WHO carried out a survey to map treatment and care efforts by community based organisations. The survey showed that there is an extensive community response to HIV care and treatment which fills gaps in prevention and care services and appears to respond and change according to community needs. Community efforts to provide treatment represent an important opportunity to enrol more people in ART. National governments and the international community need to quickly provide support to expand coverage and impact of community based treatment.

One aim is for community based organisations (CBOs) to work closely with the public sector (UNAIDS, 2005). The work of some CBOs demonstrates an ability to carry out high quality work and improve access to treatment. For example, L'Association Nationale de Soutien Aux Séropositifs et Sideens (ANSS) in Burundi provide better services than the government as they provide personal follow up, group support and counselling services leading to improved adherence. CBOs also have the knowledge and motivation to monitor community and national responses to HIV and AIDS, particularly on treatment and can report on drug prices, minority access issues, poor advice or information or mistreatment by healthcare workers (UNAIDS, 2005).

## CONCLUSION

Communicating and preparing individuals and communities to understand and support people on ART is an important component of a comprehensive response to HIV and AIDS that includes prevention, treatment, care and support. Accurate information communicated through a variety of formats using appropriate channels is needed in all places where ART is introduced so that communities become ‘treatment literate’. Civil society organisations need support to facilitate this process, which should include the active participation of local leaders, community members, families and people living with HIV and who are on treatment. This in turn needs to be part of a broader empowerment agenda where people and communities can actively engage with health providers around their treatment and are able to negotiate health and social situations. Engaging with individuals and communities effectively around ART can improve people’s quality of life, contribute to greater uptake of voluntary counselling and testing services and lead to a greater belief in the effectiveness of ART.

## REFERENCES

- AIDS Law Unit (no date) *Treatment for HIV/AIDS: a Guide*, AIDS Law Unit, Legal Assistance Centre, South Africa
- Children’s Institute (2004) *What about the children? Antiretroviral roll-out in South Africa. Where do children feature?* Children’s Institute, University of Cape Town
- Chopra M (2005) *ARV Treatment and health systems: avoiding the pitfalls* [online], Medical Research Council of South Africa, South Africa  
[www.mrc.ac.za/aids.march2005/arvtreatment.htm](http://www.mrc.ac.za/aids.march2005/arvtreatment.htm) accessed 29 April 2005
- Clayden P (2006) Presentation of ‘Adapting materials, four case studies: Nepal, Namibia, South Africa and Bulgaria’ at the Treatment Education Consultation, November 23, 2005 in UNESCO/WHO (2006) *Report on the HIV Treatment Education Consultation co-organized by UNESCO and WHO*, UNESCO, Paris, forthcoming 2006.
- Coetzee and Schneider (2004) ‘Editorial’, *South African Medical Journal* (SAMJ) Vol 93, No 10, pp72-3 cited in Robins S (2005) ‘Rights passages from “near death” to “new life”’: AIDS activism and treatment testimonies in South Africa’ IDS Working Paper 251, University of Sussex, Brighton
- Family Health International (2006) *Fact sheets on HIV and AIDS care and treatment* [online], Family Health International, North Carolina <http://www.fhi.org/en/HIVAIDS/pub/fact/index.htm> accessed 14 March 2006
- G8 Communiqué (2005) *UK Presidency G8 Press fact-sheet – highlights of the G8 Communiqué (Africa)* [online], G8 [http://www.g8.gov.uk/Files/KFile/PostG8\\_Africa\\_Highlights%20of%20G8%20Communique.pdf](http://www.g8.gov.uk/Files/KFile/PostG8_Africa_Highlights%20of%20G8%20Communique.pdf) accessed 14 March 2006
- Green C (2005) ‘Treatment preparedness – engaging communities for effective delivery and support of antiretroviral treatment’ Powerpoint presentation WHO/UNESCO Treatment Education Technical Consultation Paris 22-23 November 2005
- Green C (2006) Personal communication with Carolyn Green, Senior Technical Advisor, Care and Support, International HIV/AIDS Alliance, Brighton, UK 16 February 2006
- Healthlink Worldwide (2006) *HIV and AIDS – Strengthening support for Orphans and Vulnerable Children affected by HIV and AIDS* [online], Healthlink Worldwide, London [http://www.healthlink.org.uk/projects/hiv/ovc\\_act.html](http://www.healthlink.org.uk/projects/hiv/ovc_act.html) accessed 12 October 2006

HIV/AIDS STI Knowledge Programme (2001) 'Establishing and sustaining HIV Post-Test Clubs (PTCs): Lessons learnt from Kenya', Policy Briefing Number 4 / October 2001, Liverpool School of Tropical Medicine, Liverpool

HIV i-Base (2006) *Adapting materials: why do we need treatment information?* [online] HIV i-base, London <http://www.i-base.info/education/adapting.html> accessed 14 March 2006

id21 (2002) 'Delivering HIV treatment to the poor: report from an email discussion' *id21 Perspectives discussions on line*, Institute of Development Studies, University of Sussex, Brighton

International HIV/AIDS Alliance (2003) *Voices from Zambian communities: Experiences of HIV/AIDS related treatment in urban and rural settings. A report of community consultations on HIV/AIDS-related treatment in urban and rural Zambia, 2002-2003 – with a practical guide on consulting individuals and community groups about HIV/AIDS related treatment*, International HIV/AIDS Alliance, Brighton

International HIV/AIDS Alliance (2004) *Antiretroviral treatment in Zambia: A study of the experiences of treatment users and health care workers* [online], International HIV/AIDS Alliance, Brighton [http://synkronweb.aidsalliance.org/graphics/secretariat/publications/cim0304\\_Zambia\\_ARV\\_treatment.pdf](http://synkronweb.aidsalliance.org/graphics/secretariat/publications/cim0304_Zambia_ARV_treatment.pdf) accessed 14 March 2004

International HIV/AIDS Alliance (2005) *ARV treatment fact sheets: 1: HIV/AIDS and treatment, 2: ARV treatment, 3: Testing and counselling, 4: Adherence, 5: Side effects, 6: Side effects detailed information, 8: Food for people on treatment, 12: Stigma, 13: Living with a chronic condition 18: Symptom control and palliative care* [online], International HIV/AIDS Alliance, Brighton <http://www.aidsalliance.org/sw7418.asp> accessed 14 March 2006

International HIV/AIDS Alliance (2006) *Burkina Faso: Alliance linking organisation: Initiative Privée et Communautaire Contre le VIH/SIDA au Burkina Faso (IPC)* [online] International HIV/AIDS Alliance, Brighton <http://www.aidsalliance.org/sw7220.asp> accessed 12 October 2006

International Treatment Preparedness Coalition (ITPC) (2005a) *Missing the Target: A report on HIV/AIDS treatment access from the frontlines* [online], ITPC <http://www.aids-treatment-access.org/itpcfinal.pdf> accessed 14 March 2006

International Treatment Preparedness Coalition (ITPC) (2005b) *Treatment preparedness – anti-retrovirals* [online], ITPC [http://www.globaltreatmentaccess.org/content/tx\\_prep/arv.html](http://www.globaltreatmentaccess.org/content/tx_prep/arv.html) accessed 14 March 2006

Irunde H, Temu F, Maridadi J, Nsimba S, Comoro C (2006) *A study on antiretroviral adherence in Tanzania: A pre-intervention perspective 2005*, WHO, Geneva

Kgatlwane J, Ogyeni R, Ekezie C, Madaki H, Moyo S, Moroko T (2005) *Factors that facilitate and constrain adherence to ARV drugs among adults at four public health facilities in Botswana – A pre-intervention study*, WHO, Geneva

Kujinga T (2006) Personal communication with Tapiwanashe Kujinga at Family AIDS Caring Trust (FACT), Zimbabwe 14 July 2006

Machtinger E and Bangsberg D R (2005) *Adherence to HIV Antiretroviral Therapy HIVInSite Knowledge Chapter* [online; May 2005, content reviewed Jan 2006] UCSF HIV InSite, Center for HIV Information, University of California, San Francisco <http://hivinsite.ucsf.edu/InSite?page=kb-03-02-09> accessed 24 March 2006

Makwiza I, Nyirenda L, Bongololo G, Loewenson R, Theobald S (2005) 'Monitoring equity and health systems in the provision of anti-retroviral therapy (ART)' *EQUINET Discussion Paper* Number 24, The REACH Trust, with the Regional Network for Equity in Health in Southern Africa (EQUINET)

Muyoti A (2006) Personal communication with Dr A Muyoti at Kenya AIDS NGOs Consortium (KANCO)

Rabkin M, El-Sadr and W, Abrahams E (2003) *MTCT-Plus Clinical Manual*, Mailman School of Public Health Columbia University, New York Also available at [http://www.mtctplus.org/intranet/pdf/ad\\_treatment.pdf](http://www.mtctplus.org/intranet/pdf/ad_treatment.pdf)

Ritzenthaler R (2005) *Delivering antiretroviral therapy in resource-constrained settings: Lessons from Ghana, Kenya and Rwanda*, Family Health International (FHI) and USAID, Washington

Robins S (2005) 'Rights passages from "near death" to "new life": AIDS activism and treatment testimonies in South Africa' *IDS Working Paper* 251, University of Sussex, Brighton

Southern Africa HIV and AIDS Information Service (SAfAIDS) (2005) *Guide to Women's HIV/AIDS treatment literacy toolkit*, SAfAIDS, Harare

Sherr L (2005) 'Young children and HIV/AIDS: Mapping the field', *Working Papers in Early Childhood Development – Young children and HIV/AIDS sub-series*, Bernard van Leer Foundation, The Hague

Theobald S, Makwiza I, Mwansambo A, Agabu A & Schouten E (2006) 'From 3 by 5 to universal access: an equity advocacy opportunity for access to antiretroviral therapy in Malawi?' *Malawi Medical Journal* 18:1

Treatment Access Campaign (2006) *Treatment Literacy* [online], Treatment Access Campaign, Muizenberg <http://www.tac.org.za/literacy.html> accessed 12 October 2006

UNAIDS (2005) *Expanding access to HIV treatment through community-based organisations: A Joint publication of Sidaction, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization* [UNAIDS Best Practice Collection], UNAIDS, Geneva

UNAIDS Inter-Agency Task Team (IATT) on Education (2006) *HIV and AIDS Treatment Education: A Critical Component of Efforts to Ensure Universal Access to Prevention, Treatment and Care* [forthcoming], UNESCO, Paris

UNESCO/WHO (2006) *Report on the HIV Treatment Education Consultation co-organized by UNESCO and WHO* [forthcoming], UNESCO, Paris

UNGASS (2006) *Political Declaration on HIV/AIDS* [online], UNAIDS, Geneva [http://data.unaids.org/pub/Report/2006/20060615\\_HLM\\_PoliticalDeclaration\\_ARES60262\\_en.pdf#search=%22UNGASS%20political%20declaration%22](http://data.unaids.org/pub/Report/2006/20060615_HLM_PoliticalDeclaration_ARES60262_en.pdf#search=%22UNGASS%20political%20declaration%22) accessed 15 June 2006

Vincent R (2006) *Facing up to HIV and AIDS – effective communication for prevention treatment and care, for a sustained response*, Panos, London

WHO (2003) 'Case study. Perspectives and practice in antiretroviral treatment' in *Antiretroviral therapy in primary health care: experience of the Khayelitsha programme in South Africa*, WHO, Geneva

WHO (2005a) *Progress on Global Access to HIV Antiretroviral Therapy: an update on "3 by 5"* [online] WHO/UNAIDS, Geneva <http://www.who.int/3by5/fullreportJune2005.pdf> accessed 15 June 2005

WHO (2005b) *ARV Toolkit: a public health approach for scaling up anti-retroviral (ARV) treatment* WHO; International HIV/AIDS Alliance; PharmAccess International; and GTZ, Geneva

## ACKNOWLEDGEMENTS

This Findings paper was written by **Alison Dunn**.

Thank you to the reviewers: Christiana Brown, Christopher Castle, Andrew Chetley, Judith Cornell, Kate Elder, Sarah Hammond-Ward, Tapiwanashe Kujinga, Christoforos Mallouris, Dr A Muyoti, Justine Sass, Robin Vincent, Mac Bain Mkandawire, Sally Theobald



## Key list

» [www.asksource.info](http://www.asksource.info)

### TREATMENT LITERACY

A list of key organisations, articles, newsletters, books and websites on this topic is available from Source International Information Support Centre.

## ABOUT FINDINGS PAPERS

Findings papers are snapshots of key areas of health communication to inform development practitioners and policy makers and to stimulate critical reflection.

Findings papers were originally produced by Exchange – a networking and learning programme on health communication which was hosted by Healthlink Worldwide. Exchange has been integrated into a Communication, Networking and Learning programme at Healthlink Worldwide, which will continue to produce Findings papers.

We welcome your feedback on this paper.

**HEALTHLINK  
WORLDWIDE**

Healthlink Worldwide  
56-64 Leonard Street  
London EC2A 4LT  
United Kingdom

T: +44 207 549 0240  
F: +44 207 549 0241  
[info@healthlink.org.uk](mailto:info@healthlink.org.uk)  
[www.healthlink.org.uk](http://www.healthlink.org.uk)

