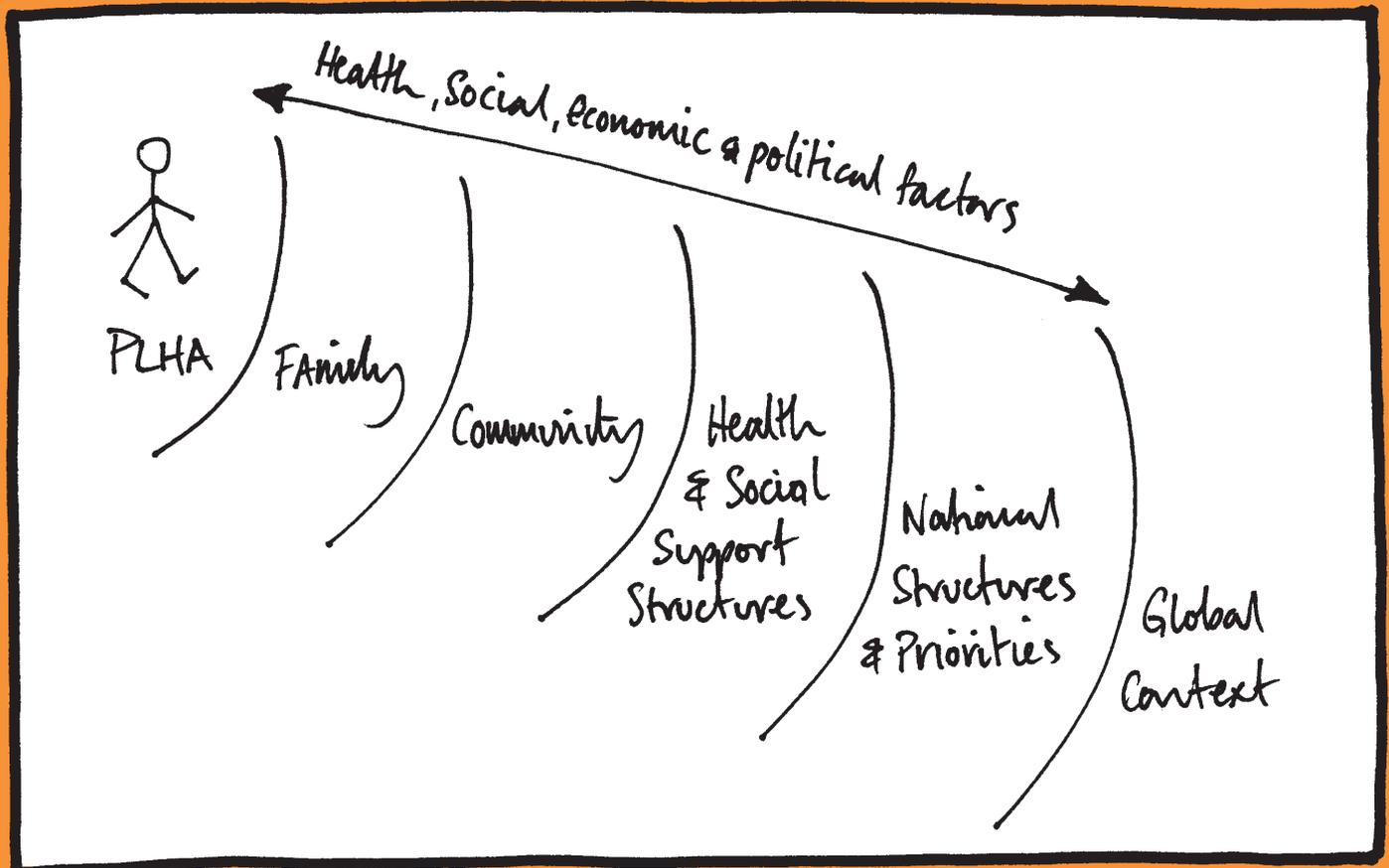


Improving access to HIV/AIDS-related treatment

A report sharing experiences and lessons learned on improving access to HIV/AIDS-related treatment



Preface

The International HIV/AIDS Alliance (the Alliance) is an international non-governmental organisation that supports communities in developing countries to make a significant contribution to HIV prevention, AIDS care and support to children affected by the epidemic.

Since its establishment in 1993, the Alliance has provided financial and technical support to NGOs and CBOs from more than 40 countries. In addition, the Alliance promotes good practice in community responses to HIV/AIDS more broadly through evaluation, operations research, the development of training materials and tools, as well as policy and advocacy activities.

The mission of the Alliance is to support communities in developing countries to play a full and effective role in the global response to AIDS.

The Alliance accomplishes this by mobilising a broad range of non-governmental and community groups, increasing their access to resources at a local level and enhancing their technical and organisational skills. The Alliance also supports groups to share lessons learned, to collaborate with others and to have a voice in national and international policy development. In this way, the Alliance encourages creative prevention, care and impact-mitigation efforts that respond to the real needs of communities, are owned by local people and have a sustainable impact. By learning from these partnerships, the Alliance has developed a reputation as a centre of expertise on non-governmental organisation (NGO) support and community mobilisation.

The Alliance's involvement with improving access to HIV/AIDS-related treatment arose from experiences gained by working with communities in many different countries.

This report aims to share these experiences and lessons learned and is based on the Alliance's work with its partners to develop the publication ***Mobilising NGOs, CBOs and PLHA Groups for Improving Access to HIV/AIDS-Related Treatment – A Handbook of Information, Tools and other Resources.***

Section 1 of this report sets the scene, outlining the key issues and discussion points around access to HIV/AIDS-related treatment, the experience and learning of the Alliance and its partners in this area and the process of developing the handbook. **Section 2** looks at the different elements that contribute to good practice in HIV/AIDS-related treatment. **Section 3** explores key issues in improving access to HIV/AIDS-related treatment.

Glossary of terms

| | |
|------------------|--|
| AIDS | acquired immune deficiency syndrome |
| ARV | antiretroviral therapy |
| CBO | community-based organisation |
| CPT | care and prevention team |
| DOTS | directly observed treatment – short course; for example, TB medication |
| EDL | Essential Drugs List |
| EDM | essential drugs and medicines |
| HIV | human immuno-deficiency virus |
| LO | linking organisation |
| MTCT | mother-to-child transmission |
| NACO | National AIDS Control Organisation, India |
| NGO | non-governmental organisation |
| OI | opportunistic infection |
| OVC | orphans and vulnerable children |
| PLHA | people living with HIV/AIDS |
| STI | sexually transmitted infection |
| TB | tuberculosis |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| USAID | United States Agency for International Development |
| VCT | voluntary counselling and testing |
| WHO | World Health Organization |
| WHO – EDM | World Health Organization – Department of Essential Drugs and Medicines Policy |

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Alliance country offices

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- Philippines National AIDS Council, Manila
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- Remedios AIDS Foundation, Manila

Zambia

- Archdiocese of Lusaka Home Based Care Programme, Lusaka
- Catholic Agency for Overseas Development (CAFOD), Lusaka
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Section 1: Setting the scene

Early discussions on access to HIV/AIDS-related treatment

PLHA groups, NGOs and CBOs have been at the forefront of prevention and care since the world first became aware of the HIV/AIDS epidemic. The mobilisation of NGOs, CBOs and PLHA groups has catalysed hope, developed skills and ensured better delivery of HIV/AIDS-related commodities and services. In some places they have been the only providers of these commodities and services. They have also courageously built roles for themselves as advocates and teachers, changing the way the world thinks about HIV/AIDS and responds to people living with the virus.

The early discourse around treatment in the developing world focused primarily on medical technologies and treatment delivery through existing health services. The critical role of NGOs, CBOs, PLHA groups and faith-based organisations was often overlooked, despite some clear examples of their good practice in care and treatment, and their unique ability to use local resources and keep costs down.

At the same time, even though the HIV/AIDS epidemic continued to spread aggressively and a climate of concern evolved around medical treatment for HIV and related health problems, many NGOs, CBOs and PLHA groups were reluctant to take up work on HIV/AIDS-related treatment. This was because they perceived it to be too technical, too complex and too costly.

During early discussions on improving access to HIV/AIDS-related treatment a number of key points emerged.

- ✓ Drugs, meaning both antiretrovirals (ARVs) and other essential medicines, are unavailable to people in many parts of the world. Even when they are available, many factors such as affordability, discrimination against people with HIV and lack of effective health infrastructures combine to prevent individuals gaining access to the health care that they need. This also affects other basic health supplies such as gloves, condoms, syringes, laboratory tests etc.
- ✓ The inability to fulfil the right to health means that most people with HIV, their families and communities, especially in resource-poor settings, have limited choices about HIV/AIDS-related treatment, if any.
- ✓ ARV treatment in well-resourced situations makes a radical difference to the survival and life quality of people with HIV. Ethical considerations then arise. Should poor people with limited health choices have any right to these new and expensive treatments? If so, how can they be made affordable and accessible? Should general levels of health care be improved before adding in costly and complicated new technologies?
- ✓ The broader contexts outside of ARVs were more difficult to think about, with the result that people in developing countries were excluded to a large extent from the debate. Their views, especially about the need to integrate HIV/AIDS-related treatment with the contexts in which it might be delivered, took a long time to be heard. Specifically, health needs relating to tuberculosis (TB), malaria and other infectious diseases posed huge problems. Acute community needs for food, shelter, clean water and education also had to be considered.

Section 1: Setting the scene

- ✓ Medicalised assumptions that treatment was not an activity for 'lay' people got in the way of learning lessons from communities and providing support for local services. Experience showed that care and treatment through community approaches could be demystified, that 'lay' people could understand the uses and limitations of treatment and that they could make a significant difference to the health of people with HIV, whether or not ARVs were available and accessible.

1.1 The Alliance and its partners: learning from experience

Since 1994 much of the Alliance's support to NGOs and CBOs has focused on work to prevent the spread of HIV and to provide care and support for people with HIV. In recent years access to treatment has emerged as an important issue requiring specific attention.

The approach of the Alliance and its partners to support for community action on HIV/AIDS has always focused on learning by doing. Work on improving access to HIV/AIDS-related treatment is no exception. The Alliance has learned lessons from community-based work in a number of countries: from home care, voluntary counselling and testing (VCT), vulnerable children and from the involvement of people with HIV. The Alliance and its partners continue to build on these experiences in their work on improving access to treatment.

Section 1: Setting the scene

Examples of the Alliance's learning about access to HIV/AIDS-related treatment

In Cambodia, the experiences of solidarity groups, supported by the Alliance linking organisation (LO) in Cambodia, the Khmer HIV/AIDS NGO Alliance (KHANA), showed that discrimination is a key barrier preventing access to treatment, and that material needs and support are often a priority for people with HIV and their families. Initially, groups helped with small amounts of household supplies such as soap and sugar, but it soon became clear that more was needed. People required treatment as part of their care, and medicines were expensive and hard to obtain. Home care teams developed a home care kit containing basic medicines for minor infections and symptoms, and hygiene supplies such as bleach, dressings and condoms.

VCT has been a central element of NGO and CBO support and care for people in Zambia from the beginning. As a member of the Zambia VCT partnership, the Alliance – through its Zambia country office – learned that a key obstacle to the uptake of VCT was that people believed HIV treatment was not available, and that the appearance of symptoms (often the first point at which people consider being tested) guaranteed an early death. VCT projects that allied themselves to home care programmes found that with the availability of basic treatments and consequent longer survival, people became more hopeful and more willing to have an HIV test and act on advice about healthy living and prevention.

In Burkina Faso and India, community-based care and support focusing on orphans and vulnerable children (OVC) is supported by the Alliance's LO in Burkina Faso, Initiative Privée et Communautaire contre le SIDA au Burkina Faso (IPC), and by the India HIV/AIDS Alliance. This work showed that infected children are not receiving the care and support they need. Treatment services for children are very limited due to lack of understanding of their needs and of clinical expertise.

The Horizons¹ diagnostic study on the involvement of PLHA in the delivery of community-based prevention, care and support services in Burkina Faso, Ecuador, India and Zambia showed that people with HIV are not only passive recipients of services, but also that they have a valuable contribution to make in terms of planning and implementing these services. Although access to treatment is a prime concern for people with HIV, the study also found that this has to be accompanied by psycho-social support, provision of accurate information and training on such issues as positive living, support group formation and opportunities for involvement within NGOs and CBOs.

¹ Horizons is a global operations research programme designed to identify solutions to improve prevention, care and support programmes, and service delivery. Horizons is implemented by the Population Council under a co-operative agreement with the US Agency for International Development (USAID). Horizons partners are the Alliance (which co-ordinated the current study as part of this partnership), the International Centre for Research on Women (ICRW), the Programme for Appropriate Technology in Health (Path), Tulane University, Family Health International (FHI), and Johns Hopkins University.

Section 1: Setting the scene

1.2 Sharing experiences with others: developing a handbook

Assessing the needs

Mobilising NGOs, CBOs and PLHA Groups for Improving Access to HIV/AIDS-Related Treatment – A Handbook of Information, Tools and other Resources

(the Handbook) was developed as a collaborative project of the World Health Organization – Department of Essential Drugs and Medicines Policy (WHO – EDM), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Alliance. Building on its extensive experience with community-based participatory approaches and working with NGOs, CBOs and PLHA groups, the Alliance led the development of the Handbook with the support of WHO – EDM and UNAIDS.

As background research to developing this resource, the Alliance carried out needs assessments on access to HIV/AIDS-related treatment in India, Zambia and Côte d'Ivoire. These included participatory activities, questionnaires and interviews covering topics such as attitudes to treatment and availability of drugs, and involved a broad range of local stakeholders, including NGO staff and health care workers, as well as national leaders and international agencies.

The assessments were a challenge, requiring a blend of various appraisal techniques to find out what people knew about HIV/AIDS-related treatments, what they wanted from treatment services, what they thought constituted good practice in treatment, what role NGOs, CBOs and PLHA groups thought they should have and what their priorities were for getting involved with and sustaining treatment. The tools used in the assessments were published by the Alliance as a ***Facilitator's Guide for Needs Assessment on Access to HIV/AIDS-Related Treatment***.

Field testing the Handbook

The draft Handbook was field tested with NGOs, CBOs and PLHA groups through workshops in India, Zambia, Cambodia and the Philippines. The Alliance's experience with these workshops showed that a participatory approach worked well by allowing people to share their knowledge and build on it through training inputs.

Through the process of field testing, what had been conceived originally as a simple toolkit on access to treatment evolved into a more comprehensive handbook designed to help NGOs, CBOs and PLHA groups make better decisions about improving access to treatment and address gaps. NGOs, CBOs and PLHA groups who had been delivering prevention and support services often became involved in treatment simply in response to demand – they saw a need and tried to meet it. Although some of the personnel involved had medical skills, they were faced with unfamiliar tasks when it came to sourcing and providing supplies of medicines. Communities and people with HIV also needed to improve their 'treatment literacy', developing a clearer understanding about medicines, what they can do and how they should be used, as well as how to improve access to them.

Section 1: Setting the scene

1.3 Summary of lessons learned on improving access to HIV/AIDS-related treatment

The experience of the Alliance and its partners has shown that improving access to treatment is about ensuring that treatment responses:

- aim to reduce the stigma and discrimination that still persists around HIV/AIDS
- occur within approaches of **comprehensive care**, linking to other HIV/AIDS efforts such as HIV prevention and psycho-social support. Responses should also be situated within a **continuum of care**, involving effective communication of information, support and resources between a range of sectors and people, including people with HIV, communities and government
- are based upon appropriate **attitudes, skills and behaviours** of those providing and receiving treatment, and ensure an ethical approach to treatment
- ensure the provision of accurate, up-to-date and accessible **information**
- ensure available and **accessible treatment and prevention services, and commodities**; wherever possible **integrating existing services** so as to make the best use of scarce resources
- actively involve **people with HIV, their families, community members and leaders**
- are, where appropriate, adapted to the needs of **specific populations**, particularly those who are marginalised by society
- have their foundations in the **assessed needs** of the community, organisation and policy environment
- are based upon strong, **strategic decisions** by organisations, followed by careful monitoring and adaptation of their work.

The experience of the Alliance and its partners has shown that improving access to treatment also requires ensuring that treatment and prevention services, and commodities are better managed at all levels. This will mean:

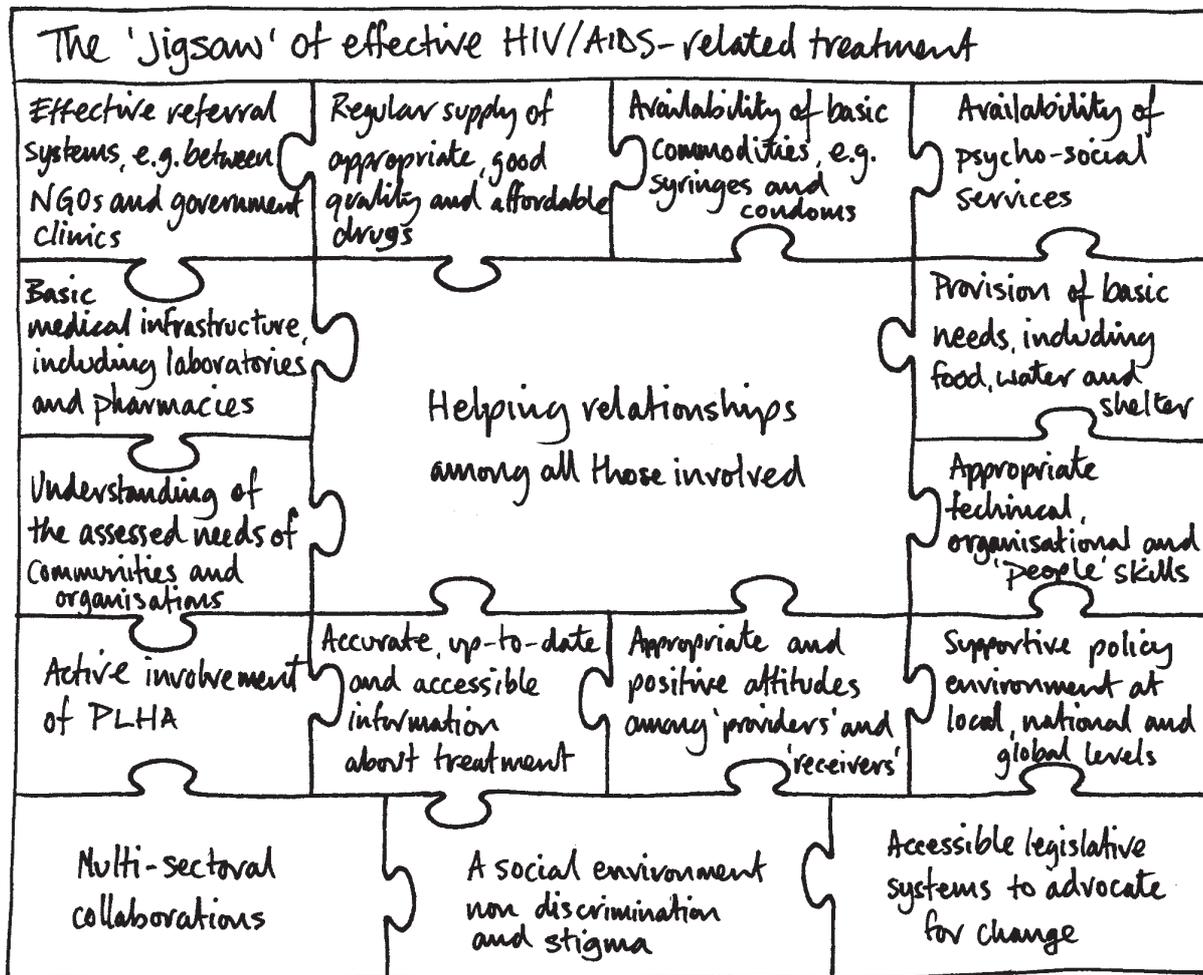
- **guidance for choosing treatment and prevention strategies that are evidence-based and relevant to the people and communities** who will take part, keeping patients, medical workers, families, and local communities central to the strategies and supporting them with sound policies and action from governments, non-governmental or civil society groups and international organisations
- **building and maintaining skills** for managing procurement and supply of medicines and other commodities so that availability, accessibility and cost-effectiveness are sustained

Section 1: Setting the scene

- **building and maintaining skills for the networks of helping relationships** that both support access to treatment and encourage its success, by keeping those who need treatment central to assessing, planning, implementing and evaluating the work that needs to be done. If this is achieved, good management is accepted as worthwhile and treatment or prevention planning focuses on realistic and achievable interventions.

Section 2: Good practice in HIV/AIDS-related treatment

Introduction: safe and effective HIV/AIDS-related treatment



Safe and effective treatment for any kind of disease requires that technical interventions should not be harmful and should be used in ways that achieve the best advantage for the patient – the person who receives treatment. Safe and effective HIV/AIDS-related treatment is a process involving a variety of elements. **Ensuring access to safe and effective HIV/AIDS-related treatment is not just a question of one action, one service or one policy.** It is not, for example, just about providing drugs. Each element is a vital aspect of good practice around HIV/AIDS-related treatment. **However, only when combined together does each element of the 'jigsaw' add up to give the complete picture of safe and effective HIV/AIDS-related treatment.**

During the assessment and development phase of the Handbook, NGO, CBO and PLHA group participants strongly agreed that 'helping relationships' (see Section 2.1) were central to safe and effective treatment. When the importance of these helping relationships is understood, it is possible to identify further what are the knowledge, skills and attitudes that are required for good treatment, and what other elements need to be in place to support them and help them remove the barriers to safe and effective treatment.

Section 2: Good practice in HIV/AIDS-related treatment

There are a number of key points to remember about making treatment effective and safe.

✓ Treatment should be defined in the context of care and support

Different people have different understandings about what treatment is, so planning for treatment should include finding out what are the expectations for treatment and what other elements of care and support are required alongside any medical interventions.

Viewpoints

"Care and support are very much related to treatment - helping people to have well being by preventing suffering, disease, discrimination."

"Social support makes a better environment for the patient to live with HIV, helping families to plan for the future and avoid problems such as selling their house and land to pay for treatment, becoming homeless and destitute as a result."

"If we say we want to help the patient get a better quality of life, we also have to talk about prevention - of OIs [opportunistic infections], of how HIV/AIDS-related disease can be transmitted, of reducing exposure of others through sex."

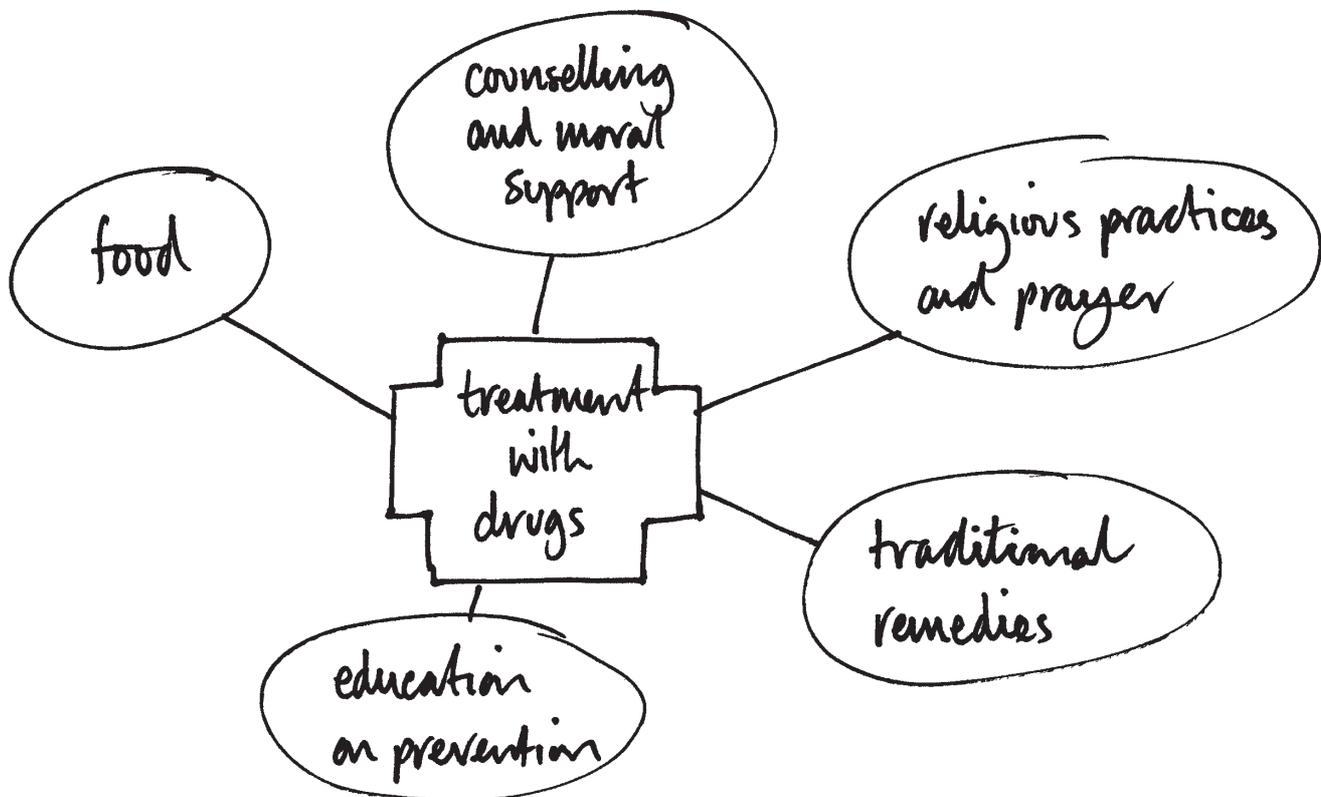
Comments on the relationship between treatment care and support from participants at the workshop on access to HIV/AIDS-related treatment, KHANA and the Alliance, Cambodia, May 2001.

Section 2: Good practice in HIV/AIDS-related treatment

✓ Treatment with medicines does not work in isolation

Treatment must be supported by other elements of care and support, and related to the environment in which it is delivered. At the workshop in Cambodia on access to HIV/AIDS-related treatment, hosted by the Alliance and its LO, KHANA, participants drew a diagram (see below) to show that in order for treatment with drugs to be effective it should be combined with and supported by other elements of care and support, such as food and counselling.

Diagram from the workshop in Cambodia



Section 2: Good practice in HIV/AIDS-related treatment

✓ Treatment and prevention are interlinked

Treatment and prevention of TB and HIV/AIDS-related infections are interlinked from a clinical perspective: treatment reduces morbidity and deaths but also reduces exposure of uninfected people to infectious organisms. This is also true in terms of other HIV/AIDS-related conditions. In Cambodia, people with HIV found that their overall well being improved due to the visits from the home care teams supported by KHANA. Their families spent less money on medicines and had to make fewer visits to hospital. In addition, neighbours, friends and family members came to understand more about HIV and to be less afraid of the virus. There was less stigma and discrimination around HIV/AIDS in the community, making it easier to educate on HIV prevention. In some settings, provision of VCT facilities attracted people for testing, but also revealed that if treatment facilities were available, more people were willing to be tested and to return to hear their results.

Again, in prevention of mother-to-child transmission (MTCT), drug treatment is a key measure to prevent the baby acquiring HIV infection. But it requires attention also to the mother's health and nutrition, to breastfeeding practices and to health and social support for mother and infant after birth.

✓ Good referral networks and procedures are required to sustain safe and effective treatment

No single organisation or treatment facility can hope to meet all of the needs of people with HIV. Knowledge, skills and resources are required in many different areas for a quality people with HIV-centered treatment. It is vital, therefore, to form networks with people and organisations who can ensure that safe and effective treatment is accessible to people with HIV. This will involve an assessment of what treatment people with HIV want, what resources and services are already available to them and who is involved in providing and supporting safe and effective HIV/AIDS-related treatment.

The following section takes a closer look at some examples of good practice for safe and effective HIV/AIDS-related treatment.

Section 2: Good practice in HIV/AIDS-related treatment

2.1 Attitudes and behaviours for safe and effective treatment

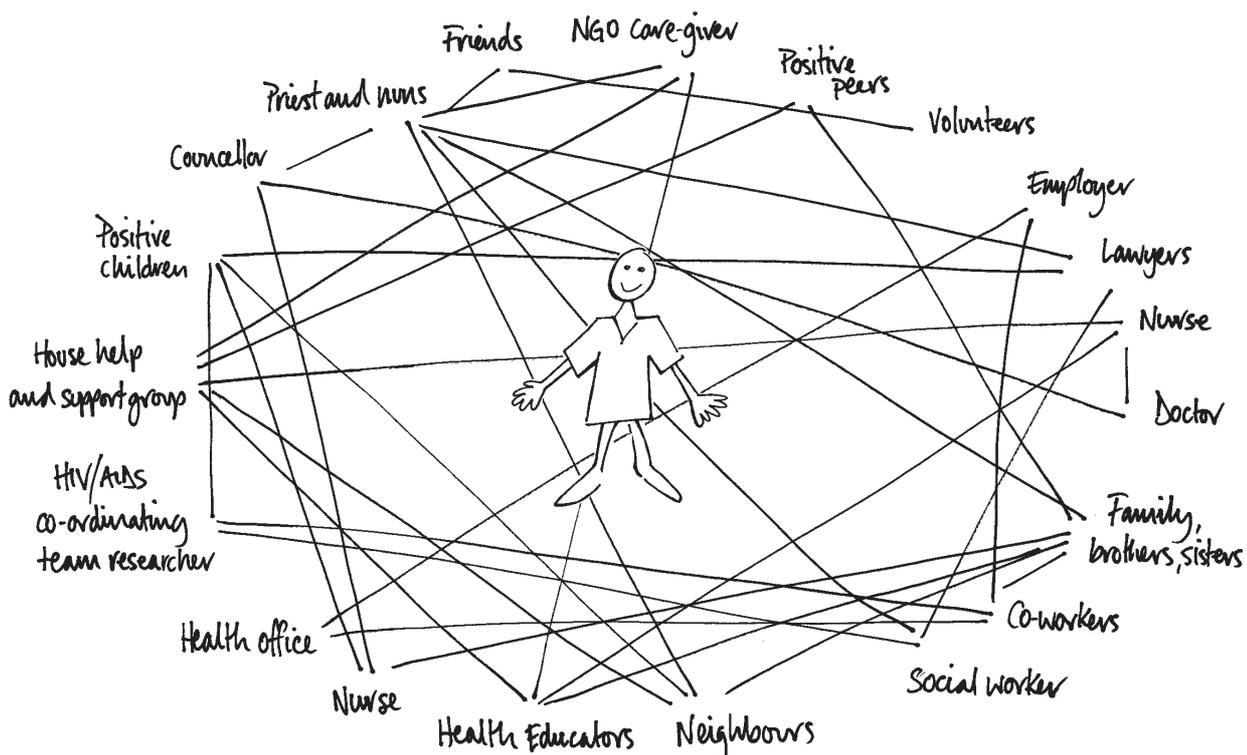
For safe and effective HIV/AIDS-related treatment, it is vital that people treat themselves and others in a helpful and responsible way. Therefore, **the attitudes and behaviours of those both providing and receiving treatment are crucial if treatment is to be safe and effective.** Even medicines need a supportive environment in which to work well.

At the heart of these attitudes and behaviours lies the **'helping relationship'**. This aims to respond to the needs of people with HIV seeking treatment and to improve the quality of their lives. It is a two-way process, with both parties being open and co-operative within a dynamic of trust and respect.

The helping relationship does not only occur between doctors and patients. It is also necessary among others involved in treatment, including family members, pharmacists, counsellors, church members and neighbours. At the workshop on involving people with HIV for improving access to HIV/AIDS-related treatment in the Philippines, hosted by the Alliance and its LO, the Philippines HIV/AIDS NGO Support Programme (PHANSuP), participants felt that rather than creating dependency syndromes, helping relationships are about developing inter-dependency, both between the recipients and providers and also among and between different providers.

The diagram below, drawn by participants during the Philippines workshop, shows the many different types of people that can become involved in helping relationships to improve the quality of life of people with HIV.

Diagram from the workshop in the Philippines



Section 2: Good practice in HIV/AIDS-related treatment

Those involved in treatment provision need to have the appropriate:

- ✓ **knowledge** – understanding and information about new treatments, side-effects of drugs, HIV transmission, nutrition, drug storage, positive living etc.
- ✓ **skills** – a good balance of technical and ‘people’ skills, such as active listening, counselling, selecting treatment, making referrals, monitoring the effects of drugs etc.
- ✓ **attitudes** – an approach that is honest and empowering for people with HIV, based upon compassion, tolerance, non-discrimination and common sense.

Of particular note: the attitudes of treatment providers can make a world of difference. For example, a care worker interviewed during the Alliance’s assessment of HIV/AIDS-related treatment in Zambia told of how people receiving the same medicines from a home-based care project and from a hospital were certain that the those provided by the home-based care project worked better because they were accompanied by caring and supportive attitudes.

Action on HIV/AIDS-related treatment needs to be carried out within an **ethical approach**. **Ethics are about a person’s code of behaviour, based upon the principles of doing no harm, minimising risk and empowering people to make their own choices**. They are particularly important within the context of HIV/AIDS-related treatment, which can often be a complex and controversial subject.

Where possible, an ethical approach should be developed in a participatory way, involving both providers and recipients of treatment. It is likely to involve attention to areas such as maintaining confidentiality, seeking non-discrimination and ensuring the equitable distribution of benefits as well as of difficult choices. For example, in its own work on improving access to ARVs, the Alliance supports approaches whereby selection criteria for ARV treatment programmes are developed in an inclusive manner, involving people with HIV and community members.

Putting ethics into everyday practice is vital for the effective provision of treatment. However, it is also important for NGOs, CBOs and PLHA groups to know the national legislative context in which their work is based. At the workshop on involving people with HIV for improving access to HIV/AIDS-related treatment in the Philippines, participants were encouraged to learn about their country’s constitution, Bill of Rights and national AIDS law, which outline concepts such as the right to health, equal protection under the law and non-discrimination on the basis of HIV status.



At the workshop in Zambia on access to HIV/AIDS-related treatment, hosted by the Catholic Diocese of Ndola and the Alliance, participants drew a diagram to describe the knowledge, skills and attitudes required by an ‘ideal’ treatment provider.

Section 2: Good practice in HIV/AIDS-related treatment

This photo depicts a role play, based upon the real experiences of people with HIV, which was used at the workshop on access to HIV/AIDS-related treatment hosted in Cambodia by KHANA and the Alliance to discuss the ethical issues around access to HIV/AIDS-related treatment. The participants, representing a home care worker, a person with HIV, a family member and neighbours, role play a situation in which the home care worker spreads news about a person's HIV status and expresses their dislike of that person by using derogatory language.



Comments from participants after the role play

- The home care worker does not maintain confidentiality; seems to blame the spouse; is impatient and does not describe how to use the medication.
- The worker does not listen to the person with HIV and fails to teach the spouse how to care for the patient, so the person with HIV does not trust the worker and feels oppressed.
- The person with HIV needs encouragement and support to understand the medicine they are being given and to keep taking it
- If the worker is afraid of HIV/AIDS, other people, including the family, will behave in the same way; for example, they will not want to touch the patient.

Viewpoints

"Helping relationships and treatment take teamwork!"

Participant at the Catholic Diocese of Ndola and Alliance workshop on improving access to HIV/AIDS-related treatment, Zambia.

"Giving treatment is about the person receiving the treatment. You should know the treatment and know the person if you want the treatment to be effective."

Cedric Fernandes, Michael's Care Home, India.

"This network of helping relationships identifies resources and helps to solve the problems."

Participant at the Catholic Diocese of Ndola and Alliance workshop on improving access to HIV/AIDS-related treatment, Zambia.

Section 2: Good practice in HIV/AIDS-related treatment

2.2 Treatment information

Good treatment information is essential for ensuring safe and effective HIV/AIDS-related treatment. If the information needs of patients, health workers, and carers are satisfied, they can co-operate with each other to ensure that appropriate treatments are made accessible and used to the best advantage of the patient. Without the right information for all concerned, there is risk of inappropriate treatment, treatment failure or no treatment at all. Experience with Alliance partners during the development of the Handbook showed awareness among NGOs, CBOs and PLHA groups that treatment information should cover a range of other questions alongside the medical ones.

Good treatment information includes a variety of elements. It is not just a question of ensuring that medical workers have treatment guidelines or prescribing and safety information about drugs, although these are essential. People with HIV will not seek treatment if they do not know that it is available – people with HIV, their carers and the medical workers need to be aware of available services before they can seek access or try to improve access to treatment. Prescribers can only prescribe in a useful way if they know what possible treatments can be chosen for patients.

Treatment Information Sheet

Basic information

What is the treatment called? (*may have more than one name...*)

How does the treatment help people living with HIV/AIDS?

Using the treatment

What form does the treatment take and how is it used? (*e.g. lotion to rub on skin, tablets to swallow...*)

How much of the treatment should you use at a time? (*e.g. two tablets, a teaspoon of syrup...*)

How often should you use the treatment? (*e.g. whenever you feel the need, twice a day...*)

How long should you use the treatment for? (*e.g. for one week, until the problem gets better, the rest of your life...*)

Do you need to do anything else to go with the treatment? (*e.g. drink lots of water, avoid eating when taking the treatment, eat special food...*)

Effects of the treatment

Can the treatment have harmful effects? If so, what are they?

What should you do if you suffer harmful effects from the treatment?

What do people who have used the treatment say about it – good and bad?

Obtaining the treatment

Where can you get the treatment?

How much does it cost in cash or goods?

Are there any extra costs for using the treatment? (*e.g. fees to the health care provider, buying other supplies such as dressings...*)

What will the total costs be for a complete course of the treatment or (for long-term treatment) per month or week?

What is the total when the cost of the treatment is added to any extra costs?

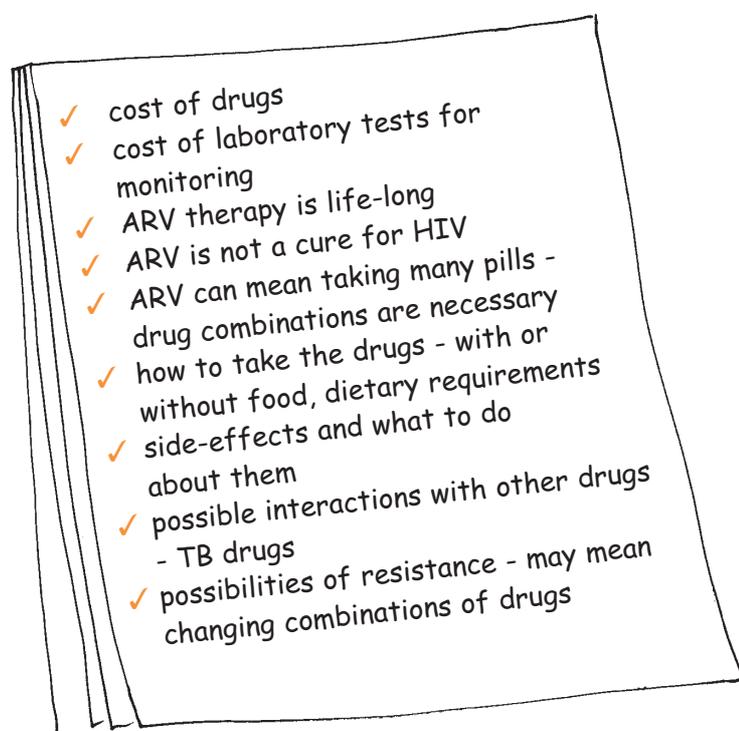
Is there any other information you should know about the treatment?

The treatment information sheet is an example of what good treatment information should include.

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Concordance – the willingness and informed co-operation between all involved in treatment – depends on each person knowing enough about what a treatment is, how it is likely to help, how it is used and what effects to expect from it (good and bad). They need to know how the treatment fits in with daily living, such as timing of drug doses or availability of food. They also need to know how to get the treatment and from where, whether supplies will be sufficient, what it costs, and what else is involved, such as transport, referrals and follow-up visits, or supplies, such as drugs, monitoring tests and dressings.

At the workshop on access to HIV/AIDS-related treatment hosted by India HIV/AIDS Alliance in February 2001, participants developed the following checklist of information that prescribers and patients need about ARV treatment:

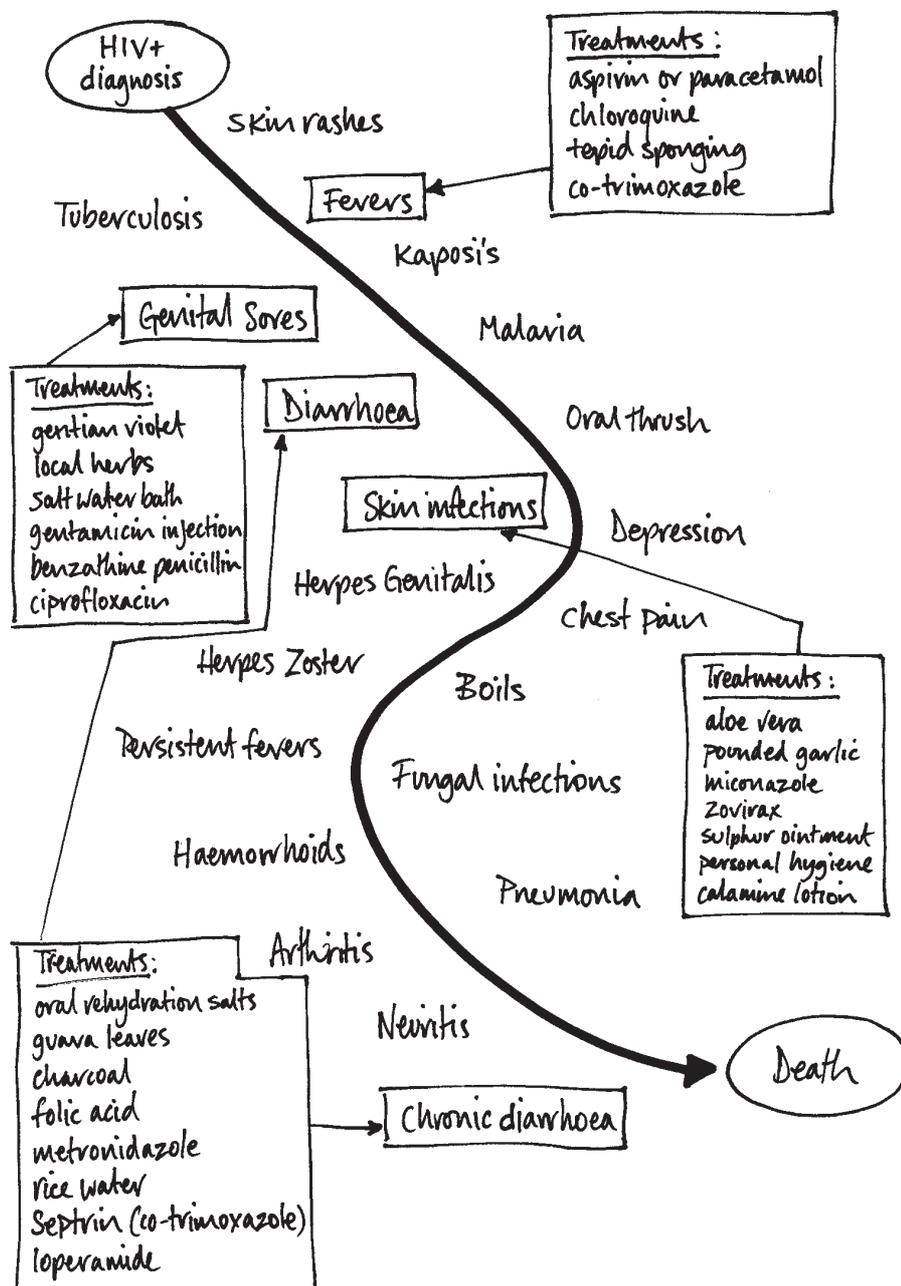


People already have some knowledge about illnesses and related treatments, but this information may not be entirely accurate. Treatment information is already 'resident' in many NGOs, CBOs and PLHA groups – members have acquired knowledge from their own and other people's experiences of illness and treatment. Also, their concern with the epidemic makes them receptive to information from the media, from outside sources and from medical workers who are part of their group or who provide advice to them. However, the information they have may be patchy or inaccurate. Knowledge gaps need to be filled, myths dispelled and accurate information clearly understood to ensure effective involvement in improving access to, and use of, treatment.

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At the workshop in Zambia on access to HIV/AIDS-related treatment, hosted by the Catholic Diocese of Ndola and the Alliance, participants from NGOs, CBOs and PLHA groups drew a lifeline identifying the different illnesses that a person with HIV/AIDS may experience and the treatments the participants knew for those illnesses. The lifeline showed that there is some knowledge about common illnesses and treatments, but it also helped to reveal the gaps. For example, not all treatments were named, some of those named are not effective and there was confusion between drug trade and generic names. Participants also discussed how there are many times in the life of a person with HIV/AIDS when there is no illness present, but preventive treatment would still be needed.

Example of lifeline from the workshop in Zambia



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2.3 Treatment for specific populations

Each person with HIV/AIDS leads a unique life, with a unique set of influences, needs and resources. Where possible, the provision of HIV/AIDS-related treatment needs to take this into account in terms of **responding to the individuality of those factors and being appropriate to the person in question.**

‘One size does not fit all.’ Indeed, ensuring that services are not only available but also appropriate is particularly important for groups that have unique needs as a result of being marginalised from society because of their gender, behaviour, profession or status. **Members of such groups may experience further barriers to accessing treatment on top of those already experienced by people with HIV.** For example, the Alliance’s assessment of HIV/AIDS-related treatment in India found that women complained of routinely coming second to their husbands in terms of access to care and treatment. Meanwhile, the Horizons diagnostic study on the involvement of people with HIV in Ecuador found that homosexual and bisexual men were deterred from accessing treatment due to discriminatory medical care. In the Ukraine, where the majority of HIV infections are among injecting drug users, these are largely excluded from access to ARVs because they are seen as unable to adhere to a complex regime of treatment.

When working with specific populations it is particularly vital that treatment work is based upon a helping relationship. It is also important that **treatment services are developed to respond to the actual needs of those they are meant to support.** For example, injecting drug users may need specific advice about how HIV/AIDS-related treatments might interact with other drugs that they use. Furthermore, in many cases it is necessary not to only respond to the expressed needs of the population in question but also to **address issues of discrimination among treatment providers, the broader community and the people with HIV themselves.** Even with the best of intentions, providing HIV/AIDS-related care and treatment for specific populations in a way that identifies them as members of a specific population is not always appropriate and can involve challenges, particularly in terms of potentially increasing their stigma and isolation. As with any treatment work, the approach needs to be holistic – responding to the person as a whole rather than as simply a medical diagnosis.

The Alliance and its partners are increasingly involved in treatment issues that affect children, both those affected by and those living with HIV. Children whose parents are HIV positive are often affected by the parents’ needs for treatment, which can impact upon family priorities and expenditure. For example, ***An Evaluation of the MoH/INGO Home Care Programme for People with HIV/AIDS in Cambodia*** found that in 40 per cent of supported families, the children had had to go without such things as food and books since the carer became sick, partly due to increased spending on medicines. In addition, children may find themselves as the primary carer of a family member, and therefore be responsible for delivering treatment on a daily basis. This raises both ethical and practical questions, such as how much responsibility should be given to children in terms of administering drugs and how treatment information should be conveyed to them.

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Children who are themselves living with HIV also have specific needs and challenges with regard to treatment. At the workshop on access to HIV/AIDS-related treatment in India, participants highlighted the fact that the size and dosage of drugs means that treatment is often not appropriate for children, and that services tend not to be 'child friendly'. The participants also shared that some organisations refuse to treat children who do not have parents or guardians.

Case study: Project CHILD, Committed Communities Development Trust (CCDT), India (Project CHILD participated in the Horizons diagnostic study on the involvement of people with HIV/AIDS in community-based prevention, care and support services)

Project CHILD of the Committed Communities Development Trust (CCDT) in Mumbai, India, works with children affected by and living with HIV/AIDS, including through a drop-in centre and a temporary shelter for six to eight year olds. As well as providing some basic treatment directly, it facilitates referrals for the children to the services of the local municipal health care system. Where necessary, it gives them financial support – either in full or on the basis of cost sharing – for the drugs for OIs.

Project CHILD's lessons include that HIV/AIDS-related treatment for children must, where possible, be planned with their family, and that decisions about how much support to give, including how many medicines, must be based upon assessing each individual case. They have also learned that it is vital not only to provide treatment to children but also to help them to cope with their illness, build life skills and access vocational guidance.

Viewpoints

"The ARV landscape in developing countries is evolving quickly. People with HIV are finding and using various routes to access – from buying drugs through the private and often unregulated sector to participation in trials, drug donation and recycling programmes. The lack of regulation, information and expertise is leading in many countries to problems with quality control and adherence, not to mention great inequity of access."

"The poorest people with HIV, including women and children and people from stigmatised groups, are least likely to gain access through any of the above routes. There is, therefore, a need to act fast to address this, both to prevent (further) drug resistance from building up and to improve equity of access."

Participants at the Alliance workshop on improving access to ARVs, United Kingdom

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2.4 Working with others

No one person, organisation or sector can ensure effective action on HIV/AIDS on their own. **Partnership is crucial, as it helps to ensure that efforts are complementary and mutually reinforcing. It also helps to ensure that the different resources of all those involved are put to best use.**

Partnership is particularly important for HIV/AIDS-related treatment work because providing it effectively requires a diverse range of perspectives, inputs and skills. **It can help to ensure both that more and better quality treatment is available and accessible to people with HIV, and also that efforts fit within existing health care systems, linking to a range of HIV/AIDS services such as VCT, TB, sexually transmitted infection (STI) and HIV prevention.** For example, while a clinic may be able to provide equipment and drugs, the delivery of treatment may depend upon a CBO to mobilise community members to use the services.

Partnerships can be developed among a **broad range of players**, ranging from PLHA groups, rural communities and church groups to pharmaceutical companies and donors to the media. For example, the Maharashtra Network of Positive People (MNP+) in India collaborates with the local government. This involves MNP+ providing teams of volunteers and counsellors who visit three to four government hospitals twice a week, provide support to people with HIV and raise awareness among health care workers.

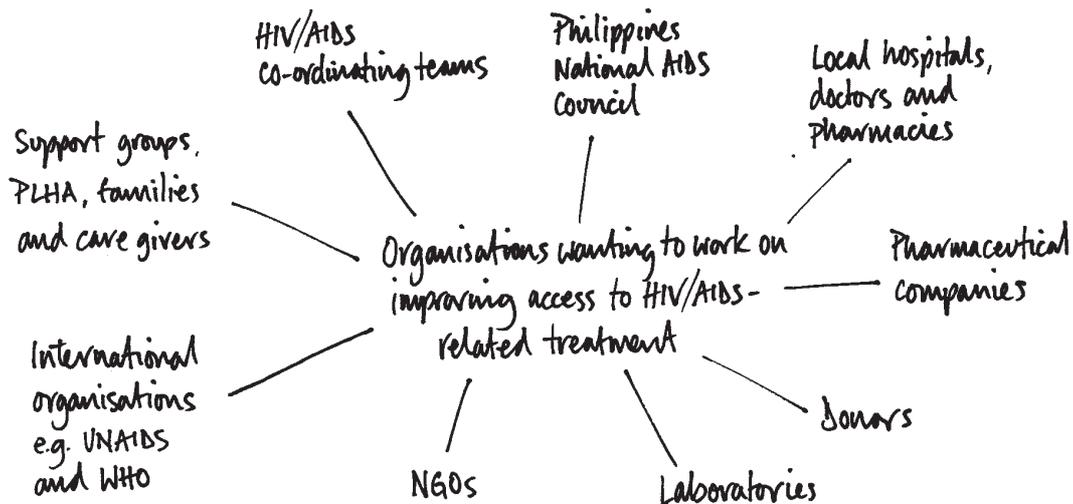
Meanwhile, the Alliance LO in Senegal, Alliance Nationale Contre le SIDA (ANCS), has helped to develop multi-sectoral *cellules* in five locations. These are run on a voluntary basis and managed by a committee of local people, including people with HIV, health professionals and social workers. They work closely with a network of health providers and community groups, including hospitals and community pharmacies, in order to provide people with HIV with as full a range of services as possible. In terms of treatment, while some *cellules* facilitate access to subsidised drugs from pharmacies or hospitals, others develop *comités de santé* – a type of local insurance scheme – whereby they buy generic drugs from the government's essential drugs list (EDL) and re-sell them to community members at a reduced, subsidised cost.

In particular, **partnerships can help organisations to be responsive in terms of adapting to the changing treatment environment and making the most of emerging opportunities.** However, they can also be very challenging, at times involving compromise and a great deal of commitment on both sides. Therefore, it is important that NGOs, CBOs and PLHA groups select their partners carefully, assessing the context in which they work and weighing up the pros and cons for their organisation and community. They also need to ensure that activities are planned in a participatory way, involving all relevant stakeholders and culminating in a formal agreement about what each party expects from one another and what they will each provide.

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Partnerships for access to HIV/AIDS-related treatment

At the workshop on involving people with HIV for improving access to HIV/AIDS-related treatment in the Philippines, participants identified the following organisations and sectors as key partners for ensuring better quality treatment.



Participants identified different partnerships that they could develop to involve people with HIV in improving access to treatment at different levels. This includes partnerships with treatment providers, peer support groups, NGOs, hospitals, religious organisations, local and national government departments, international donors, NGOs and networks of people with HIV, UN organisations, pharmaceutical companies, other businesses, and academic institutions. All of these partnerships working together can increase the involvement of people with HIV and improve access to HIV/AIDS-related treatment.

Case study: home care programme, Cambodia (programme supported by KHANA)

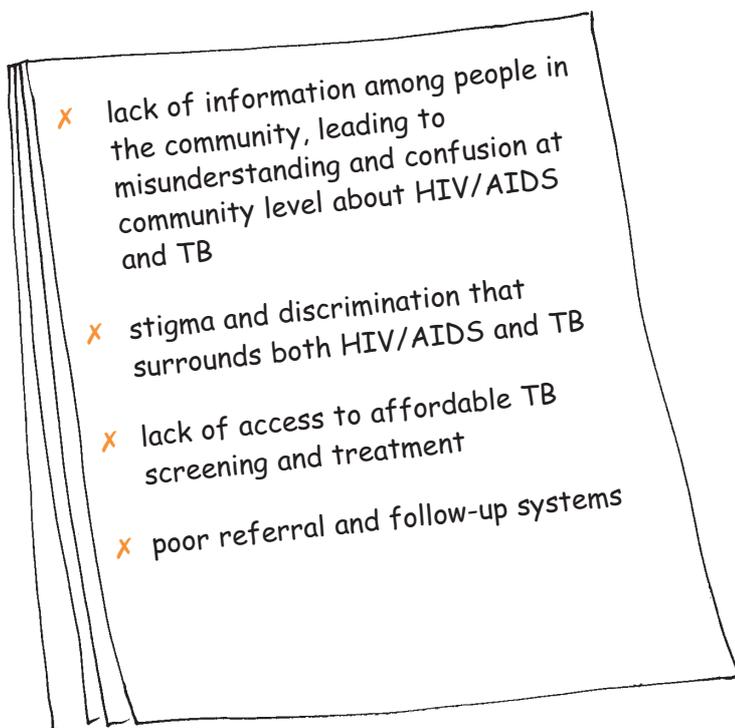
Cambodia has the highest prevalence of HIV in Asia, at an estimated 2.8 per cent. Since 1999, the Alliance LO in Cambodia, KHANA, has supported a home care programme. The programme now works in three provinces – Phnom Penh, Battambang and Siem Reap – and involves teams of three full-time NGO staff and two half-time government staff from the Ministry of Health. The teams are based in government health centres and work in local communities, providing services including clinical management, nursing and health education, counselling and social support. Each team has a recommended caseload of 80 patients and visits each one an average of three times per month.

In 2000, an evaluation of the programme found that the strong government–NGO partnership was central to the success of the project in terms of keeping costs down and maximising the comparative advantages of each player. It also found that people with HIV felt that the provision of medicines was one of the most important services provided by the teams, with 72 per cent reporting improvements in their well being and physical health. For example, a 30-year-old pregnant woman in Tonle Bassac said, "I was very weak when I found out that I had AIDS. I also became very depressed. The home care team gave me medicines and provided counselling. I now feel the same as other people."

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2.5 Integration of HIV/AIDS and TB services

Globally, levels of HIV and TB co-infection are high and continue to increase rapidly. UNAIDS and World Health Organization (WHO) data indicate that one third of all people with HIV have TB co-infection, and similarly that up to 70 per cent of TB cases are HIV positive. Globally, TB is the leading cause of death among people with HIV, indicating that TB detection and treatment may not be happening early enough. Preventing and treating TB can significantly improve the quality of life of people with HIV. Early detection and treatment of TB in people with HIV would lead to reduced morbidity and mortality, and would help control the spread of TB. In a regional consultation on exploring linkages between HIV/AIDS and TB services, hosted by the Alliance, participants from NGOs, CBOs and PLHA groups in Cambodia, India and Thailand identified barriers to early detection and treatment of TB in people with HIV as:



It seems that HIV/AIDS and TB services exist in parallel, and while both are struggling to address the needs of people with HIV, the TB epidemic continues to spread aggressively. If access to HIV/AIDS-related treatment is to be improved, clearly there is a need to exploit the synergies between HIV/AIDS and TB by integrating HIV/AIDS and TB services more effectively.

There are many examples of good practice of how NGOs are integrating HIV/AIDS and TB services. For example, the Alliance's LO in Cambodia, KHANA, has supported collaboration between the home care teams providing care and support to people with HIV and TB directly observed treatment schedule (DOTS) teams in Phnom Penh. Practically, this has meant that the home care teams provide education on TB to people with HIV and their families. The home care teams also collaborate with the National Centre for Tuberculosis and Leprosy Control (CENAT) to refer people with HIV for TB screening and treatment. However, home care teams

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report that one of the main reasons why people default on their TB treatment is because they cannot afford the cost of the treatment diagnostic and follow-up tests.

VCT also offers an important entry point for integrating HIV/AIDS and TB services. Kara Counselling and Training Trust (KCTT) (a Zambian NGO that participated in the Horizons diagnostic study), with support from WHO and UNAIDS, ran a pilot of the ProTEST initiative whereby VCT was used as an entry point for HIV/AIDS and TB prevention and care services. The ProTEST initiative's HIV/TB package provided community involvement, VCT, prevention and treatment of STIs and OIs. The aim of the ProTEST initiative was to increase access to VCT and improve HIV/AIDS and TB prevention and care.

Case study: Christian AIDS Ministry (a Thai NGO that participated in the consultation workshop 'Exploring the Linkages between HIV/AIDS and TB for Service Delivery', Cambodia, 2001)

The Christian AIDS Ministry began its work with people with HIV in 1993 and focuses mainly on pastoral care, including general care and support for families. The Christian AIDS Ministry carries out its work through clinics, home visits and community work.

Christian AIDS Ministry also provide care and support for people with HIV with OIs such as TB. TB patients and their families are visited in their homes by home care workers and are informed and educated about TB symptoms, prevention and treatment. This has helped to reduce the stigma attached to the disease. However, what has been found is that a number of HIV patients are resistant to TB drugs and the hospitals do not have the resources to fund the administration of further treatment.

Case study: SAHARA (implementing NGO in care and support programme supported by MAMTA, Alliance lead partner in Delhi)

India has the highest global burden of TB and approximately four million people with HIV. SAHARA is an NGO providing care and support to the people with HIV living in a poor, urban area (population 100,000) in northern India. SAHARA provides a range of services, which include VCT, treatment for OIs, counselling, nursing care, community outreach and income generation support.

SAHARA's HIV/AIDS-TB programme is jointly supported by the Government of India's National AIDS Control Organisation (NACO) and their TB Control Programme (RNTCP). With support from NACO and RNTCP, SAHARA now has an in-house TB clinic staffed by a doctor, nurse and counsellor. Materials (including regular supplies of drugs) and training support for the TB clinic are provided by NACO and RNTCP. Additionally, the partnership with government helps to ensure efficient and timely diagnosis and referral to specialist services such as the TB hospital. Community outreach is used to increase awareness in the community about HIV/AIDS and TB. Currently, patients undergoing treatment for TB come to the clinic to be observed taking their TB drugs. However, as the caseload increases, community monitors will be trained to observe patients taking their treatment in their own homes.

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Viewpoint

"Advocating for free TB diagnosis and treatment for people with HIV and TB prophylaxis for people with HIV is a priority."

Dr. Tith Khimuy, Programme Manager, KHANA, Cambodia

2.6 Involving people with HIV to improve access to HIV/AIDS-related treatment

People with HIV are not just the passive 'recipients' of treatment. They can also be participants, providers, educators, managers, planners, evaluators and advocates.

The involvement of people with HIV as individuals or as members of support groups has become an important principle in the work of the Alliance and its partners, and was the subject of the Horizons diagnostic study on the involvement of people with HIV in the delivery of community-based prevention, care and support services in Burkina Faso, Ecuador, India and Zambia. In Ecuador, for example, the study found that people with HIV gained many tangible benefits from involvement in NGOs and CBOs, including more and better access to medicines due to increased contacts and access to up-to-date information. In Zambia, the study found that at the Salvation Army's Chikankata Health Services, involvement in the care and prevention teams (CPTs) had helped people with HIV to identify infections at an early stage and seek medical attention as soon as they became sick. For example, an HIV-positive member of a CPT said: *"My health has really improved because I have now learnt how to look after myself properly. I used to be sickly, I was in and out of hospital...but now my health has really improved...I know how to prevent some of these opportunistic diseases."*

The Alliance has also learned that **the benefits of the involvement of people with HIV go beyond those directly related to individuals. Indeed, people with HIV have much to 'give' to the development of treatment services, especially in terms of ensuring that they are relevant, credible and people with HIV-friendly.** For example, the involvement of some 120 people with HIV in the evaluation of the Ministry of Health/NGO Home Care Programme in Cambodia proved invaluable, helping to identify the strengths of the initiative and relevant next steps, such as building partnerships with TB services and expanding the use of community volunteers.

The Alliance has also seen that people with HIV have a crucial role to play as **service providers and advocates**, as they can combine technical knowledge with their unique, first-hand experiences; for example, of side effects and drug adherence. With REVS+ in Burkina Faso (see p.31) and the multi-sectoral *cellules* in Senegal (see p.24), **people with HIV are involved in a broad range of capacities, from 'hands on' prevention and care services to increasing the 'treatment literacy' of those involved, including health care professionals.**

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The experiences of such groups have taught the Alliance that **it is vital for people with HIV to be involved in all aspects of the design, implementation and evaluation of programmes to improve access to HIV/AIDS-related treatment.** It has also shown that people with HIV need to be supported to find a **'pathway to involvement'** that suits their individual interests, needs and skills. While some may wish to focus upon a pathway as an individual, others may choose to be involved by becoming a member of a self-help group or a CBO or NGO. Equally, it is important for NGOs and CBOs to follow a pathway to involvement to understand how to involve people with HIV and how best to support this process.

Pathways to people with HIV involvement

At the workshop on involving people with HIV in improving access to HIV/AIDS-related treatment, participants explored the potential roles of people with HIV in HIV/AIDS-related treatment work in the Philippines. They started by drawing a chart showing some of the kind of roles that people with HIV might play and the advantages and disadvantages of each kind of involvement, as shown by the following example.

| Potential roles of PLHA in treatment work | Advantages of PLHA getting involved | Disadvantages of PLHA getting involved |
|---|---|---|
| Counselling or information, education and communication about treatment | <ul style="list-style-type: none"> • PLHA have first-hand experience • They can be positive role models | <ul style="list-style-type: none"> • PLHA might get too personally involved • If not trained adequately, can result in wrong information being passed on |
| Giving palliative care | <ul style="list-style-type: none"> • PLHA can provide more empathetic treatment because they can relate to the issues | <ul style="list-style-type: none"> • Can result in dependency on the PLHA • PLHA can burn out due to excessive workload or due to a 'mirror effect', whereby an asymptomatic carer can over-identify with the already symptomatic patient |
| Doing advocacy, including with medical staff | <ul style="list-style-type: none"> • PLHA can speak from personal experience and with degree of authority, which can have a positive impact • Their involvement provides an opportunity for dialogue to understand perspectives from both sides | |



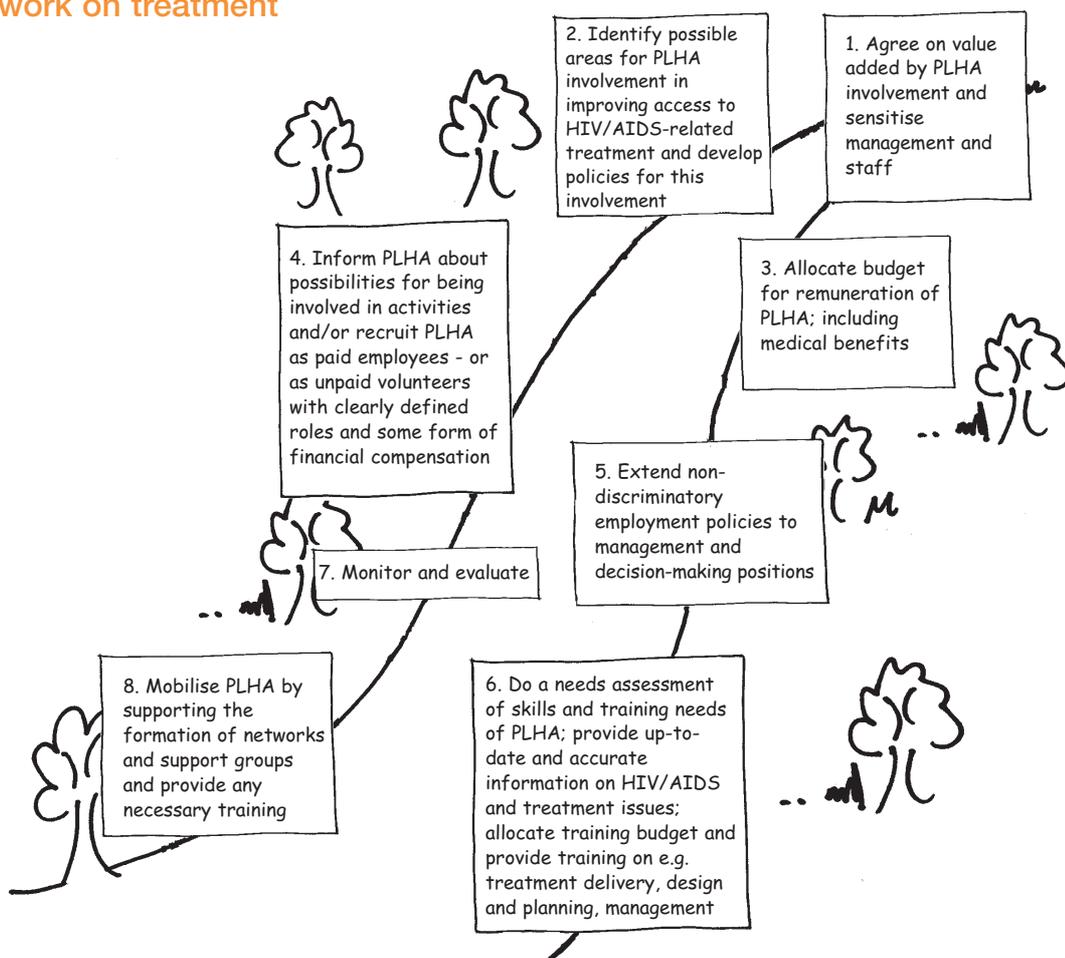
Following that, the participants discussed the steps necessary for individual people with HIV to take to become involved in improving access to HIV/AIDS-related treatment, as well as the steps for NGOs and CBOs to take to involve people with HIV in their work.

Participants in the workshop on involving people with HIV in access to HIV/AIDS-related treatment exploring pathways to involvement.

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The following 'pathway' for NGOs and CBOs to involve people with HIV in improving access to HIV/AIDS-related treatment has been adapted from the results of this exercise and also incorporates some of the learning from the Horizons/Alliance diagnostic study on the involvement of people with HIV/AIDS in community-based prevention, care and support services.

An example of a pathway to involving PLHA in CBO's/NGO's work on treatment



The Alliance and its partners have also seen that involvement must be carried out in a planned, sensitive and responsible manner. Involvement must not expose people with HIV to further stigma and breaches of confidentiality or create dependency, either of people with HIV on NGOs and CBOs or of medical staff on PLHA support groups. It is also crucial that an ethical approach is maintained throughout; for example, in terms of **ensuring that people with HIV are treated both respectfully and supportively**. For instance, the Copperbelt Health Education Project (CHEP) in Zambia has learned that if people with HIV are to carry out their vital work – including raising the profile of people with HIV in the organisation and serving as a role model for community members – they need to be offered a package of support. In practice, this includes medical insurance and treatment costs, alongside a salary, transport and training.

Indeed, the Horizons diagnostic study in Zambia concluded that: “NGOs should make sure that people with HIV involved in their activities can be treated at least for opportunistic infections, otherwise their involvement cannot be sustainable.”

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Meanwhile, a key conclusion of the study in Burkina Faso was that access to treatment, particularly ARVs, was a major motivation for people with HIV to become involved in NGOs and CBOs. Another conclusion was that NGOs and CBOs need to prepare themselves for their potential role in providing or facilitating ARVs; a process which should involve people with HIV in developing criteria for the selection of beneficiaries. However, CBOs, NGOs and PLHA groups will need to plan so that they can cope effectively with increased demand on their services. As a member of REVS+ put it: *"I can assure you that once REVS+ has tritherapy [ARVs]...it will be packed with people here, people will be queuing up."*

Case study: REVS+, Burkina Faso (one of the organisations supported by IPC and a partner in the Horizons diagnostic study on the involvement of people with HIV)

Responsabilité, Espoir, Vie et Solidarité + (REVS+) is based in Bobo-Dioulasso and supported by IPC, the Alliance LO in Burkina Faso. It serves over 150 adults and 80 OVCs, with 40 per cent of its members being people with HIV.

REVS+ mobilises people with HIV to volunteer for a broad range of HIV/AIDS activities, including treatment work, testing and social support. They do not receive payment, but work on the basis of the NGO's slogan of 'support and be supported', with REVS+ offering them support such as medication to treat OIs, either in the hospital or at their office.

REVS+ has encouraged people with HIV to become actively involved in selecting and managing their own treatment, which in turn has helped to increase acceptance and understanding about treatment among medical professionals, the public and community leaders. The organisation has also become a local and national leader in HIV/AIDS advocacy. For example, it has lobbied the authorities and local health structures to apply the government decree that public sector care should be free for people with certain illnesses, including HIV infection. Bobo-Dioulasso is currently the only place in the country where the decree is applied.

The future challenges of the organisation include the high costs of medical supplies for OIs and the increasing demands from community members for ARVs. As members put it:

"People say that REVS+ is a CBO of people with HIV and so we must have medicines. When they realise that we ourselves never get to see these products, they back down."

"Antiretroviral therapy: we see them, we feel them, but we cannot touch them."



Members of REVS+ during an HIV/AIDS-awareness-raising campaign.

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2.7 Involving communities

Mobilising and involving communities lies at the heart of the work of the Alliance and its partners to support community action on HIV/AIDS in developing countries. **Involving local people and leaders is crucial to improving access to HIV/AIDS-related treatment. This is because it helps to address issues of stigma and discrimination, to ensure that responses are appropriate and that scarce resources are put to best use.** For example, community members can help to ensure that efforts complement local cultural and health-seeking practices, and that NGOs, CBOs and PLHA groups are not duplicating services that are already available.

Communities can be involved in HIV/AIDS-related treatment work in a number of different ways. They can, for example, **participate in community assessments to identify local needs and resources, and regular monitoring meetings to assess progress.** They can also **provide vital support to the running of NGOs, CBOs and PLHA groups;** for example, with community members participating in management committees or contributing resources such as venues and equipment.

Community members have a particularly vital role to play as **home-based carers for people with HIV and volunteers with NGOs and CBOs.** For example, the Salvation Army in Mumbai, India, includes volunteers in its community-based teams that work in 11 locations throughout the city, providing support to people with HIV and referring them to local clinics for treatment. Meanwhile, each of the home care teams of the Ministry of Health/NGO Programme in Cambodia involves five community volunteers, including village leaders, students and professionals. They are recruited from the community in which they live and provide a major source of referrals of new patients, as well as facilitating links with community activities. The evaluation of the programme concluded that the work done by the community volunteers – which involves providing ongoing psycho-social support to people with HIV and their families – enables the medical professionals in the teams to focus on providing treatment. It also found that the volunteers had good relationships with traditional healers and were able to break down the mutual mistrust between traditional and orthodox medical practitioners.

Above all, the Alliance has learned that **it is important to involve communities in a way that is genuine and respectful, rather than tokenistic or intrusive.** In practice, this involves respecting local traditions and ways of working, while also sharing new methodologies and information; for example, about advances in available treatments.

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Case study: Seva Nilayam, India (an implementing NGO in the care and support programme supported by PWDS, Alliance lead partner in Tamil Nadu)

Seva Nilayam is a community health and development organisation in Tamil Nadu that provides high quality and low cost health services for TB, HIV/AIDS and community health care. Throughout its work, it has emphasised involving the local community, including through supporting self-help groups for poor women. By involving more people, expanding its services and reducing its costs, it has experienced an increase in its success rate for treating patients.

Seva Nilayam's lessons include that mutual trust is essential for involving the community; that previously treated patients can be effective DOTS providers; and that immediate attention to drug compliance can reduce defaulters. They have also learned that it is vital to maintain confidentiality in all aspects of their treatment work with the community, and that it is equally vital to provide continuous education and follow-up for home care providers, including about issues relating to drugs.

With the rapidly changing political and economic climate around the provision of ARVs in resource-poor settings, **'community preparedness' for ARVs is essential.** This involves an ongoing process of understanding community beliefs and needs around the drugs, facilitating community dialogue, carrying out consumer education on HIV/AIDS-related treatment and monitoring and evaluation. Central to 'community preparedness' is the involvement of members of the community, including people with HIV. It will also involve fostering active collaboration among diverse local stakeholders, including those outside of the health sector, and maximising the potential role of NGOs, CBOs, PLHA groups and the church in building relevant community-level knowledge, understanding and skills.

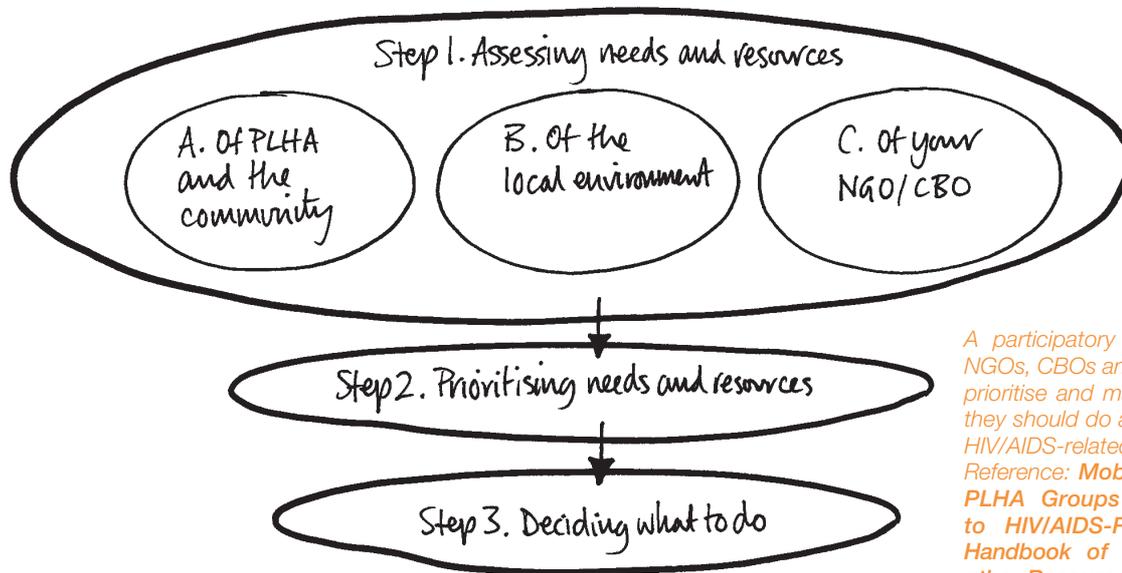
Viewpoints

"It is important to have an understanding about community norms, values and beliefs about ARV treatment if an ARV treatment programme is to be successful. There is also an immediate need for communities to have information about ARV treatment that is easy to understand, objective and accurate. There needs to be community dialogue about ARVs so that a clear understanding of the issues can be developed. Communities should also have a role in the monitoring and evaluation of an ARV treatment programme. Community preparedness will contribute to increasing understanding of adherence issues. It can also be a way of understanding what the community can contribute towards an ARV treatment programme."

International HIV/AIDS Alliance, **Technical Guidance Note (draft) Access to Anti-Retrovirals**, Zambia, April 2002

Section 2: Good practice in HIV/AIDS-related treatment

2.8 Assessment, decision-making and keeping track of work

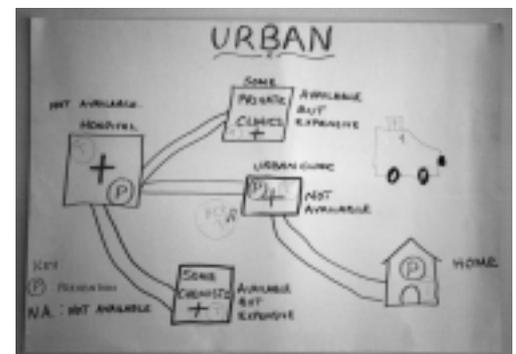


A participatory process that can assist NGOs, CBOs and PLHA groups to assess, prioritise and make decisions about what they should do about improving access to HIV/AIDS-related treatment.
Reference: *Mobilising NGOs, CBOs and PLHA Groups for Improving Access to HIV/AIDS-Related Treatment – A Handbook of Information, Tools and other Resources.*

Responses to HIV/AIDS are most effective when based upon an assessment of the needs and resources of those involved. Ensuring access to safe and effective HIV/AIDS-related treatment is no exception.

Assessments provide an opportunity for organisations to mobilise their local community and find out about local needs and resources. They can help organisations to gain a realistic understanding of the context of their work and to go on to make good, strategic decisions about the best way forward. It is vital that those who are directly in need of services, particularly people with HIV, are active participants rather than the 'objects' of assessments on HIV/AIDS-related treatment. It is also important that assessments are carried out regularly, so that organisations can identify and respond to changing needs and circumstances.

Assessment of treatment needs and resources of people with HIV and the community should include people with HIV, families, carers, traditional healers, spiritual leaders and community leaders, and can look at issues such as the needs of people with HIV, where people get treatment and how people with HIV use treatment. Groups can use a **community mapping** tool to identify the variety of locations in their local area where people can access different types of treatments. For example, in Zambia, during the workshop on access to HIV/AIDS-related treatment, participants mapped out the availability of TB treatment in an urban area.

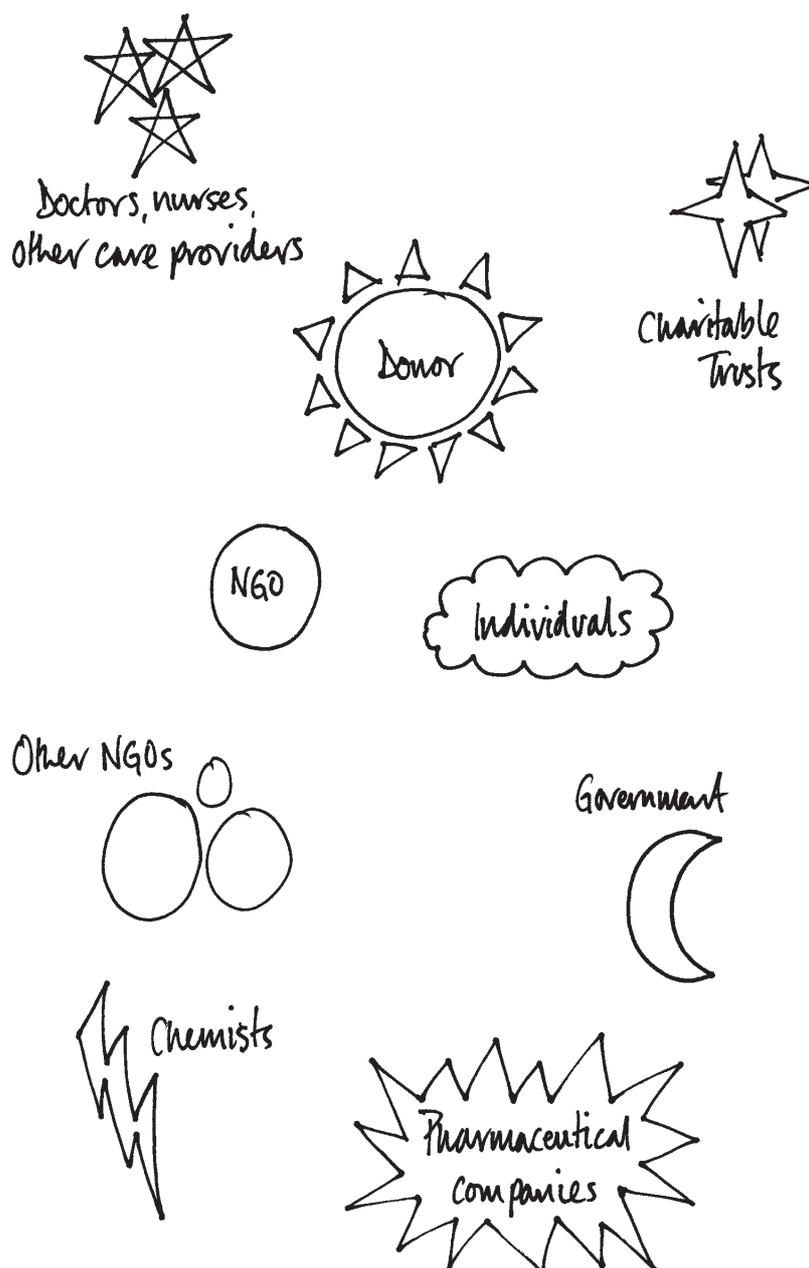


An example from Zambia showing the availability of TB treatment in an urban area.

Section 2: Good practice in HIV/AIDS-related treatment

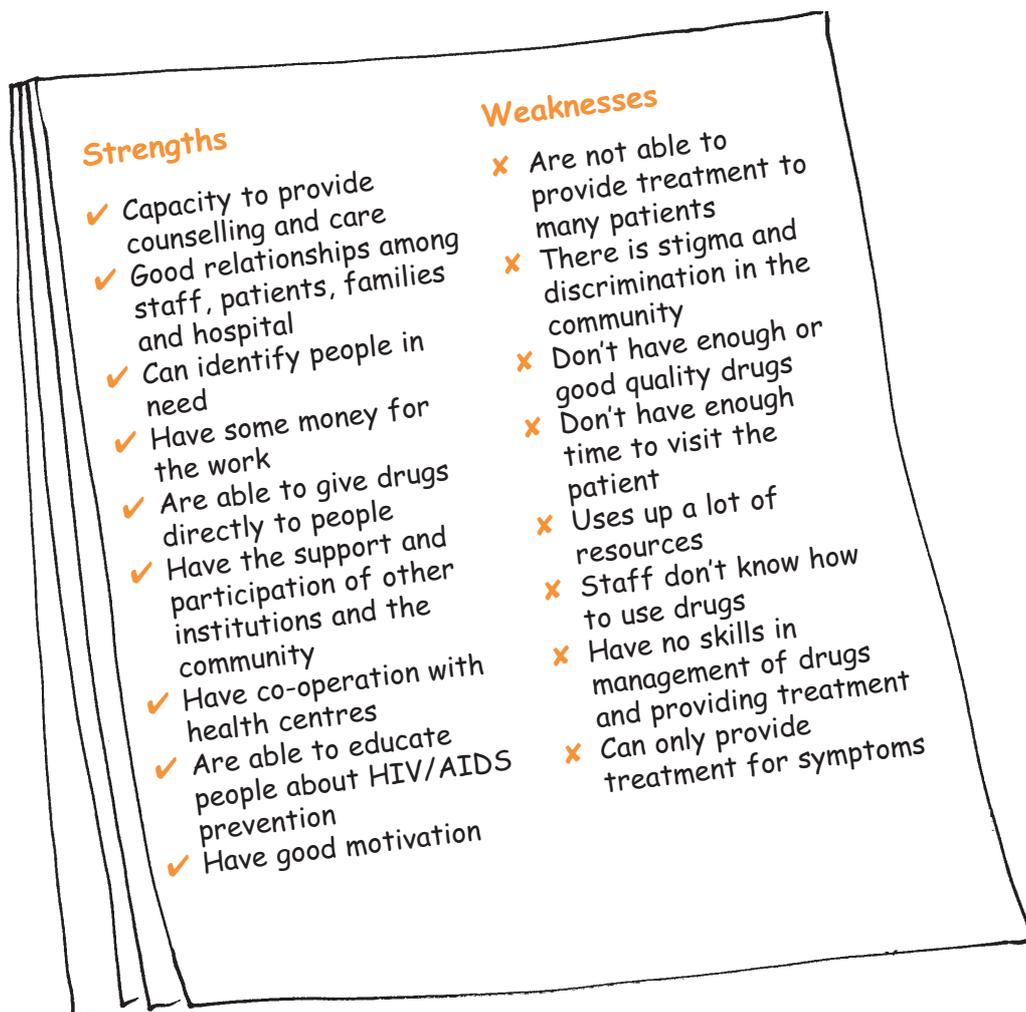
Assessment of needs and resources in the local environment should include other NGOs, government, donors and doctors, and can look at issues such as who is involved in HIV/AIDS-related treatment, what services other organisations provide and how effective their work is. Groups can use a **universe map** to identify the other organisations involved in treatment work and their relationships with each other. For example, in India, during the workshop on access to HIV/AIDS-related treatment, participants drew a map to show the key players in treatment work for HIV-positive women in a slum area.

Map from the workshop in India



Section 2: Good practice in HIV/AIDS-related treatment

Assessment of an NGO, CBO, or PLHA group should involve the organisation's staff, volunteers, people with HIV, trustees and management committee, and can look at issues such as how treatment fits with the group's mission, what resources it has and how current programmes might support future work on treatment. Groups can use a **strengths and weaknesses chart** to identify their relevant skills and resources. For example, in Cambodia, during the workshop on access to HIV/AIDS-related treatment, participants drew up this chart to summarise the combined strengths and weaknesses of all of their NGOs and CBOs.



Having carried out an assessment, it is vital that an organisation **thinks carefully and strategically about what treatment work it can and wants to carry out**. This process involves weighing up everything that it knows about the different levels of need, identifying gaps and priorities, and developing a realistic plan of action. The organisation can base this process upon the types of strategic planning and project cycle that it is used to, ensuring that any new areas of work are carefully integrated into its overall vision and work plan. This is a vital part of the process of finding a balance with other areas of the organisation's work, as well as the most natural and effective 'entry point' for treatment work; for example, through VCT, PLHA groups or home-based care.

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There are some specific issues to consider when planning HIV/AIDS-related treatment work. For example, considering the risks of short courses of certain treatments, the Alliance encourages partners to commit to providing access to treatment for at least a minimum period, while seeing sustainable life-long access to ARVs as an additional, long-term goal. It is also important for organisations to address internal issues about HIV/AIDS-related treatment. For example, the Alliance has developed its own HIV/AIDS in the workplace and medical benefits policies, and is supporting its LOs in Cambodia and Senegal to develop HIV/AIDS in the workplace and medical benefits policies for their own staff. The policies will contribute to creating a favourable and non-discriminatory workplace environment and help to compensate for existing discriminatory practices of the private health insurance sector. This approach combines ensuring access to treatment with addressing the social dimension of HIV/AIDS, including the broader questions of stigma and discrimination.

Once an organisation has decided what type of work to do, it needs to **inform others and to plug into relevant networks in order to exchange lessons and work towards a complementary approach**. Once it has started its work, the organisation also needs to monitor its efforts, assessing its results and achievements against realistic indicators. It also needs to review its efforts on a regular basis in order to respond to the rapidly changing treatment landscape and avoid internal crises, such as the 'burn out' of frontline workers.

In the course of time, the organisation might need to **plan how to scale up its work to respond to a growing epidemic and increased demands for its services**. For example, Asociación de Salud Integral – an organisation that shared its experiences at an Alliance/Horizons seminar on scaling up action on HIV/AIDS – initially planned for an average 15 per cent increase in counselling and treatment patients in their hospital clinic in Guatemala City. In practice, this was the case for the first two years, but in 2000 there was an increase of over 100 per cent due to both the growing epidemic and greater awareness of their work. Therefore, they had to adjust their plans and services accordingly.

Viewpoints

"The point is not to duplicate what is already being done but to fill the gaps. We need also to look at the possibility that if we start to do something, others might relinquish their responsibility. That is not what we are aiming for."

Participant at Catholic Diocese of Ndola and Alliance workshop on access to HIV/AIDS-related treatment, Zambia.

"It is important to set priorities. NGOs working in treatment and care should not feel compelled to respond to every need."

Krupa Shinde, India HIV/AIDS Alliance.

Section 3: Key issues for improving access to HIV/AIDS-related treatment

Introduction: HIV/AIDS-related treatment in context

HIV/AIDS-related treatment must always be relevant to the context in which it is planned, delivered or evaluated.



Each individual person with HIV is living within several layers of context. The most immediate context is that of his or her family, and their ability (or not) to provide care, support and treatment. They, in turn, live in communities that may or may not have available health and social support services, which also depend on national priorities and resources, all within a global setting which may or may not see treatment for people with HIV as a priority.

One example of how each level affects the others can be seen with regard to food supplies and TB treatment programmes. According to a recent United States Agency for International Development (USAID) review on HIV/AIDS and nutrition, wasting and increased nutritional needs were identified as characteristic of HIV disease and of TB, particularly with regard to protein foods and certain vitamins. Many people are co-infected with both diseases, and food supplies are therefore a major priority for them. At the same time, most of those infected are among the poorest populations, whose immunities are already compromised by lack of food supplies, sanitation and clean water.

Further, food and water supplies are not just matters of individual or local community concern. They are key elements of health and social welfare programmes and a matter of international concern when countries are unable to produce sufficient food or water supplies for their populations. In the presence of HIV and TB, adequate food supplies are both preventative in supporting healthy immune systems and curative in that they are essential for drug treatment to be effective and to prevent

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re-infection. Medical treatment of these diseases risks failure if people are hungry and if they cannot get the right nutrients.

The different levels of context are all affected by a variety of health, social, economic and political factors, and interact on all the different levels. Providing technical, financial and human resources for improved access to safe and effective HIV/AIDS-related treatment requires an understanding of these differing factors and layers of context. Assessment of context is therefore as important as assessment of disease prevalence and morbidity and mortality patterns for the planning and implementation of treatment.

What is available or accessible to people has a direct effect on what kind of treatment people with HIV hope for or expect from NGOs, CBOs or PLHA groups. Generally, it seems that where safe and effective treatment from government or other health providers is lacking, people turn to the NGOs, CBOs or PLHA groups for help, with expectations that may or may not be possible to meet. Faced with potentially overwhelming demand, NGOs, CBOs, PLHA groups and those who support them must therefore pay careful attention to assessing and involving the various sectors that form the context of treatment activities in order to achieve effective planning and service delivery. As one member of a CBO participating in the Alliance/Horizons diagnostic study said, *“we know that those who come to us in the sick stage of their illness come in search of medicines. They hope to find treatment and be immediately cured.”*

3.1 Availability and accessibility of HIV/AIDS-related treatment

In order for it to be used safely and effectively, HIV/AIDS-related treatment should be both available and accessible to those who need it.

A treatment is available if the resources needed for the treatment can be found in the community. Availability of treatment can be limited by many different factors. For example, participants at the workshop on involving people with HIV in access to HIV/AIDS-related treatment in the Philippines reported that treatment is only available in the capital, Manila, which leads many people with HIV to move from their home areas, leaving behind their families and informal support networks. Meanwhile, the Alliance assessment on HIV/AIDS-related treatment in Zambia found that many essential drugs were regularly unavailable due to inadequate and interrupted drug supplies. A similar assessment in Côte d'Ivoire showed that the full continuum of care, including treatment, is not available in any one place. For example, there is no one site where a person with HIV can obtain and be monitored for treatment with ARVs as well as having common infections diagnosed and treated. The assessment also showed that generic drugs were not widely available, and as a result prescribers were not always familiar with their optimal use.

At the workshop on access to HIV/AIDS-related treatment in Cambodia, participants drew a map to show the availability of HIV/AIDS-related treatment in the capital, Phnom Penh. It shows that treatment is available in a number of health institutions and pharmacies, and that traditional healers and home care teams are important sources of treatment.

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For people to use treatment it must not only be available; the treatment must also be accessible. This means that it should be easy for people to obtain and use the treatment safely and effectively. Accessibility of treatment is also limited by a range of factors, not least of all cost. The Alliance's recent consultation on access to ARVs in Zambia showed that they had been available through the private sector since 1992, but that triple therapy at its current cost was still too expensive – well out of reach for most Zambians. Meanwhile, participants at the workshop in the Philippines reported that another factor that limited access to treatment was the discriminatory attitudes and behaviour of health workers.

In practice, NGOs, CBOs and people with HIV in developing countries find that there are **multiple, interconnected barriers to access to HIV/AIDS-related treatment.** These operate at all levels, from the individual to the community and global, and can be divided into four main groups:

- **financial** – such as families having to prioritise money for food rather than drugs
- **organisational** – such as lack of skilled staff within NGOs or CBOs to administer drugs
- **physical** – such as lack of transport for people with HIV to get to sources of drugs
- **social** – such as treatment providers discriminating against people with HIV by refusing treatment or offering sub-standard treatment.

In practice, the barriers to access to HIV/AIDS-related treatment can seem simple, and yet remain difficult to overcome. For example, the Alliance's assessment of HIV/AIDS-related treatment in Zambia showed that lack of food is the most common and urgent barrier because people are simply hungry and cannot afford the most basic diet. This means that money cannot be diverted to health care needs, and that even when people can afford drugs the outcomes may be poor because of their undernourishment. The Alliance's assessment of HIV/AIDS-related treatment in Côte d'Ivoire found that poor patients are often given sub-standard treatment because they cannot afford full courses of drugs, while in Burkina Faso people in an advanced stage of illness are turned away from hospitals because it is perceived that nothing can be done for them.

The Alliance's assessment of HIV/AIDS-related treatment in India found that secrecy and ostracism were major barriers to safe and effective treatment because, for example, doctors refused to treat people with HIV or gave them sub-standard treatment. There, the lack of access to ARVs meant that HIV/AIDS was seen as a life-threatening disease rather than a non life-threatening chronic illness. One participant commented, "everything would change if we had them [ARVs] – we ask for these drugs for our children, not for ourselves."



An example of the Phnom Penh group's map showing where HIV/AIDS-related treatment is available.



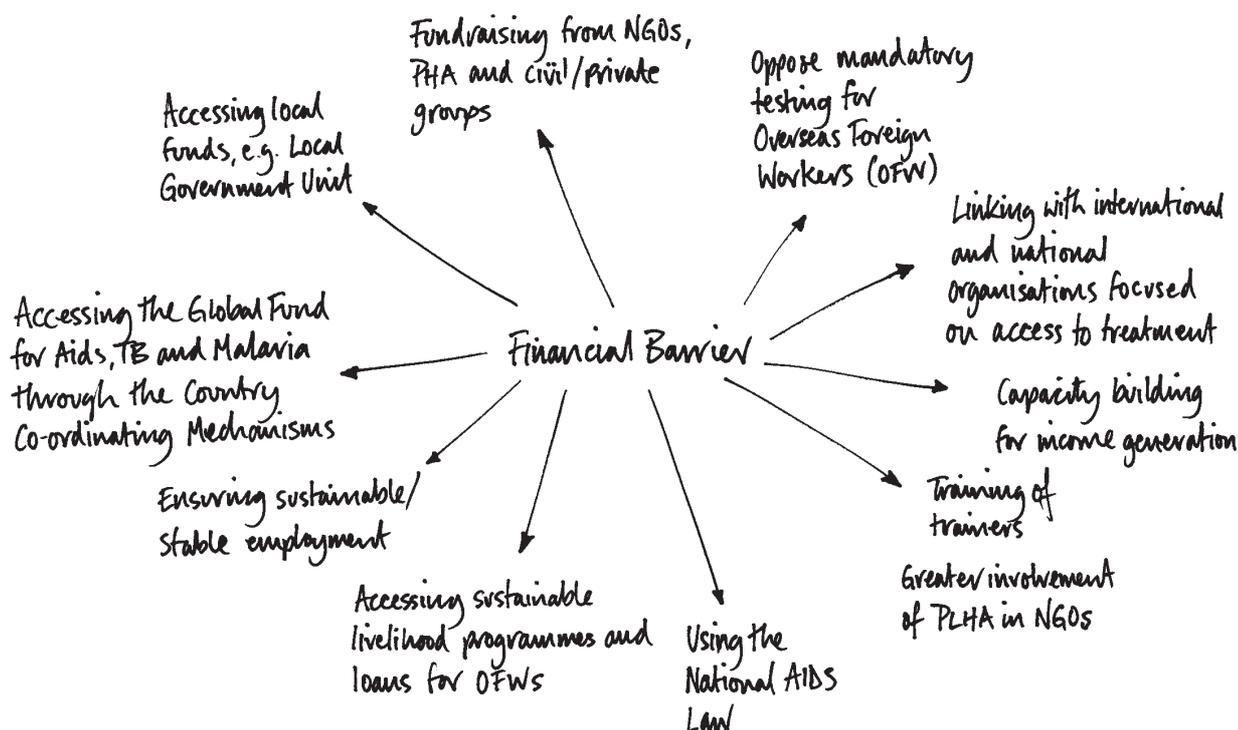
Barriers to HIV/AIDS-related treatment identified by participants at a workshop on access to HIV/AIDS-related treatment in India.

Section 3: Key issues for improving access to HIV/AIDS-related treatment

| Financial barriers | Organisational barriers | Physical barriers | Social barriers |
|--|--|--|---|
| <ul style="list-style-type: none"> • High drug prices • Treatment services unaffordable • Lack of investment in health care systems | <ul style="list-style-type: none"> • Lack of trained personnel • Refusal to treat PLHA • Irregular supply of drugs • No monitoring systems • No testing • No counselling | <ul style="list-style-type: none"> • Distance to services • People too sick to travel to services • Treatments not available in the right place | <ul style="list-style-type: none"> • Stigma and fear • Lack of respect for dignity of PLHA • Other basic needs get preference • Lack of decision-making power of women and children |

In some instances, the number of barriers to HIV/AIDS treatment can seem overwhelming. However, Alliance partners have found that **something can be done about many of them, and that even small successes can make an immense difference**. For example, Y.R. Gaitonde (YRG) Care in Chennai, India, found that obtaining some of its drugs from overseas organisations meant that it could reduce its charges to clients, and that linking with TB research and treatment centres could improve people with HIV's access to TB drugs. Meanwhile, the evaluation of the Ministry of Health/NGO Home Care Programme in Cambodia showed that advice and information from home care teams had helped 98 per cent of people with HIV and their families to reduce their expenditure on drugs and traditional remedies by US\$0.80 – 1.30 per week. Participants at the workshop on access to HIV/AIDS-related treatment in the Philippines drew a diagram showing the various opportunities to overcome financial barriers to access to HIV/AIDS-related treatment.

Diagram from the workshop in the Philippines



Section 3: Key issues for improving access to HIV/AIDS-related treatment

Viewpoints

"This country is very poor. The majority of people with HIV have died because of their economic situation and because of a lack of medicines. If we don't find help and medicines we do not stand a chance. It's not a question of taking one pill a month - we need proper, long-term medication."

Participant in the Horizons diagnostic study on the involvement of PLHA, Ecuador.

"In general, anything a person needs is always available from somewhere, but at a price, and access depends largely on ability and willingness to pay."

Alliance needs assessment on access to HIV/AIDS-related treatment, India.

"There is always a solution - we have to look for opportunities for ourselves to overcome these barriers."

Participant at the workshop on involving people with HIV in improving access to HIV/AIDS-related treatment, the Philippines

"Barriers such as lack of food, clean water, adequately trained health workers and infrastructure, and the stigma and discrimination which surrounds HIV/AIDS, all hinder poor people's access to care and treatment. While working towards solving these problems, the priority must be to prolong life and improve its quality by whatever means are immediately available, accessible, affordable and safe."

Alliance policy statement on access to HIV/AIDS-related treatment

3.2 Drugs and other commodities for treatment and prevention

Material supplies for treatment must be available, accessible and better managed at all levels. These supplies include:

- ✓ medicines
- ✓ condoms and other materials for HIV prevention
- ✓ syringes, dressings and other materials for treatment
- ✓ reagents, diagnostics and laboratory materials for diagnosis and monitoring.

Drugs for TB treatment have proved a clear example of how much can be achieved when drug availability, accessibility and management are successful. In Nepal, for instance, the number of deaths among TB patients managed under the WHO DOTS strategy reduced by over 40 per cent between 1994 and 1999. Such reductions provide further benefits in reduced morbidity and improved prevention. Unfortunately, there are many instances where drug supply failures have contributed to the increasing spread of TB instead of its reduction. Often NGOs working in HIV/AIDS-related treatment find that they must add TB medicines to their list of treatments when government TB programmes cannot supply them.

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The essential drugs concept must be central to planning for HIV/AIDS-related treatment. This concept arose directly from experiences of trying to ensure treatment availability for the main health problems faced by the majority of people in the world. An Essential Drugs List (EDL) is a key element, but it has grown beyond its initial aim to simplify prescribing and procurement into becoming a natural consequence of a vital first step: ensuring accurate diagnosis and choosing evidence-based, cost-effective treatment strategies. These strategies should be based on standard treatment guidelines and reliable, objective treatment information sources. The lists of essential drugs and other commodities can be drawn from these sources into what is now more correctly referred to as a list of essential medicines and other supplies.



Reference: Mobilising NGOs, CBOs and PLHA Groups for Improving Access to HIV/AIDS-Related Treatment – A Handbook of Information, Tools and other Resources.

More and more countries use this approach for public health care, as do NGOs that act as significant health providers in some of the poorest countries. Thus, treatment guidelines, drug formularies, essential medicines lists and market information (knowing what is available, what it costs and how to get it) can provide a solid framework for action: a basis for setting up reliable and sustainable supply systems, appropriate training/skills, and patient-centred treatment services.

NGOs, CBOs and PLHA groups have a significant role to play in the development of national treatment guidelines and lists of essential medicines and commodities. Many of them have done this through first developing their own guidelines and lists for the work they are involved in. For example, in 2000 the Alliance supported YRG Care in Chennai, India, to develop and publish HIV/AIDS-related treatment guidelines. Home care programmes in several countries, including Cambodia, India and Zambia, have worked out the basic medical supply needs for their context and have standardised them in order to ensure that:

- ✓ their clients receive the best available care and support
- ✓ the carers understand the medicines they are using
- ✓ the medicines and commodities are used and managed in the most cost-effective ways possible.

The lessons learned by NGOs, CBOs and PLHA groups should be communicated to national bodies and shared with their peers. Their experiences should, and can, directly influence the development of national policies and strategies for improving treatment and care for people with HIV.

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The realities of delivering treatment in resource-poor settings mean that many NGOs, CBOs and PLHA groups have very limited resources for purchasing medicines, even when treatment guidelines and essential medicines lists have been developed. The use of off-patent, good quality **generic drugs** – generally available at lower costs than the original branded ones – is a priority because of cost, but also because generic prescribing simplifies treatment and reduces confusion over drug names.

Many NGOs also find themselves relying on **drug donations** from well-wishers. As one NGO worker said, *"If we do not get donations, there may be no availability of drugs."* However, the many disadvantages of drug donations seem to be well understood, including the unsustainability of supplies, lack of drug information and receiving drugs that are close to expiry dates or inappropriate to local needs. Support for NGO, CBO and PLHA group-based treatment activities must adhere to WHO recommendations for managing donations and be based on the stated needs of the recipients. Supplying or accepting donations of drugs and commodities on the basis of being 'grateful for anything we can get' is not a sound strategy for safe and effective HIV/AIDS-related treatment.



A serious headache for NGOs, CBOs and PLHA groups – unwanted and expired drugs.

Viewpoints

"If we do not get drug donations, there may be no availability of drugs. If we have them, we can use our money to buy other things."

"Sometimes we get donations that we don't need - maybe they are already available in the country or they are not on the essential drugs list and we don't know how to use them."

Comments on donations from participants in the Cambodian workshop on access to HIV/AIDS-related treatment, hosted by KHANA and the Alliance.

Section 3: Key issues for improving access to HIV/AIDS-related treatment

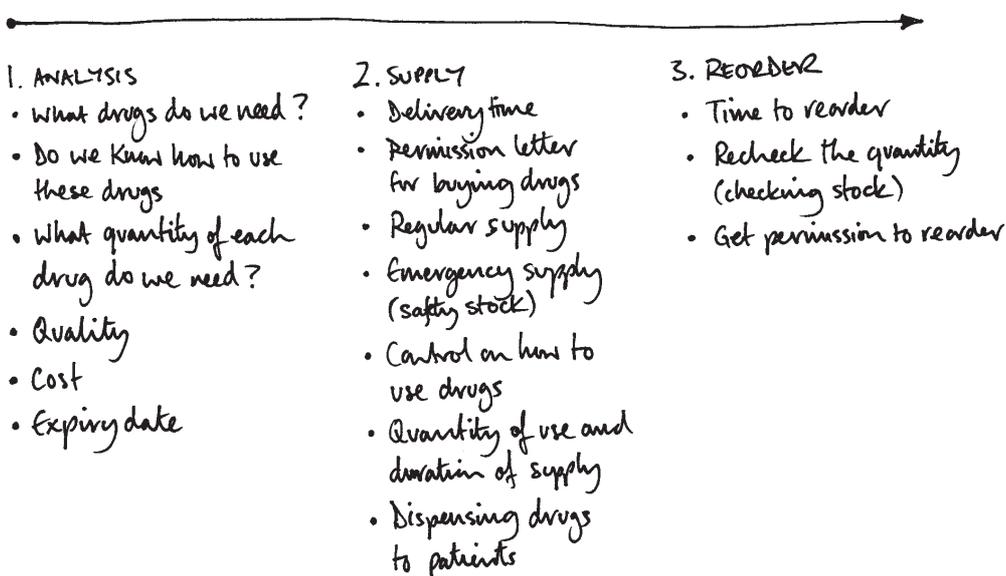
Support for HIV/AIDS-related treatment activities must include improving access to pharmaceutical skills. NGOs and CBOs involved in HIV/AIDS-related treatment often come from a background of community support and education for prevention. Many, at least initially, lack the basic skills of pharmacy for setting up and sustaining provision of medicines. These skills include:

- ✓ logistic, financial and negotiating skills for obtaining and distributing medical supplies to the point of use
- ✓ skills for dispensing – preparation and labelling of medicines for use, instructing patients and carers about drug use, encouraging and supporting adherence to treatment regimes
- ✓ skills in sourcing, evaluating and using medicines information to help patients and prescribers make the best use of drugs and manage problems such as side-effects or resistance to anti-infective drugs

The development of HIV/AIDS-related treatment services must therefore include provision for improving access to such skills, preferably through the use of trained pharmacists, pharmacy assistants or pharmacy technologists. If these are not available as staff for the service, the advice and guidance of volunteer pharmacists must be used whenever possible to ensure safe and effective practice in providing medicines. Examples of good practice in this respect can be found in countries such as Kenya and Zambia, where church-based organisations like the Mission for Essential Drugs and Supplies of Kenya and the Churches Health Association of Zambia, who have been providing general health services for many years, have pharmaceutical training programmes that have been expanded to cover HIV/AIDS-related treatment.

At the workshop on access to HIV/AIDS-related treatment in Cambodia, participants drew a timeline (see below) and identified a range of steps involved in managing supplies of HIV/AIDS-related drugs effectively. The discussion of the timeline highlighted that the cycle (and all its steps) for managing drugs and other supplies for treatment must be carried out without disruption and in the right order to prevent gaps in treatment that might result in causing physical and psychological harm to people with HIV.

Timeline from the workshop in Cambodia



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3.3 Advocacy: working towards change

Advocacy to improve access to HIV/AIDS-related treatment (a process of action that entails working towards changes in attitudes, policies and practices) needs clear strategies to bring about change on several different levels, including the community, national and global levels. Advocacy for improving access to HIV/AIDS-related treatment is essential for addressing the many interlinked barriers preventing people with HIV from accessing the treatment they need.

Advocacy at each level can effect change at the other levels. Recent developments in the reduction of prices of ARVs have demonstrated how advocacy to lower drug prices at the global level with international pharmaceutical companies can effect change at several other levels:

- ✓ at the national level, whereby more governments from developing countries may consider making ARVs available through their public health care systems
- ✓ at the individual level, whereby more people with HIV may be able to afford ARVs.

Action for change should be taken at each level to improve access to HIV/AIDS-related treatment.

- ✓ **At the individual and community levels**, accompanying people with HIV to the hospital or clinic to ensure that they receive treatment is a way of advocating for improved treatment access. Similarly, influencing local pharmacists to stock drugs that people with HIV need is another way of advocating for improved access to treatment. In Zambia, at the workshop on improving access to HIV/AIDS-related treatment, participants agreed that sensitising community members about their right to health is also a way of advocating for improved access to treatment. Participants also suggested informal education with community members as an effective method of advocating for change. For example, when some local chiefs were targeted with informal education about HIV/AIDS prevention, they put rules into place in their communities forbidding men to marry under-age girls.
- ✓ **At the health system and national levels**, NGOs, CBOs and PLHA groups can participate in the development of standard treatment guidelines for HIV/AIDS and influence the government to improve the supply of HIV/AIDS-related drugs in hospitals and clinics in order to improve treatment access for people with HIV. At the workshop in Zambia, participants said that having clear national guidelines and policies for treatment that were easily accessible was an important national advocacy goal.
- ✓ **At the global level**, lobbying pharmaceutical companies to reduce the price of HIV/AIDS-related drugs and encouraging international drug suppliers to make HIV/AIDS-related drugs widely available at low cost are ways of advocating for improved access to treatment.

At the workshop on improving access to HIV/AIDS-related treatment in India, participants discussed a number of advocacy strategies for improving access to treatment for people with HIV.

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Community level

- Advocate for better collaboration between PLHA, NGOs and government on access to HIV/AIDS-related treatment
- Advocate for more information about issues relating to treatment and access to HIV/AIDS-related treatment

National level

- Advocate for an improved supply of free drugs from the government
- Advocate for more involvement of people with HIV in work on treatment issues

Global level

- Advocate on international issues such as compulsory licensing and parallel importing of HIV/AIDS-related drugs
- Advocate for lower international prices for HIV/AIDS-related drugs

Participants at the same workshop emphasised that **the voice of people with HIV must be central to any advocacy for access to HIV/AIDS-related treatment and it must be heard at all levels** for the advocacy to be meaningful, authentic and effective. Mechanisms and supportive environments for the greater and more meaningful involvement of people with HIV in treatment advocacy must be developed.

Viewpoints

"We must advocate for more visibility of people with HIV and involvement of people with HIV in treatment access issues."

NGO participant at the workshop on improving access to HIV/AIDS-related treatment, hosted by the India HIV/AIDS Alliance.

"Care and treatment is my right. I shouldn't have to demand it. It should be available to me without such struggle."

Geeta Venugopal, Indian Network of Positive People, at the workshop on improving access to HIV/AIDS-related treatment, hosted by the India HIV/AIDS Alliance.

Additionally, participants at the Philippines workshop on involving people with HIV to improve access to HIV/AIDS-related treatment, hosted by PHANSuP and the Alliance, agreed that advocacy for improving access to treatment at the various levels must be well co-ordinated and that **everyone, especially people with HIV, must speak with one voice and articulate clear, simple, strong messages.**

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