



Facilitators' Guide

For Needs Assessments on Access to HIV/AIDS Related Treatment

**A Resource to Support the Development of a
Practical Toolkit for NGOs, CBOs
and PLHA Groups**

With the support of WHO and UNAIDS

NOTE

This facilitators' guide has been developed to be used during the initial stages of a collaborative project between the International HIV/AIDS Alliance, WHO and UNAIDS. The project aims to develop a practical toolkit for NGOs, CBOS and groups of people living with HIV/AIDS on access to HIV-related treatment in developing countries.

The guide has been designed to be a practical resource to be used, tested and further developed during the needs assessment process for the toolkit. It is a draft "working document" and not, therefore, an official document of WHO or UNAIDS.

For further information, please contact:

**International HIV/AIDS Alliance
2-12 Pentonville Road**

**London N1 9HF
United Kingdom.**

Tel: + 44 171 841 3500

Fax: + 44 171 841 3501

E-mail: mail@aid alliance.org

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INTRODUCTION:

ALLIANCE / WHO / UNAIDS TOOLKIT ON ACCESS TO HIV/AIDS RELATED TREATMENT

1. Introduction to purpose of toolkit on access to HIV/AIDS related treatment

The International HIV/AIDS Alliance is an international nongovernmental organisation (NGO) that supports community action on HIV/AIDS in developing countries. To date, the Alliance has supported over 850 NGO and community initiatives in Africa, Asia and Latin America, and has provided technical support to hundreds of other groups.

The International HIV/AIDS Alliance is collaborating with WHO / UNAIDS to carry out the first stage of the development of a toolkit for NGOs and community groups concerned with issues of access to treatment in HIV/AIDS and associated conditions such as sexually transmitted infections (STIs), tuberculosis (TB), mother-to-child HIV transmission, opportunistic infections (OIs), pain relief and palliative care. Treatment is understood to include traditional, herbal and domestic remedies alongside pharmaceutical drugs.

The primary aim of this project is to improve the ability of local NGOs to deal effectively with treatment access issues by assisting them to:

- Make decisions on involvement in treatment provision and drug supply, by providing a basic understanding of the main factors involved in HIV/AIDS treatment issues;
- Gain access to and make use of existing local and national drug supply systems where available; explore and use alternatives to these systems and drugs where necessary and useful; understand the uses of donated drugs and the constraints associated with their management and use;
- Work with the practical issues involved in drug supply and financing, with special regard to cost, quantification, quality and sustainability in the context of the development of the epidemic and in relation to other public health needs;
- Ensure good practice in the use of HIV/AIDS related drugs, including clinical requirements and the use of treatment protocols, technical support (such as laboratory services) and psychosocial support (such as confidentiality and counseling); and
- Develop and sustain alliances and linkages with other organisations and resources.

2. Overview of needs assessments for toolkit on access to HIV/AIDS related treatment

The Alliance / WHO / UNAIDS toolkit project commenced in July 1999 with a review of literature and tools already available. Two groups of people with relevant expertise were identified and recruited to assist with the project:

1. A small UK-based group to monitor and provide assistance to the Alliance consultant;

2. A larger international reference group who will assist the progress of the project by taking part in the needs assessment and providing comment and advice on elements of the toolkit as and when they are written.

The next step of the project is to carry out needs assessments with NGOs, community based organisations (CBOs) and people living with HIV/AIDS (PLHA). Tools have been designed to assist in the following tasks:

- Description and clarification of the needs and perspectives of NGO / CBO / PLHA groups about treatment access issues.
- In-country research of approx. 1 - 2 weeks in three countries by 1 or 2 Alliance staff / consultants, to carry out individual and group interviews, questionnaires and observations.
- Investigations with identified individuals in other countries through a mix of questionnaires, data collection and telephone interviews, taking place from November 1999 to February 2000.

Drafting of the toolkit will commence in April 2000 when the results of the needs assessment have been analysed and discussed with the reference group. The toolkit will then be field-tested in up to three countries. The final product is expected to be available by January 2001.

3. Outline of facilitators' guide for needs assessment for toolkit on access to HIV/AIDS related treatment

Section 1

Section 1 of this Guide outlines the **scope** of the needs assessment, broadly covering five areas of investigation concerning:

- processes of choosing treatments.
- experiences of obtaining treatments.
- experiences of using treatments.
- barriers encountered.
- changes hoped for.

Section 2

Section 2 outlines the **specific topics and possible questions** which we hope to investigate with **five groups of potential participants** in the needs assessment:

- The questions cover:
 - general attitudes & understanding.
 - knowing what treatments are desirable/affordable.
 - availability & accessibility of treatments.
 - how to ensure effective treatment.
 - benefits & difficulties of providing and using treatment.
 - suggestions on potential toolkit contents.

- The groups include:
 - Group 1: PLHA.
 - Group 2. Family or community carers providing voluntary help.
 - Group 3. NGOs which provide treatments.
 - Group 4. Medical professionals who prescribe and provide treatments.
 - Group 5. Purchasers of medication and supplies for treatment.

Section 3

Section 3 contains information and data collection tools for the assessment:

- **3.1** is an **information sheet** about the toolkit project (based on the Introduction above) for copying and prior circulation to needs assessment participants and others who are interested in the project.
- **3.2** is a **data sheet** which should be completed for every participant, giving basic information about the participant and about their organisation. Any indication of HIV status is optional and for statistical purposes only - it will be treated as confidential and removed from any records when data collection is completed.
- **3.3** includes:
 - **1:** a table of '**marker**' **drugs** which WHO use as indicators of drug availability for HIV related conditions; if participants are familiar with these drugs, they can give us some indication of each drug's availability.
 - **2:** a table for participants to tell us about **other drugs or treatments which are available to them.**
 - **3:** a table for participants to tell us about **other desired drugs or treatments which they want but cannot get.**

Focus group participants should attach any completed tables to the data sheet. (The tables are included within the body of each questionnaire, so need not be completed by questionnaire participants).

Section 4

Section 4 provides **Focus Group formats** for carrying out the assessment with the above five groups of people. These are based on the 'open' format questions outlined in Sections I and II. They can also be used as a framework for individual interviews, either face-to-face or by telephone. Some individuals and organisations may belong to more than one of the above groups of people. If there is time and the participant(s) is/are willing, it would be helpful to work on more than one set of questions. However, because of time constraints it may be necessary to make a choice with the participant according to which aspect is considered more helpful for the study.

Section 5

Section 5 contains **Questionnaires** based on an expansion of the Focus Group formats, making use of 'closed' questions to allow for yes/no or tick-box answers. The questionnaires have been developed to allow for more flexibility in carrying out the needs assessment and to facilitate data collection for the needs assessment report. Wherever possible, the focus group formats should be used, but it may be more helpful to use the questionnaires with some groups, preferably allowing time for discussion when questionnaires have been completed. The questionnaires can also be used when appropriate for e-mail participants in the assessment. As with the focus group/interview materials, participants may fall into more than one category and a choice may have to be made about which questionnaires are appropriate.

SECTION 1

WHAT WE WANT TO UNDERSTAND FROM THE NEEDS ASSESSMENT ABOUT ISSUES CONCERNING DRUGS, TREATMENTS AND HIV/AIDS

*NB: It is important throughout to keep the broad focus of questions on possible contents of the toolkit. The topics and questions listed here are intended as a guide. Others may arise in the course of investigation but should be pursued **only if they seem directly relevant to NGOs and the toolkit.***

1.1 Information

- What is generally available in participants' country for HIV treatments & care?
- What is feasible or accessible locally for HIV treatments & care?
- What drugs and treatments are accessible locally, including pharmaceutical, drugs, traditional, herbal or home remedies and supportive measures?
- Where and how do people get hold of information about HIV care and treatment?
- Are people able to make effective use of the information they get? and
- Are people able to make effective use of the drugs they get?

1.2 Context

- Prevalence - of HIV infection and of other diseases, especially sexually transmitted infections (STIs);
- Basic needs (water, food, housing) and how treatment fits in with these;
- Local health culture, situation and systems, and their relationship to PLHA, HIV treatment and treatment in general;
- Family situations and how they affect treatment;
- Pregnant women, mother/child HIV transmission and prevention;
- Special needs – such as orphans, vulnerable children, women, prisoners, sex workers, men who have sex with men;
- Secrecy, stigma, discrimination and guilt;
- Who provides care when it is needed; and
- How carers are supported.

1.3 Support and management

- Diagnosis - what facilities are provided and how accessible they are;
- Voluntary testing and counselling;
- Psychosocial support, including self help (individual and groups);
- Material support – such as food, blankets and bus fares;
- Home-care / community care - what is available and how it is supported;
- Traditional medical input - healers, herbal remedies, home remedies, etc;
- Professional medical input – from nurses, doctors, pharmacists etc;
- Referral to medical facilities for specialised help; and
- Referral to other facilities, and two-way systems of referral.

1.4 Treatment needs

- STIs;
- Tuberculosis (TB);
- Specific treatment for HIV infection;
- Other infections – such as bacterial, fungal, parasitic;
- Nutrition – including undernutrition and malnutrition;
- Skin problems;
- Sinusitis;
- Diarrhoea;
- Pain; and
- Psychological problems.

1.5 Access to drugs

- What drugs are needed and how are they chosen;
- Where are they obtained from;
- How they are obtained;
- How quantities are decided;
- How they are paid for;
- How quality is assured;
- How they are used;
- Monitoring effects and impact of drugs – including diagnostic testing, side effects, adherence and resistance; and
- Evaluating access to drugs and planning for the future.

SECTION 2

POSSIBLE QUESTIONS, IN “OPEN” FORMAT, FOR SPECIFIC GROUPS

The “open format” sessions will involve a variety of methodologies. These will include interview sessions, story telling and focus group discussions. Wherever possible, they will also include participatory tools, such as mapping, ranking and cartoon strips.

NB: It is important throughout to keep the broad focus of activities on issues relating to NGOs and on possible contents of the toolkit. The topics and questions listed here are intended as a guide. Others may arise in the course of investigation but should be pursued only if they seem directly relevant to NGOs and to the toolkit.

2.1 Users of treatments (PLHA):

- When you think about treatment and HIV, what can you tell us?
- What are your commonest HIV problems?
- How do you find out and decide about treatments for HIV illnesses?
- How do you decide what drugs to get and how much you need?
- Experiences in getting treatments: where do they come from, how are they paid for, and how easy is it to get them?
- Experiences in using treatments: how easy is it to use them, do you need help to use them and how, and what difficulties are there?
- What difference do treatments make for you in living with or caring for someone with HIV/AIDS?
- What are the main difficulties, and how do you think things could be improved?
- What might NGOs do better to improve access to treatment?
- What specific issues or topics do you want to see in a toolkit for NGOs on treatment access?

2.2 Family and community carers providing voluntary help to PLHA:

- When you think about treatment and HIV, what can you tell us?
- What are the commonest HIV problems you face as a helper?
- How do you find out and decide about treatments for HIV illnesses?
- How do you decide what drugs to get and how much you need?
- Experiences with helping to get treatments for PLHA: where do treatments come from, how are they paid for, how easy is it to get them?
- Experiences in helping PLHA to use treatments: what help do PLHA need, what difficulties are there?
- What difference do you think treatments make for PLHA in living with HIV/AIDS?
- What difference do you think treatments make to caring for someone with HIV/AIDS?
- What are the main difficulties, and how do you think things could be improved?
- What might NGOs do better to improve access to treatment?
- What specific issues or topics do you want to see in a toolkit for NGOs on access to treatment?

2.3 Employees of NGOs, CBOs and PLHA groups involved in treatment provision:

- What is your group's involvement with HIV/AIDS?
- What policy/attitude/beliefs does your group have about treatments for HIV-related conditions?
- How did you decide to get involved with providing treatments?
- Who else provides treatments for PLHA in your area, what is your relationship with them?
- How did you decide what treatments to offer, how much and to whom?
- What training is provided to staff and/or volunteers, and how are they kept up to date?
- What existing materials and information do you use to support treatment practice, and how is it kept up to date?
- How are treatments paid for, and how cost-effective is it for your organisation to be involved?
- Tell us about your experiences in providing treatments.
- What are your experiences with suppliers and donors?
- What are your experiences with PLHA and families?
- What do you think are the advantages and disadvantages of providing treatments?
- What do you see as your main strengths and weaknesses in providing treatments?
- How might the situation be improved or changed for the future? What are the barriers to future change?
- What specific issues or topics do you want to see in a toolkit for NGOs on access to treatment?

2.4 Medical prescribers treating PLHA:

- What do you think about treatment for HIV and related conditions?
- How much of your work relates to HIV-related conditions?
- How do you decide what HIV-related conditions to treat and with what?
- Do you have treatment guidelines eg. for diarrhoea, persistent coughs, pain etc.?
- Where do you get information about drugs and treatment, do you feel confident about the information you have, and how do you keep up to date?
- What drugs do you prescribe most for HIV-related conditions and why?
- If you decide a PLHA needs treatment, can they access what is required, and who pays for it?
- Who supplies and/or pays for the drugs you prescribe, and what are the difficulties?
- Is clinical and technical support available, for diagnosis, monitoring, improving and adherence etc.?
- Is it possible to refer patients for specialist help, or for home/community care when needed?
- What do you think are the advantages and disadvantages of providing treatments?
- What do you see as your main strengths and weaknesses in providing treatments?
- How might the situation be improved or changed for the future, what are the barriers?
- What might NGOs do better to improve access to treatment?
- What specific issues or topics do you want to see in a toolkit for NGOs on treatment access?

2.5 NGO staff who are purchasers/providers of drugs for HIV-related treatments:

- What can you tell us about drugs and treatments for HIV-related conditions?
- How appropriate are they for the local situation of the epidemic - cost, ease of use, need for other inputs?
- What are your experiences in purchasing or obtaining (eg. through donation) materials for treatment of HIV and related conditions?
- What are your experiences with distributing these materials to their place of use?
- Where do you get information about what to purchase, how much and where from?
- How are the supplies financed?
- How do you ensure that the supplies are safe, effective and good quality?
- What are the main difficulties with supplies, and what do you think could be changed or improved for the future?
- What might NGOs do better to improve access to treatment?
- What specific issues or topics do you want to see in a toolkit for NGOs on access to treatment?

SECTION 3

TOOLS FOR USE DURING NEEDS ASSESSMENTS

3.1 INFORMATION SHEET FOR NEEDS ASSESSMENT PARTICIPANTS AND OTHERS

INTERNATIONAL HIV/AIDS ALLIANCE, WHO AND UNAIDS

PROGRAMME FOR DEVELOPMENT OF A TOOLKIT: ACCESS TO HIV/AIDS RELATED DRUGS & TREATMENTS FOR NGOs, CBOs & PLHA GROUPS

Introduction to purpose of the toolkit on access to HIV/AIDS related treatment

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- Make decisions on involvement in treatment provision and drug supply, by providing a basic understanding of the main factors involved in HIV/AIDS treatment issues;
- Gain access to and make use of existing local and national drug supply systems where available; explore and use alternatives to these systems and drugs where necessary and useful; understand the uses of donated drugs and the constraints associated with their management and use;
- Work with the practical issues involved in drug supply and financing, with special regard to cost, quantification, quality and sustainability in the context of the development of the epidemic and in relation to other public health needs;
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Overview of needs assessment for toolkit on access to HIV/AIDS related treatment

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Drafting of the toolkit will commence in April 2000 when the results of the needs assessment have been analysed and discussed with the reference group. The toolkit will then be field-tested in up to three countries. The final product is expected to be available by January 2001.

3.2 DATA SHEET FOR NEEDS ASSESSMENT PARTICIPANTS

INTERNATIONAL HIV/AIDS ALLIANCE WITH WHO AND UNAIDS

PROGRAMME FOR DEVELOPMENT OF A TOOLKIT: ACCESS TO HIV/AIDS RELATED DRUGS & TREATMENTS FOR NGOs, CBOs & PLHA GROUPS

This data sheet should be completed for every participant, giving basic information about the participant and about their organisation; please note that any indication of HIV status is optional - it will be treated as confidential, used only for statistical purposes and removed from any records when data collection is completed.

Participant's name:

Mailing address:

Telephone number:

Fax number:

E-mail address:

Current job title:

Name of organisation:

Address of organisation:

Summary of involvement with HIV/AIDS:

- professional:

- personal:

Participant's signature:

Facilitator's signature:

Date:

3.3 “CHECK LISTS” OF AVAILABLE AND / OR DESIRED DRUGS AND TREATMENTS

WHO/ UNAIDS list of “marker” drugs

WHO/UNAIDS consider the following items to be “markers” of availability and accessibility of medical treatments for HIV and related conditions. If you are familiar with these items, please indicate their local availability by ticking the appropriate box for each one:

Drug names (generic name), alternative or "trade" names, and main indication for use	Availability				
	Often	Some times	Rarely	Never	Don't know
Benzylopicillin 600 mg, 3 g (as sodium salt) 5 ml vial antibacterial					
Erythromycin 250mg tablets/capsules ('Erythromid') antibacterial					
Gentamicin injection 40mg/ml ampoules 2ml ('Genticin', 'Garamycin', 'Cidomycin') antibacterial					
Sulfamethoxazole+trimethoprim 400/80 mg tablets (co-trimoxazole, 'Bactrim', 'Septrin') antibacterial					
Isoniazid (H) tab 300 mg antituberculous					
Nystatin 0.5 M IU pessaries ('Nystan', 'Mycostatin') antifungal					
Ketoconazole 200mg tablets ('Nizoral') antifungal					
Fluconazole 100 mg tablets/capsules ('Diflucan') antifungal					
Aciclovir 200mg tablets (acyclovir, 'Zovirax') anti-herpesvirus					
Pyrimethamine tab 25 mg antitoxoplasmosis					
Sulfadiazine tab 500 mg antibacterial					
Antitoxoplasmosis					
Calcium folinate tablet 15 mg cytotoxic					
Calamine lotion with sulphur 2%, bottle anti-Inflammatory and antipruritic					
Loperamide tablet 2mg anti-diarrhea					
Codeine tab 30 mg opioid analgesic					
Morphine sulfate injection 2mg/ml ampoules 2ml opioid analgesic					
Vinblastine powder for injection, 10 mg (sulfate) or vincristine powder for injection, 1 mg, 5 mg (sulfate) anti-cancer (Kaposi sarcoma)					
Zidovudine 100mg capsules (AZT, 'Retrovir') anti-retroviral					
Didanosine (ddI) anti-retroviral					
Stavudine (d4T) anti-retroviral					
Lamivudine (3TC) anti-retroviral					
Nevirapine anti-retroviral					
Protease inhibitor (indinavir or nelfinavir or ritonavir or saquinavir)					
Condoms, female					
Condoms, male					

Other drugs or local treatments not available

Please tell us about other drugs or treatments which you regularly want but cannot get. Please tell us what each one is, what it is used for and what stops you getting it:

Drug or Treatment	What would you use it for?	What stops you from getting it at present?

SECTION 4

GUIDE FOR FOCUS GROUPS AND / OR INDIVIDUAL INTERVIEWS

4.1 Users of treatments (PLHA)

1. Last time someone in your family was ill, what did you do about it and where do you normally get help?

- *mapping exercise*

eg. where did you go, what did you get, did it help / make things worse etc.

- *cover various alternatives eg. wait to see what happens, consult other members of family, consult traditional healer, go to injectionist, visit local drug store, visit local pharmacy, go to local health worker, go to hospital*

2. When you think about treatment and HIV, what can you tell us?

- *brainstorm, no pre-determined form of diagram; group results under themes; make diagram*

3. What are some of your problems with health and HIV? How do you find out and decide what to do about them?

- *'star' diagrams, mapping, input/output diagrams:*

- Commonest problems: *eg. diarrhoea, skin, cough, weight loss, headaches, other pains etc.*

- Finding out: *eg. radio, television, newspapers, magazines, family & friends, other PLHAs, health workers, traditional practitioners, unlicensed healers, injectionists etc.*

- Decision making: *eg. do what the doctor says; ask health worker (pharmacist, nurse, etc.); see how much money available; choose between treatment and other needs such as food; accept donation or 'leftovers' if offered; consult with family/friends*

4. What are your experiences with getting and using treatments?

- *mapping, cartoon strips, lifelines*

- Where do your treatments come from? *eg. govt. health services, NGO health services, informal contacts (family etc.), pharmacy, drug store, market trader, traditional healer, unlicensed healer, injectionist etc.*

- What stops you getting them? *eg. need to preserve secrecy, govt. drug supply system doesn't work, other sources don't have supplies, no transport, no money, health workers won't/don't prescribe them, frightened of adverse effects*

- How are they paid for? *eg. free to user, user fees, user pays full costs, insurance scheme pays full or part cost, NGO pays full or part cost, community purchasing schemes, buyers' clubs, donated by NGOs, donated by well-wishers, donated by PLHAs*

- What is it like to use them? *eg. ease of use, need for equipment (syringes, needles) adverse effects, need help to use them (carer), remembering doses regime, stopping/ starting use according to symptoms / other reasons, relationship to food/ mealtimes, need fluid to take them*

- Who is involved in helping you to use them? *eg. family, community (homecare) worker, health centre, hospital, pharmacist, injectionist*

5. Do treatments make a difference to PLHA and their families? What are the main difficulties in accessing or using them, and what improvements could be made?

- *diagram:*

-

Benefits here and now	Improvements for future
Disadvantages here and now	Barriers to future change

4.2 Family and community carers providing voluntary help to PLHA

1. Last time you or someone in your family was ill, what did you do about it and where do you normally get help?

- *mapping exercise*

eg. where did you go, what did you get, did it help / make things worse etc.

- *various alternatives eg. wait to see what happens, consult family, traditional healer, unlicensed doctor, visit injectionist, local drug store, local pharmacy, health worker, hospital*

2. When you think about treatment and HIV, what can you tell us?

- *brainstorm, no pre-determined form of diagram*
- *group results under themes, make diagram based on these if possible*

3. How did you get involved in helping PLHA, what kind of help do you give and what support do you get?

- *timelines, social map, input/output charts*

eg. route to getting involved, inputs on a typical day/week, support system

4. What are some problems you see with health and HIV when you are helping PLHA? How do you find out and decide what to do about them?

- *'star' diagrams, mapping, input/output diagrams:*
- Commonest problems: *eg. diarrhoea, skin, cough, weight loss, headaches, other pains*

- Finding out: *eg. radio, television, newspapers, magazines, family & friends, other PLHAs, health workers, traditional practitioners, unlicensed healers, injectionists etc.*

- Decision making: *eg. do what the doctor says; ask health worker (pharmacist, nurse, etc.); see how much money available; choose between treatment and other needs, accept donation or 'leftovers' if offered; consult with family/friends*

5. What are your experiences in helping PLHA to get and use treatments?

- *mapping, cartoon strips, lifelines*

- Where do treatments come from? *eg. govt. health services, NGO health services, informal contacts (family etc.), pharmacy, drug store, market trader, traditional healer, unlicensed healer, injectionist etc.*

- What stops you getting them? *eg. need to preserve secrecy, govt. drug supply system doesn't work, other sources don't have supplies, no transport, no money, health workers won't/don't prescribe them, frightened of adverse effects*

- How are they paid for? *eg. free to user, user fees, user pays full costs, insurance scheme pays full or part cost, NGO pays full or part cost, community purchasing schemes, buyers' clubs, donated by NGOs, PLHAs, well-wishers*

- What is it like to use them? *eg. ease of use, need for equipment (syringes, needles) adverse effects, need help to use them (carer, nurse), remembering doses regime, stopping/ starting use according to symptoms or other reasons, relationship to food/ mealtimes, need fluid to take medicines.*

- Who is involved in helping you to use them? eg. family, community (homecare) worker, health centre, hospital, pharmacist, injectionist

6. Do treatments make a difference to PLHA and their families? What are the main difficulties in accessing and using them and what improvements could be made?

- *diagram:*

Benefits here and now	Improvements for future
Disadvantages here and now	Barriers to future change

4.3 Employees of NGOs, CBOs & PLHA groups involved in treatment provision

(Note: Questions for medical prescribers of treatments are included in Group D)

1. Organisational issues:

- What is your group's involvement with HIV/AIDS?
 - *statements, diagrams:*
eg. if HIV/AIDS is only part of what NGO does, how does it fit with other work?
- Understanding of HIV within organisation
 - *statements re. staff knowledge, beliefs, attitudes:*
eg. 'when I think about HIV/AIDS I know... I believe... I feel...
- What are participants' personal feelings about treating HIV/AIDS?
 - *statements re. staff knowledge, beliefs, attitudes:*
eg. 'when I think about HIV/AIDS I know... I believe... I feel...
- How and why has group's involvement with HIV/AIDS developed?
 - *timeline of activities*
eg. where they started, what changes were made and why, who makes decisions, what developments are expected for future?
- How and when was the decision made to get involved with treatment?
 - *timeline of activities*
eg. where they started, what changes were made and why, who makes decisions, what are the expected developments for future?
- Treatment policy development and adherence:
 - *statements:*
eg. *who was consulted, who is responsible for policy, what would make it change, if written policy available, who knows about it, must adhere to it, can we have a copy*
- What sources of funding did you explore, which did you decide to use & why?:
 - *'star' diagram?*
eg. *government provides full funding, NGO pays full or part cost, insurance scheme pays full or part cost, user pays fee, user pays full costs, community purchasing schemes, buyers' clubs, donations from NGOs, well-wishers or PLHAs*

2. Providing treatment to the community:

- What treatment 'package' is offered and to whom?
 - *lists, diagrams*
eg. package offered, how delivered to recipients, what follow-up, what other services offered to back up treatment (eg. counselling, testing, monitoring, preventive work)
- How did you find out what should be provided?:
eg: guidelines, local demand from physicians, local demand from PLHA, advice from pharmacists, advice from physicians, information from suppliers, other sources such as international information providers (eg Healthlinks, WHO etc.)

- What training is provided to staff &/or volunteers, how are they kept up to date?
- What existing materials & information do you use to support treatment practice, how is it kept up-to-date?
- What sources of supply did you explore, which did you decide to use & why?
eg. government medical supply system; local pharmacies, markets or drugstores; national non-profit or commercial suppliers; international non-profit or commercial suppliers; donations from NGOs; pharmaceutical companies; others
- What are your experiences with PLHA and carers in using the treatments you provide?
- What are your experiences with PLHA and carers in requesting or using other treatments which you do not provide or do not consider appropriate?
- Do you think your treatment involvement and strategies have been successful, have you changed them and why?
 - *stories, case material*

3. Contextual issues:

- Who else is involved in providing treatments in your area?
 - diagrams (eg mapping, concentric circles)
eg. to show how they relate to each other, how they relate to PLHA
- What are your experiences with suppliers?
- What are your experiences with donors of medical supplies?
- What are your experiences with donors of funds?
- How is the epidemic changing in your area, and how do you think it is affecting treatments needs?

4. What are the advantages and disadvantages of providing treatments? How might the situation be improved or changed for the future? What are the barriers to future change?

- *use diagram to produce categorised lists:*

Benefits here and now	Improvements for future
Disadvantages here and now	Barriers to future change

5. What specific issues would you like to be included in a toolkit for NGOs on access to treatment? (NB Facilitator must ensure time is available to go into detail on this section - toolkit is primarily intended for this target group

- *review & listing of responses to questions 1-5*
- *themes*
- *topics*
- *techniques/tools*
- *information*
- *priorities - what three things are most essential for the toolkit?*

4.4 Medical Prescribers treating PLHA

1. Personal and policy issues

- What is your attitude / approach to (how do you feel about) treating people with HIV and related conditions?
eg. some treatment is possible with simple drugs; simple drugs are available but not really worth doing anything; if we can get antiretrovirals it is worth doing something; don't want HIV patients coming to my clinic - puts off other patients; worth treating early illness but nothing can be done for late-stage patients; palliative care is important, but we need good analgesics; can't get morphine so can't do palliative care
- How much of your work relates to HIV-related conditions
-eg: proportion of time taken up, how has practice changed as epidemic developed
- How do you decide what conditions to treat and with what?
- *tools*
eg. *do you have up to date information & training on HIV?; do you have up to date drug information, if not what is the problem;*
- Do you have standard treatment guidelines (a) symptom based eg. for diarrhoea, coughs, pain etc. (b) based on diagnosis eg. for tuberculosis, sexually transmitted infections etc.?
-eg: nationally agreed guidelines, locally agreed guidelines, personal written guidelines based on experience, WHO or other publications, use my own skills, guidelines don't suit my situation

2. Treatment - prescribing, access, adherence, follow-up

- Who pays for treatments?
eg. *free to user, user fees, user pays full costs, insurance scheme pays full or part cost, NGO pays full or part cost, community or joint NGO purchasing schemes, buyers' clubs, donated by NGOs, donated by well-wishers, donated by PLHAs*
- What technical support is available for treatment
-eg: diagnostic tests, monitoring CD4 / viral loads, improving adherence via pharmacist, nurse, doctor, counselling, family/volunteers etc?
- What psychosocial help is available to support treatment?
- Are you able to refer patients for specialist help when needed?
-eg: where to, under what conditions, what barriers are there, what happens, are patients referred back to community when specialist help no longer appropriate?
- Are you able to refer patients for home/community care when needed?
-eg: under what conditions, what care and support is available, what other needs have to be met as well as treatment?

3. Contextual issues

- Who supplies drugs etc. for treatment,
-eg: sources of supply, local, national, international

- What is their quality like?
-eg: comments on quality, concerns about expiry dates, reliability, safety etc.,

- Are they suitable for local use?
-eg: ease of use vs. local skill levels, need for training, need for regular monitoring etc.

- What alternatives are possible if the supplies you want are unavailable or unaffordable?
-eg: have to choose different drugs; have to interrupt treatments or give short courses only; have to provide basic care only (eg. pressure sore care, bathing, laundry); have to cease treatments altogether

- Are traditional treatments or local remedies used alongside or instead of conventional medical treatments?
-eg: no, do not consider them effective; no, do not have access to practitioners or they will not cooperate with us; yes, would like to have them available; yes, people use them anyway; ask for description of some useful ones; how can use of these treatments/ remedies be improved?

5. What are the current advantages and disadvantages of providing treatments? How might the situation be improved or changed for the future? What are the barriers to future change?

- use diagram to produce categorised lists

Benefits here and now	Improvements for future
Disadvantages here and now	Barriers to future change

6. What specific issues do you think would be helpful in a toolkit for NGOs on access to treatment?

- review & listing of responses to questions 1-5
- themes
- topics
- techniques/tools
- information
- priorities - what three things are most essential for the toolkit?

4.5 NGO staff who are purchasers / providers of drugs for HIV-related treatments

1. What can tell you us about drugs and treatment for HIV-related conditions?

- personal feeling and attitudes
- types of drugs and treatments available
 - *generally available essential drugs; essential drugs for HIV-related conditions; new treatments for HIV-related conditions; other treatments used eg. traditional, unlicensed*
- appropriateness for local situations
 - *need: stage & dynamics of epidemic; other needs of local population; ease of use; need for other inputs such as testing, counselling, psychosocial help, local attitudes*
- cost and cost-effectiveness
 - *from PLHA perspective*
 - *from public health perspective*
 - *from community perspective*
 - *from NGO perspective*

2. What are your experiences with obtaining drugs and supplies for treatment of HIV & related conditions?

stories, case material

- where do you get information about what to purchase and how do you decide what drugs are needed?
 - *national essential drugs list, prescribers decide, depends what is available locally, NGO advisers decide; if standard lists are normally used, are any exceptions allowed and when; if donations used, are WHO or other guidelines applied?*
- what methods are used to decide how much to get?
 - *morbidity data and standard treatment guidelines, previous consumption and stock records, purchased on replacement only basis, don't know about calculations - purchase amount I am told to get*
- how are the supplies financed and how are costs contained?
 - *NGO pays full or part cost, other donors pay full or part cost, revolving fund generates some or all of necessary funds, income generating activities provide some or all of necessary funds, costs reduced by using community or joint NGO purchasing schemes, buyers' clubs, donations*
- what sources of supply are available?
 - *government drug supply system; national NGO drug supply system; local pharmacy; local drug store; in-country commercial drug suppliers; international commercial drug suppliers; international low-cost suppliers; donations from: NGOs, well-wishers, PLHA, drug producers/suppliers*

- how do you decide which sources to use?
- *lowest cost; prompt deliveries; most reliable quality and good expiry dates; only use suppliers we have previously approved or checked with other purchasers; use whatever supplier seems most convenient at the time; ask suppliers to quote prices and delivery times before choosing where to order from*

3. How do you ensure that the supplies are of good quality and are safe and effective to use?

- what expertise do you have on this aspect?
eg. does NGO have in-house expertise, are pharmaceutical &/or clinical advisers used, do they have specific training in drug quality & safety?
- what quality checks are used?
eg. - are suppliers' quality credentials checked before placing orders? are goods physically checked on receipt for: damage, discoloration, labelling, expiry dates; is certification of quality normally requested/received/reliable; what storage is available, is it adequately protected from light, moisture, heat/cold? do recipients of your supplies know how to look after drugs, control stocks, monitor expiry dates etc.
- what do you understand about safety aspects of drug supply?
eg - safe storage and prevention of theft, pilfering, misuse
 - disposal of unwanted or expired drugs
 - provision of supplies for safe administration *eg. syringes, needles, gloves, swabs*
- what responsibility / expertise do you have to ensure drugs are used effectively & safely?
eg. - are the requested drugs approved for use in the way that is intended, do they have full market authorisation, are they experimental, is an established drug being used in a novel way?
 - are the requested drugs safe for use in the intended recipients, *eg. children, pregnant women, elderly, people with kidney or liver problems etc?*
 - who takes responsibility for patient safety when drugs are used?

4. What factors help you to obtain supplies, what makes it difficult for you? What could be improved for the future and what would stop this?

- use diagram to produce categorised lists

Benefits here and now	Improvements for future
Disadvantages here and now	Barriers to future change

5. What specific issues do you think would be helpful in a toolkit for NGOs on access to treatment?

- *review & listing of responses to questions 1-5*
- *themes*
- *topics*
- *techniques/tools*
- *information*
- priorities - what three things are most essential for the toolkit?

SECTION 5

TOOLS FOR USE DURING FOCUS GROUPS AND / OR INDIVIDUAL INTERVIEWS

5.1 Instructions for questionnaires

1. ***Read the information sheet*** so that you understand what we are trying to find out about treatment access and HIV/AIDS
2. ***Complete the data sheet*** so that we know something about you and your work
3. ***Complete the parts of the questionnaire which are relevant to you*** so that we can understand something about your experiences and difficulties with HIV and access to treatment
4. ***Return the completed data sheet and questionnaire to the facilitator***

5.2 Information sheet for needs assessment participants and others

INTERNATIONAL HIV/AIDS ALLIANCE WITH WHO AND UNAIDS

PROGRAMME FOR DEVELOPMENT OF A TOOLKIT: ACCESS TO HIV/AIDS RELATED DRUGS & TREATMENTS FOR NGOs, CBOs & PLHA GROUPS

Introduction to purpose of toolkit on access to HIV/AIDS related treatment

The International HIV/AIDS Alliance is an international nongovernmental organisation (NGO) that supports community action on HIV/AIDS in developing countries. To date, the Alliance has supported over 850 NGO and community initiatives in Africa, Asia and Latin America, and has provided technical support to hundreds of other groups.

The International HIV/AIDS Alliance is collaborating with WHO / UNAIDS to carry out the first stage of the development of a toolkit for NGOs and community groups concerned with issues of access to treatment in HIV/AIDS and associated conditions such as sexually transmitted infections (STIs), tuberculosis (TB), mother-to-child HIV transmission, opportunistic infections (OIs), pain relief and palliative care. Treatment is understood to include traditional, herbal and domestic remedies alongside pharmaceutical drugs.

The primary aim of this project is to improve the ability of local NGOs to deal effectively with treatment access issues by assisting them to:

- Make decisions on involvement in treatment provision and drug supply, by providing a basic understanding of the main factors involved in HIV/AIDS treatment issues;
- Gain access to and make use of existing local and national drug supply systems where available; explore and use alternatives to these systems and drugs where necessary and useful; understand the uses of donated drugs and the constraints associated with their management and use;
- Work with the practical issues involved in drug supply and financing, with special regard to cost, quantification, quality and sustainability in the context of the development of the epidemic and in relation to other public health needs;
- Ensure good practice in the use of HIV/AIDS related drugs, including clinical requirements and the use of treatment protocols, technical support (such as laboratory services) and psychosocial support (such as confidentiality and counseling); and
- Develop and sustain alliances and linkages with other organisations and resources.

Overview of needs assessment for toolkit on access to HIV/AIDS related treatment

The Alliance / WHO / UNAIDS toolkit project commenced in July 1999 with a review of literature and tools already available. Two groups of people with relevant expertise were identified and recruited to assist with the project:

1. A small UK-based group to monitor and provide assistance to the Alliance consultant;
2. A larger international reference group who will assist the progress of the project by taking part in the needs assessment and providing comment and advice on elements of the toolkit as and when they are written.

The next step of the project is to carry out needs assessments with NGOs, community based organisations (CBOs) and people living with HIV/AIDS (PLHA). Tools have been designed to assist in the following tasks:

- Description and clarification of the needs and perspectives of NGO / CBO / PLHA groups about treatment access issues.
- In-country research of approx. 1 - 2 weeks in three countries by 1 or 2 Alliance staff / consultants, to carry out individual and group interviews, questionnaires and observations.
- Investigations with identified individuals in other countries through a mix of questionnaires, data collection and telephone interviews, taking place from November 1999 to February 2000.

Drafting of the toolkit will commence in April 2000 when the results of the needs assessment have been analysed and discussed with the reference group. The toolkit will then be field-tested in up to three countries. The final product is expected to be available by January 2001.

5.3 Data sheet for needs assessment participants:

INTERNATIONAL HIV/AIDS ALLIANCE WITH WHO AND UNAIDS

PROGRAMME FOR DEVELOPMENT OF A TOOLKIT: ACCESS TO HIV/AIDS RELATED DRUGS & TREATMENTS FOR NGOs, CBOs & PLHA GROUPS

This data sheet should be completed for every participant, giving basic information about the participant and about their organisation; please note that any indication of HIV status is optional - it will be treated as confidential, used only for statistical purposes and removed from any records when data collection is completed.

Participant's name:

Mailing address:

Telephone number:

Fax number:

E-mail address:

Current job title:

Name of organisation:

Address of organisation:

Summary of involvement with HIV/AIDS:

- professional:

- personal:

Participant's signature:

Facilitator's signature:

Date:

5.4 Questionnaire on access to treatment in HIV/AIDS

INTERNATIONAL HIV/AIDS ALLIANCE WITH WHO AND UNAIDS

**PROGRAMME FOR DEVELOPMENT OF A TOOLKIT:
ACCESS TO HIV/AIDS RELATED DRUGS & TREATMENTS
FOR NGOs, CBOs & PLHA GROUPS**

Please answer all the questions that are relevant to you. You may tick several answers in each section, or none, depending on your personal experience and knowledge.

There are no 'right' answers. If you do not answer questions for any reason, just leave them blank, for example: if they are not relevant to your situation, if you do not understand the question, or if you do not want to tell us something which is private.

A space is given at the end of each set of questions if you want to tell us something extra, or you may use a separate piece of paper.

Instructions:

All participants please answer all relevant questions under Sets 1, 2 and 8.

Users of treatments (PLHA), please also answer questions in Set 3.

Family carers or community volunteers, please also answer questions in Set 4.

NGO/CBO/PLHA group workers, please also answer questions in Set 5.

Medical prescribers treating PLHA, please also answer questions in Set 6.

NGO purchasing/procurement staff, please also answer questions in Set 7.

SET 1:

**QUESTIONS ON PERSONAL EXPERIENCES WITH
ANY KIND OF ILLNESS AND TREATMENT (NOT JUST HIV/AIDS)**

(NB. Questions in Set 1 are for all participants)

1.1. When you or someone in your family is ill, what is the first thing that you do?

-please tick all that apply to you:

- 1.1.1. rely on your own knowledge.....
- 1.1.2. consult other members of the family.....
- 1.1.3. consult a medical worker (doctor, nurse, pharmacist)
- 1.1.4. consult a local healer or unlicensed doctor.....
- 1.1.5. take some kind of medicine.....
- 1.1.6. use home remedies.....

1.1.7. other - please tell us what:

1.2. If you decide you need medicine, where do you go to get it?

-please tick all that apply to you:

- 1.2.1. local health post or health centre
- 1.2.2. community health worker
- 1.2.3. nearest hospital
- 1.2.4. a retail pharmacist
- 1.2.5. a local shop
- 1.2.6. a local healer
- 1.2.7. local market
- 1.2.8. collect plants to prepare home remedy
- 1.2.9. other - please tell us what:

1.3. How do you pay for care and treatment when you are ill?

-please tick all that apply to you:

- 1.3.1. all care and treatment are free
- 1.3.2. all care and treatment have to be paid for by the user (patient)
- 1.3.3. care is free but treatments such as medicines have to be paid for
- 1.3.4. insurance scheme pays entire cost
- 1.3.5. insurance scheme and user each pay part of the cost
- 1.3.6. other - please tell us what:

SET 2:
QUESTIONS ON EXPERIENCES WITH ILLNESS
AND TREATMENT RELATED TO HIV/AIDS

(NB. Questions in Set 2 are for all participants)

2.1. What are your feelings, attitudes, beliefs about treatment for illnesses related to HIV/AIDS?

-please tick all that apply to you:

- 2.1.1. treatments are always worthwhile
- 2.1.2. treatments are not as important as counselling and support
- 2.1.3. treatments are worthwhile but usually too expensive to try
- 2.1.3. I don't believe treatments are useful
- 2.1.4. treatments are only possible if you have good laboratory services
- 2.1.6. food and other basic needs are more important
- 2.1.7. I believe treatment is not worthwhile, drugs are too difficult to use
- 2.1.8. other - please tell us what
-
-

2.2. What are some of the health problems you experience with HIV, either personally or with the PLHA you help?

-please tick all that apply to you:

- 2.2.1. diarrhoea
- 2.2.2. problems with swallowing
- 2.2.3. skin infections
- 2.2.4. weight loss
- 2.2.5. hunger due to lack of food
- 2.2.6. headaches
- 2.2.7. other pains
- 2.2.8. psychological problems
- 2.2.9. coughs
- 2.2.10. tuberculosis
- 2.2.11. genital sores, swellings, discharge from vagina or penis
- 2.2.12. other problems- please say what they are.....
-
-

2.3. How do you find out which treatments are available for these problems?

-please tick all that apply to you:

- 2.3.1. family and friends
- 2.3.2. PLHA who are already receiving treatment
- 2.3.3. community support groups
- 2.3.4. health workers - doctors, nurses, pharmacists
- 2.3.5. traditional healers
- 2.3.6. radio, television
- 2.3.7. newspapers, popular magazines
- 2.3.8. e-mail networks or the internet

- 2.3.9. advertising by drug companies or drug sellers
- 2.3.10. medical journals, textbooks
- 2.3.11. other - please say what.....
-

2.4. When you know what treatment is available, how do you decide what to get?

-please tick all that apply to you:

- 2.4.1. do what doctor tells you
- 2.4.2. ask a qualified health worker to help you decide
- 2.4.3. consult with family/friends
- 2.4.4. see what is available free of charge
- 2.4.5. see how much you can get with the money you have
- 2.4.6. decide what other items to go without (eg food, transport)
- 2.4.7. ask for donations from drug suppliers
- 2.4.8. ask for unwanted medicines left over from someone else's treatment
- 2.4.9. other – please say what
-
-

2.5. If you or those you help have problems getting treatments, what are they?

-please tick all that apply to you:

- 2.5.1. not enough money to pay for them
- 2.5.2. health workers don't or won't prescribe them
- 2.5.3. government drug supply system does not work
- 2.5.4. commercial suppliers don't stock them
- 2.5.5. commercial supplies too expensive
- 2.5.6. supplies not always available
- 2.5.7. need to preserve secrecy means we can't ask for treatment
- 2.5.8. other - please say what
-
-

SET 3:
QUESTIONS FOR USERS OF TREATMENTS (PLHA)

(NB. The following questions are for users of treatments (PLHA) only).

3.1. How easy is it to use the medicines you have to take?

-please tick all that apply to you:

- 3.1.1. They are easy to use - I don't have any problems
- 3.1.2. It is difficult to know the proper way to use the medicines
- 3.1.3. It is difficult to remember when to take the medicines
- 3.1.4. It is difficult to swallow the medicine
- 3.1.5. It's difficult to have food with some medicines
- 3.1.6. I can't take the medicines without help
- 3.1.7. I can't use the medicines without extra equipment (eg. syringe/needle)
- 3.1.8. Sometimes the medicines have bad effects
- 3.1.9. Other - please say what:
-
-

3.2. Who helps you with taking the medicines when you need it?

-please tick all that apply to you and underline the ones you find most helpful:

- 3.2.1. Family/friend helps to remember when to take them
- 3.2.2. Written information or leaflets help me very much
- 3.2.3. Illustrated instructions help me very much
- 3.2.4. Local health worker or volunteer observes me taking them (DOT)
- 3.2.5. Local health worker gives me injections when I need them
- 3.2.6. Pharmacist gives advice about taking medicines
- 3.2.7. Other - please say what:
-
-

3.3. What makes you interrupt or resume treatment?

-please tick all that apply to you:

- 3.3.1. I stop if the medicines make me feel bad
- 3.3.1. I stop if the symptoms go away
- 3.3.1. I stop if I don't have food
- 3.3.1. I restart treatment if the symptoms come back
- 3.3.1. I sometimes forget doses if I am occupied with something else
- 3.3.1. I always take every dose until the medicine is finished
- 3.3.1. Other - please say what:
-
-

3.4. What are the effects do treatments have on your life with HIV/AIDS?

Please, briefly, give us your opinions on each of the following questions:

3.4.1 What treatments have been most helpful to you?

.....

3.4.2. What treatments have been most problematic?

.....
.....
.....
.....

3.5. Any further comments?

.....
.....
.....
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.....

SET 4:
QUESTIONS FOR FAMILY CARERS OR COMMUNITY VOLUNTEERS

(NB. The questions in Set 4 are for family carers or community volunteers only).

4.1. What help do you give to PLHA?

- please tick all that apply to you:

- 4.1.1. I help someone in my close family
- 4.1.2. I help my friends
- 4.1.3. I help in my local community
- 4.1.4. I give my time freely
- 4.1.5. I give a regular amount of time
- 4.1.6. I give a bit of time regularly

4.2. What support or training do you get to assist you in helping PLHA?

- please tick all that apply to you:

- 4.2.1. I just do it without any support or training
- 4.2.2. My local community supports me with encouragement
- 4.2.3. My local community supports me with material help
- 4.2.4. My local community helps me to go for training
- 4.2.5. A local NGO provides support
- 4.2.6. A local NGO provides training

4.3. How easy is it for the PLHA you help to use their medicines?

-please tick all that apply to you:

- 4.3.1. They are easy to use - no problems
- 4.3.2. It is difficult to know the proper way to use the medicines
- 4.3.3. It is difficult to remember when to take the medicines
- 4.3.4. It is difficult to swallow the medicine
- 4.3.5. It's difficult to have food with some medicines
- 4.3.6. They can't take the medicines without help
- 4.3.7. They can't use the medicines without extra equipment (eg. syringe/needle)
- 4.3.8. Sometimes the medicines have bad effects
- 4.3.9. Other - please say what:
-
-

4.4. What help is available for them with taking the medicines?

-please tick all that apply:

- 4.4.1. Family/friend helps to remember when to take them
- 4.4.2. I help and I have training to help me understand what is needed
- 4.4.3. I help but I don't have any training

- 4.4.4. Written information or leaflets are very helpful
- 4.4.5. Illustrated instructions are very helpful
- 4.4.6. Local health worker observes me taking them (DOT)
- 4.4.7. Local health worker gives injections when needed
- 4.4.8. Pharmacist gives advice about taking medicines
- 4.4.9. Other - please say what:

4.5. What effects do treatments have on the lives of the PLHA you help?
please, briefly, give us your opinions on each of the following questions:

4.5.1. What treatments have been most helpful to them?
.....
.....
.....
.....

4.5.2. What treatments have been most problematic?
.....
.....
.....
.....

4.6. Any further comments?
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SET 5:
QUESTIONS FOR NGO/CBO/PLHA GROUP WORKERS

(NB. The questions in Set 5 are for NGO/CBO/PLHA group workers only).

5.1. Please draw a simple diagram to show how your organisation is involved with PLHA and how any work to do with treatment fits in with other activities:

5.2. Please briefly describe the treatment ‘package’ which you offer to PLHA, including material support, psychosocial support, training and any other aspects

5.3. If treatment materials (drugs, medical supplies) are provided, how are they paid for?

-please tick all that apply:

- 5.3.1. NGO pays full or part cost
- 5.3.2. Government pays full or part cost
- 5.3.3. Insurance scheme pays full or part cost
- 5.3.4. Users pay a set fee
- 5.3.5. User pays full costs
- 5.3.6. Users never have to pay
- 5.3.7. Donated funds are used to buy drugs and materials
- 5.3.8. Donated drugs and supplies are used without charge whenever possible

5.3.9. Other - please say what:
.....
.....
.....

5.4. What effects do the treatments provided by your organisation have on the lives of the PLHA you help?

please, briefly, give us your opinions on each of the following questions:

5.4.1 What treatments have been most helpful to them?

.....
.....
.....
.....

5.4.2 What treatments have been most problematic?

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5.5. Any further comments?

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SET 6:
QUESTIONS FOR MEDICAL PRESCRIBERS TREATING PLHA

(NB. Questions in Set 2 are for medical prescribers treating PLHA only).

6.1. What are your experiences with PLHA coming for treatments?

-please tick all that apply:

- 6.1.1. Patients come for treatment whenever they have symptoms
- 6.1.2. Most patients do not know if they are HIV+
- 6.1.3. Patients only come when other measures have failed
- 6.1.4. Patients prefer to try traditional remedies or healers first
- 6.1.5. It's better to see HIV+ patients separately from other patients
- 6.1.6. People believe there is no treatment for HIV/AIDS
- 6.1.7. People have heard of antiretroviral drugs and want to have them

6.2. What support is available to help you with treating PLHA?

-please tick all that apply:

- 6.2.1. Treatment guidelines are available for HIV-related conditions
- 6.2.2. I can refer patients to hospital if necessary
- 6.2.3. Hospitals will refer patients back to local services when appropriate
- 6.2.4. Laboratory services are available for HIV testing only
- 6.2.5. Laboratory services are available for CD4 counts
- 6.2.6. Laboratory services are available for viral load testing
- 6.2.7. I mostly have to manage without laboratory services
- 6.2.8. Regular training and updates are available to me
- 6.2.9. I find it difficult to get up to date information
- 6.2.10. I am too busy to read new information or attend training sessions

6.3. Prescribing and access to drugs

-please tick all that apply:

- 6.3.1. People are mostly too poor to afford any treatments
- 6.3.2. People can afford simple treatments, but not expensive anti-infective drugs
- 6.3.3. Patients can mostly get the treatments I prescribe
- 6.3.4. Patients can't usually get what you prescribe
- 6.3.5. If drugs are unavailable or unaffordable, I have to change prescription
- 6.3.6. Treatment is sometimes interrupted if patients don't have money
- 6.3.7. Patients are more interested in getting food than medicines
- 6.3.8. I try to give short courses of drugs so people can afford them

- 6.3.9. Patients usually understand and remember how to use their drugs
- 6.3.10. Patients often do not take their drugs as prescribed

6.4. What effects do the treatments prescribed by you have on the lives of the PLHA you help?

please, briefly, give us your opinions on each of the following questions:

6.4.1 What treatments have been most helpful to them?

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6.4.2. What treatments have been most problematic?

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6.5. Any further comments?

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SET 7:

QUESTIONS FOR NGO PURCHASING/PROCUREMENT STAFF

(NB. Questions in Set 7 are for NGO purchasing/procurement staff only).

7.1. How do you know what to obtain?

-please tick all that apply:

- 7.1.1. Prescribers decide
- 7.1.2. Depends what is available locally
- 7.1.3. NGO advisers decide
- 7.1.4. Depends what goods donors are prepared to send
- 7.1.5. We refer to national essential drugs list or prescribing guidelines
- 7.1.6. We refer to WHO essential drugs list or prescribing guidelines
- 7.1.7. We observe WHO donation guidelines
- 7.1.8. Suppliers help us to decide

7.2. How to you know how much to obtain?

-please tick all that apply:

- 7.2.1. We calculate from morbidity data and treatment guidelines
- 7.2.2. We calculate from previous consumption and stock control data
- 7.2.3. We aim just to replace what has been used
- 7.2.4. Don't know how calculations are made - just obtain what I am told to get
- 7.2.5. Other - please say what

7.3. What sources of supply are available?

-please tick all that apply:

- 7.3.1. Government drug supply system
- 7.3.1. National NGO drug supply system
- 7.3.1. Local pharmacy or drug store
- 7.3.1. Local market traders
- 7.3.1. In-country commercial drug suppliers
- 7.3.1. International commercial drug suppliers
- 7.3.1. International low-cost or not-for-profit suppliers
- 7.3.1. Donations from NGOs, PLHA groups, or individuals
- 7.3.1. Donations from drug companies

7.4. How are supplies financed and costs contained?

-please tick all that apply:

- 7.4.1. NGO pays part or all of the costs
- 7.4.2. Other donors pay part or all of the costs
- 7.4.3. Revolving fund generates some or all of necessary funds
- 7.4.4. Costs reduced by using community or joint NGO buying schemes
- 7.4.5. Donations in kind are free, but NGO pays in-country transport and other costs
- 7.4.6. PLHA organise themselves in 'buyers clubs' to negotiate lower prices

7.5. How do you decide which sources to use?

-please tick all that apply:

- 7.5.1. Only use suppliers previously checked by us or sister organisations
- 7.5.2. Use whatever supplier offers cheapest prices at the time
- 7.5.3. Always compare quotations from suppliers before placing orders
- 7.5.4. Depends on supplier's history with efficiency and promptness of deliveries
- 7.5.5. Depends on supplier's history with drug quality and shelf-life

7.6. How do you make sure that the drugs are of good quality?

-please tick all that apply:

- 7.6.1. Don't know how to do this
- 7.6.2. Drugs are always urgently needed, so it is difficult to stop them being used before we check them
- 7.6.3. We always check the appearance and labelling on receipt of goods
- 7.6.4. We make sure that drugs are always stored away from heat and light
- 7.6.5. We get advice from a trained pharmacist
- 7.6.6. We have some useful written information on this
- 7.6.7. We provide training and advice to recipients of our supplies about storing and looking after drugs
- 7.6.8. We run regular stock checks and destroy out of date items

SET 8:

**QUESTIONS ABOUT “CHECK LISTS” OF AVAILABLE
AND / OR DESIRED DRUGS AND TREATMENTS**

(NB. The questions in Section 8 are for all participants for whom the questions are relevant).

8.1. WHO/ UNAIDS list of “marker” drugs

WHO/UNAIDS consider the following items to be “markers” of availability and accessibility of medical treatments for HIV and related conditions. If you are familiar with these items, please indicate their local availability by ticking the appropriate box for each one:

Drug names (generic name), alternative or "trade" names, and main indication for use	Availability				
	Often	Some times	Rarely	Never	Don't know
Benzylpenicillin 600 mg, 3 g (as sodium salt) 5 ml vial antibacterial					
Erythromycin 250mg tablets/capsules ('Erythromid') antibacterial					
Gentamicin injection 40mg/ml ampoules 2ml ('Genticin', 'Garamycin', 'Cidomycin') antibacterial					
Sulfamethoxazole+trimethoprim 400/80 mg tablets (co-trimoxazole, 'Bactrim', 'Septrin') antibacterial					
Isoniazid (H) tab 300 mg antituberculous					
Nystatin 0.5 M IU pessaries ('Nystan', 'Mycostatin') antifungal					
Ketoconazole 200mg tablets ('Nizoral') antifungal					
Fluconazole 100 mg tablets/capsules ('Diflucan') antifungal					
Aciclovir 200mg tablets (acyclovir, 'Zovirax') anti-herpesvirus					
Pyrimethamine tab 25 mg antitoxoplasmosis					
Sulfadiazine tab 500 mg antibacterial Antitoxoplasmosis					
Calcium folinate tablet 15 mg cytotoxic					
Calamine lotion with sulphur 2%, bottle anti-Inflammatory and antipruritic					
Loperamide tablet 2mg anti-diarrhea					
Codeine tab 30 mg opioid analgesic					
Morphine sulfate injection 2mg/ml ampoules 2ml opioid analgesic					
Vinblastine powder for injection, 10 mg (sulfate) or vincristine powder for injection, 1 mg, 5 mg (sulfate) anti-cancer (Kaposi sarcoma)					
Zidovudine 100mg capsules (AZT, 'Retrovir') anti-retroviral					
Didanosine (ddl) anti-retroviral					
Stavudine (d4T) anti-retroviral					
Lamivudine (3TC) anti-retroviral					
Nevirapine anti-retroviral					
Protease inhibitor (indinavir or nelfinavir or ritonavir or saquinavir)					
Condoms, female					
Condoms, male					

8.3 Other drugs or local treatments not available

Please tell us about other drugs or treatments which you regularly want but cannot get. Please tell us what each one is, what it is used for and what stops you getting it:

Drug or Treatment	What would you use it for?	What stops you from getting it at present?

**THANK YOU FOR YOUR TIME AND HELP - PLEASE RETURN YOUR
DATA SHEET AND QUESTIONNAIRE TO THE FACILITATORS**

*If you have any further comments which you want to add,
please do so on this sheet.*