

Expanding access to HIV treatment through community-based organizations

A joint publication of Sidaction, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO)

UNAIDS BEST PRACTICE COLLECTION



Cover photos by
D. Sentle/ACHAP and L.Alyanak/UNAIDS

UNAIDS/05.10E (English original, July 2005)

© Joint United Nations Programme on HIV/AIDS (UNAIDS) 2005.

All rights reserved. Publications produced by UNAIDS can be obtained from the UNAIDS Information Centre. Requests for permission to reproduce or translate UNAIDS publications—whether for sale or for noncommercial distribution—should also be addressed to the Information Centre at the address below, or by fax, at +41 22 791 4187, or e-mail: publicationpermissions@unaids.org.

The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of UNAIDS concerning

the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by UNAIDS in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

UNAIDS does not warrant that the information contained in this publication is complete and correct and shall not be liable for any damages incurred as a result of its use.

WHO Library Cataloguing-in-Publication Data

Expanding access to HIV treatment through community-based organizations.

(UNAIDS best practice collection)

1.HIV infections - therapy 2.Acquired immunodeficiency syndrome - therapy 3.Anti-retroviral agents - supply and distribution 4.Patient care 5 Community networks 6.Health care surveys 7.Africa I.Sidaction II.UNAIDS III.World Health Organization IV.Series.

ISBN 92 9 173421 7

(NLM classification: WC 503.2)

UNAIDS – 20 avenue Appia – 1211 Geneva 27 – Switzerland
Telephone: (+41) 22 791 36 66 – Fax: (+41) 22 791 41 87
E-mail: unaids@unaids.org – Internet: <http://www.unaids.org>

Expanding access to HIV treatment through community-based organizations

A joint publication of Sidaction,
the Joint United Nations Programme on HIV/AIDS (UNAIDS)
and the World Health Organization (WHO)



UNAIDS, the World Health Organization and Sidaction gratefully acknowledge the support of many community-based organizations around Africa; without their help this report would not have been possible.

These organizations include the Association nationale de soutien aux Séropositifs et Sidéens (ANSS) of Burundi, the Women Fighting AIDS in Kenya (WOFAK), and the Association de recherche, communication et accompagnement à domicile des personnes vivant avec le VIH-SIDA (ARCAD-SIDA) of Mali. We also acknowledge the contribution made by Solidarité Sida of France.

We are grateful also for the many formal and informal contributions made by colleagues and friends too numerous to list. The text of this publication was prepared by Marie de Cenival and Clémence Prunier-Duparge of Sidaction (France).

Table of contents

Abbreviations and acronyms	4
Foreword	6
Executive Summary	8
Introduction	11
Methodology	12
Results	13
Filling gaps with a range of structures and services	16
Providing comprehensive care, including medical care and antiretroviral therapy	17
Providing support for affected people	22
Networking for treatment access	24
Working through faith-based associations	26
Attending to the needs of women and children	26
Supporting free-of-charge treatment	28
Responding to the increasing demand for treatment	29
Expanding treatment through different growth models	30
Strengthening the community response	32
Funding the purchase of antiretroviral therapy	32
Decentralizing treatment	34
Managing drug supplies	35
Building client and staff capacity	35
Meeting structural needs	37
Taking steps in support of community-based access to treatment	37
Conclusion	39
Annex 1: Questionnaire 1	40
Annex 2: Questionnaire 2	43
Annex 3: Geographic distribution of responses to Questionnaire 1	46
Annex 4: Community-based organizations that responded to Questionnaire 1	48
Annex 5: Community-based organizations that responded to Questionnaire 2	55
Annex 6: Antiretroviral treatment coverage and need at the time of the Survey	57

Abbreviations and acronyms

AAS	Association African Solidarité
AEDES	Agence Européenne pour le Développement et la Santé
AFSU	Association des Frères et Sœurs Unis
AFXB	Association François-Xavier Bagnoud
AIDS	Acquired immunodeficiency syndrome
AIDSETI	AIDS Empowerment and Treatment International
ALCS	Association de Lutte Contre le Sida
ANSS	Association Nationale de Soutien aux Séropositifs et Sidéens
ARCAD Sida	Association de Recherche, de Communication et d'Accompagnement à Domicile de Personnes Vivant avec le VIH/SIDA
ARV	Antiretroviral (drug)
ART	Antiretroviral therapy
BUWAI	Budiope Welfare Action Initiative
CAMEBU	Centrale d'Achat des Médicaments Essentiels du Burundi
CBO	Community-based organization
CERKES	Centre de Reference de Kenedougou Solidarité
CESAC	Centre d'Ecoute, de Soins, d'Animation et de Conseils (managed by ARCAD Sida)
CIC-Doc	Centre d'Information, de Conseil et de Documentation
CICR	Comité International de la Croix-Rouge
CSAS	Centre Solidarité Action Sociale de Bouaké
DACASA	Dandora Community AIDS Support Organization
DFID	Department for International Development (UK)
ESTHER	Ensemble Pour une Solidarité Thérapeutique en Réseau
FHI	Family Health International
FIDA	International Federation of Women Lawyers, Kenya
FOPHAK	Foundation of People Living with HIV/AIDS in Kenya
FSU Com	Formation Sanitaire Urbaine Communautaire
GATAG	Ghana Aids Treatment Access Group
GNP+	Global Network of People living with HIV/AIDS
HAI	Health Action International
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
IAS	International AIDS Society
IBAARV	Initiative Béninoise d'Accès aux ARV
ICASO	International Council of AIDS Service Organizations
ICW	International Community of Women with HIV/AIDS
IMEA	Institut de Médecine et d'Epidémiologie Appliquée
JAAIDS	Journalists Against AIDS
JCRC	Joint Clinical Research Centre, Uganda
KANCO	Kenya AIDS NGOs Consortium
KMA	Kenya Medical Association
LAHACO	Laikipia HIV/AIDS Control Organization
MAP	Multi-Country HIV/AIDS Programme
MDM	Médecins Du Monde
MSF	Médecins Sans Frontières
NAP	National AIDS programme
NEPHAK	National Empowerment of People living with HIV/AIDS in Kenya
NGO	Nongovernmental organization

PATAM	Pan African Treatment Access Movement
PLWHA	People living with HIV and AIDS
PMTCT	Prevention of mother-to-child transmission (of HIV)
PSF	Pharmaciens Sans Frontières
PWAs	People With AIDS
RAME	Réseau Accès Médicaments Essentiels
REVS+	Responsabilité Espoir Vie Solidarité
RIBUP	Renforcement de l'Initiative Burundaise dans le domaine de la Prévention et la prise en charge des PVVIH
RIP+	Réseau Ivoirien des ONG de Personnes vivant avec le VIH/SIDA
SAIL	Stop AIDS in Liberia
SAS Centre	Centre Solidarité Action Sociale
STI	Sexually transmitted infection
SWAA	Society for Women and AIDS in Africa
SWAK	Society for Women and AIDS in Kenya
TAC	Treatment Access Campaign
TAM	Treatment Action Movement
TAPWAK	The Association of People Living With AIDS in Kenya
TASC	The AIDS Information and Support Centre
TASO	The AIDS Support Organisation
UNALS	Union Nationale des Associations de Lutte contre le Sida
VCT	Voluntary counselling and testing
VIH	Virus de l'immunodéficience humaine
WHO	World Health Organization
WOFAK	Women Fighting AIDS in Kenya

Foreword

Every day, 8000 people living with HIV die from AIDS. Many of these deaths could be prevented through access to care, in particular, antiretroviral treatment. WHO and UNAIDS estimate that nearly six million people in low- and middle-income countries need this treatment; yet at the end of 2004, only 700 000 were on antiretroviral therapy. This was a significant increase from just six months earlier, and many countries are on the verge of expanding access to HIV treatment on a large scale. However, today nearly nine out of ten people in need still cannot obtain antiretroviral therapy. This lack of HIV treatment in low- and middle-income countries remains a global public health emergency.

The vast majority of people in need cannot obtain care and treatment in time to prolong their lives. Therefore, community-based organizations have been compelled to do for treatment what they did for prevention—place themselves on the cutting edge of treatment advocacy. Increasingly, they also lead and undertake operational programmes to deliver treatment while awaiting a much-needed public sector response.

This Best Practice document describes a ground-breaking survey by Sidaction, a Paris-based treatment rights group which supports community responses to AIDS in low- and middle-income countries. For the first time, Sidaction has mapped treatment and care efforts by community-based organizations in Africa. The survey results show that many African community-based organizations are already dispensing antiretroviral therapy on a significant scale. Others will soon begin, and still others are facilitating access to treatment through advocacy, education, voluntary counselling and testing, bulk purchasing of medicines, and mutual support.

Indeed, some are providing comprehensive, free-of-charge “total patient care” services, from entry into testing, followed by treatment, monitoring, and support for adherence to treatment regimens. These community efforts are often mounted by people living with HIV and are in direct response to the actual needs of those affected, including underserved groups such as women and children. With few resources, community-based organizations are responding through a wide range of flexible arrangements that support increased access to treatment. The Sidaction survey is a first effort to study, describe and recognize their efforts.

The survey confirmed that community efforts to provide treatment represent an important opportunity to enrol more people in antiretroviral therapy. To seize this opportunity, national governments and the international community need to quickly provide support to expand the coverage and impact of community-based treatment. The aim is not to replace

work rightfully done by the public sector with action by community-based organizations. The challenge is to find ways for community organizations to mobilize to respond to their particular HIV situation, while working closely with the public health sector, so that each reinforces the efforts of the other.

The survey showed that this is already happening in many places—community-based organizations are coming together and joining with the public sector to provide services that complement public health efforts. But community efforts need support. These organizations need funding to finance the purchase of antiretrovirals, other medicines and diagnostics. They need national and sub national policies that support decentralizing treatment beyond urban centres and selected physicians. They need the ability to train staff and clients in treatment literacy, and they need technical assistance to improve and monitor quality of services.

As they have done throughout the AIDS epidemic, communities will rise to confront the challenges they face and will struggle to do what needs to be done. They should not have to struggle alone. They should be recognized as full partners and supported in a united effort to reduce the tragic and unnecessary deaths and suffering caused by this epidemic, and by the glaring inequities in health care and treatment throughout the world.

Dr Purnima Mane

Director

Department of Policy, Evidence and Partnerships

Joint United Nations Programme on HIV/AIDS

July 2005

Executive Summary

In the course of the AIDS epidemic, community-based organizations have emerged to provide essential services in HIV-related prevention, care and treatment. They have done so in response to the desperate needs of those affected by the epidemic and to fill gaps in public sector provision of these services. As antiretroviral medicines have become more affordable, community-based organizations have fought for, and begun to provide, greater access to treatment, including antiretroviral therapy.

Yet little has been done to catalogue the work of community-based organizations in care and treatment. This UNAIDS Best Practice Collection document aims to highlight and advocate the work of civil society, community-based organizations in particular, in responding to the AIDS epidemic in Africa. It is hoped that this will inspire civil society organizations in other regions to replicate the African experience. We equally hope that this document could demonstrate the valuable contributions of civil society as active partners in the response to both national authorities and funding agencies so that the work of community based organizations is supported and strengthened.

In 2004, Sidaction, a Paris-based treatment rights group, in cooperation with the UNAIDS Secretariat and WHO, conducted research on community-based responses to care and treatment in Africa. This research was the first attempt to map the contributions of community-based organizations in these areas. It aimed to better understand and support the work of community groups, including associations of people living with HIV, in creating greater access to care and treatment. This research was co-funded by the UNAIDS Secretariat and Sidaction.

The research involved creating a database of contacts, sending out two questionnaires, and analysing responses. Survey responses included self-reported data that were not independently verified. Nevertheless, the responses (which were consistent, wide-ranging and similar in tone and content) identified and described: (a) community-based organizations involved in providing care and treatment; (b) the nature and extent of their work; (c) the opportunities and constraints they faced; and (d) ways to support and expand their efforts.

The survey confirmed the existence of an extensive community response to HIV care and treatment which appears to respond and change according to community needs. Flexible community action comes from medical providers, support groups, networks and consortiums of people living with HIV, and faith-based organizations. Most of these community-based organizations are run by and for people living with HIV. Because they are driven by the needs of their clients, they have become increasingly involved in treatment access. Many report they are shifting, or want to shift, their activities towards treatment.

For example, support groups for affected people have become involved in treatment and compliance support. Networks and consortiums of people living with HIV have oriented their advocacy and policy and programme input towards treatment access. Some faith-based organizations with major experience in health care and dedicated funding sources have moved towards providing antiretroviral therapy. These diverse groups represent significant potential for scaling up access to treatment through different types of community responses and services.

Many community-based organizations are already providing critical care and treatment services which support or ensure treatment access. These include: community mobilization; pre- and post-test counselling; HIV testing and results analysis; psychosocial support; treating

opportunistic infections and providing palliative care; home-based care; information, education and advocacy sessions on antiretroviral therapy and treatment access; financial support and income-generation for purchasing antiretroviral medicines; treatment programmes for women and children; antiretroviral bulk-ordering; prescribing antiretroviral drugs; training health-care workers; medical follow-up; and treatment compliance clubs.

Some community-based organizations report they provide the full range of medical services needed for antiretroviral therapy: medical consultations; prescribing antiretroviral medicines and drugs against opportunistic infections; ordering pre-treatment tests and follow-up on antiretroviral therapy; therapeutic choice based on laboratory results and stage of HIV infection; monitoring and managing possible adverse effects; and counselling on compliance. The survey said the organizations showed a high level of professionalism and obtained positive therapeutic results.

Several community-based organizations combine their services to provide “total or comprehensive patient care” which encourages clients to come out of isolation, enter HIV testing services, receive and manage results, receive care and treatment, and sustain compliance over time. In some places, it appears that public sector providers have come to recognize and even depend on the work of community-based organizations. This is because they provide much-needed activities and ensure efficient use of public services by doing such things as keeping client/patient lists, supporting clients through appointments and procedures, attending to their needs in hospital, and following up on medical and psychosocial issues.

Community-based organizations providing treatment access say that being able to do so has removed the terrible psychological weight of helplessness their staff have felt in the face of sickness and death. Furthermore, in a relatively easy manner they have been able to acquire the new knowledge and skills needed to provide and monitor antiretroviral therapy. However, they struggle with difficult ethical decisions such as the allocation of limited supplies, and are under enormous pressure to expand their programmes so they can provide antiretroviral therapy to more clients.

Community-based organizations are also struggling to respond to the financial challenges posed by increasing access to treatment. In the survey, they unanimously supported providing antiretroviral therapy free of charge, stating that free-of-charge services were necessary to bring people into treatment, as well as to sustain treatment and compliance over time. However, the organizations say their greatest challenge is funding the purchase of antiretrovirals for delivery to their clients. Many organizations reported that increased funding would immediately allow them to expand services to more clients, or move into providing antiretroviral therapy if they have not yet done so.

The organizations also report that they have difficulty in obtaining access to antiretroviral medicines because authorization to purchase or prescribe them is limited in some countries to only a few capital city distribution centres, and/or to mainly city-based physicians. Other challenges include: difficulty in acquiring funding for costs such as salaries, rent, premises and equipment, which prevents them from retaining staff and the services of physicians; the need for antiretroviral therapy for their own staff, many of whom are HIV-positive; training staff, clients and the community in treatment and antiretroviral therapy literacy; and managing drug supplies to avoid shortages that can harm clients.

The research confirmed that community care and treatment responses should be recognized as an important component of greater access to treatment; brought to the attention

of policy-makers, programme-managers and donors; and supported in ways that will lead to greater impact, quality and appropriate partnership with public health efforts. The steps required to support community care and treatment responses include:

(a) Providing advocacy and support for community-based responses through North-South and South-South exchanges, funding for purchasing antiretroviral therapy and paying for various operational costs, and policies and programmes that decentralize treatment access;

(b) Providing support for networking among community-based organizations on information, experience, training, drug procurement, supply management, and funding, including for antiretroviral medicines;

(c) Carrying out additional research on community-based treatment opportunities and constraints and ways to: monitor and evaluate service quantity, quality and impact; provide technical assistance to improve quality and coverage; strengthen community responses while supporting primary health responses; and

(d) Undertaking similar efforts to map community involvement in care and treatment on other continents;

If national authorities and donors commit to providing these forms of support, the valuable care and treatment work of community-based organizations will receive the recognition and strengthening it deserves. Their work presents an incredible opportunity to expand treatment. We must ensure this opportunity is not lost.

Introduction

In the context of the global HIV epidemic, millions of people desperately need care and treatment, particularly life-prolonging antiretroviral therapy. More than ever before, greater political will, increased resources and more affordable drugs now make it possible to meet this need.

However, enormous challenges remain as countries hardest hit by the epidemic struggle to find the capacity and resources to deliver care and treatment to those who need it. In many places throughout Africa and elsewhere, community-based organizations, often run or staffed by people living with HIV, are providing critical advocacy, action and services towards providing HIV care and treatment, including access to antiretroviral medicines.

Community action for access to treatment

In Burkina Faso, two community-based organizations began to import generic HIV medicines before other providers and procurement agencies. In Burundi, community groups, particularly the largest organization of people living with HIV, have been the primary agencies that prescribe and deliver antiretroviral drugs in the country. In Mali, before the government launched its own programme, antiretrovirals were first brought into the country through community organizations with the support of patients and health professionals. In South Africa, AIDS treatment activists have conducted ground-breaking work in advocacy, community mobilization and litigation to increase access to care and treatment across the continent and beyond.

However, the crucial role played by community-based organizations has not been widely recognized outside of their communities. Their potential to be partners in providing care and treatment has also not been adequately explored. To raise awareness of this issue, Sidaction decided to undertake a survey of community-based organizations involved in providing care and treatment in Africa. Its efforts received support from UNAIDS and WHO, and the survey activities were carried out in cooperation with a working group of three African community-based organizations—ANSS, ARCAD Sida and WOFAK. The survey's overall purpose was to better understand and support the work of community groups, including associations of people living with HIV, in creating greater access to care and treatment. Their work is particularly relevant in relation to WHO's "3 by 5" Initiative—to have 3 million people on antiretroviral treatment by the end of 2005.

Specific objectives of the survey included:

- identifying community-based organizations involved in providing care and treatment;
- identifying opportunities and constraints faced by community-based organizations face in helping to create greater access to care and treatment;
- identifying ways to support the efforts of community-based organizations in order to increase the impact of their work;
- bringing the work of these organizations to the attention of policy-makers, programme managers and donors, and
- creating a database of these organizations for networking, exchange and support purposes.

To meet these objectives, Sidaction conducted a survey throughout Africa from January to April 2004. This UNAIDS Best Practice Collection publication presents survey findings outlining the work of civil society in Africa and offers suggestions about the current and potential role of community-based organizations in providing HIV care and treatment. The survey results confirm that these organizations, including groups of people living with HIV, have been and can continue to be powerful partners which support and/or provide access to HIV care and treatment. Their efforts cover a wide spectrum of activities that facilitate treatment access. These include advocacy, bulk purchase of antiretroviral drugs, establishing health-care organizations for a variety of medical follow-up services, and providing antiretroviral therapy, care and other services.

Governments have a fundamental responsibility to protect and ensure the human right to health and health care. However, community-based organizations and people living with HIV represent much-needed and underused partners that provide critical services, reach marginalized groups missed by mainstream health services, and fill gaps along the continuum of care. At a time of growing and urgent demand for treatment, the research in this document suggests that much more needs to be done to support increased involvement by community-based organizations in providing care and treatment. This includes lining up resources for their activities, convincing governmental partners and donors to recognize their work, and developing ways to monitor and evaluate their efforts.

Methodology

Based on quantitative and qualitative data, the research included a survey and analysis of the extent and nature of involvement of community-based organizations in HIV care and treatment in African countries. The term “community-based organization” was defined to include: all types of groups such as organizations, associations, networks, and support groups that were community-based, locally- or nationally-directed, funded by individuals, or that sought and received external funds. The survey covered all countries in Africa.

The research involved: (a) creating a list of potential contacts from various sources; (b) sending out a short questionnaire (Questionnaire 1, see Annex 1) to all of those on the contact list, and tabulating results; (c) based on responses to Questionnaire 1, sending out a second more detailed questionnaire (Questionnaire 2, see Annex 2) to those with experience in providing care and treatment, and tabulating results; and (d) analysing survey results and selected material from reports sent to Sidaction by its partners, as well as experience drawn from Sidaction’s partnerships with 40 African community-based organizations over seven years.

Questionnaire 1 was sent to: (a) more than 1000 organizations which make up Sidaction’s international contacts;¹ (b) 140 network contacts at organizations such as FHI, ICW, ICASO, IMEA, ESTHER, World Vision, Ford, MDM, MAP, ICRC, and others; and (c) contacts on the mailing lists of PATAM, E-Forum (Nigeria), E-Med, E-Drug, CARE International, and WHO’s “3 by 5” Initiative.

In Questionnaire 1, respondents were asked to report whether they were involved in HIV testing, medical follow-up of people living with HIV, and facilitating or intending to facilitate access to antiretroviral therapy. They were also asked to list other community-based organizations in their countries that appeared to be actively involved in obtaining access to antiretroviral medicines. All contacts were followed up by e-mail, fax or telephone. The goal of this distribution was to reach all known contacts of AIDS organizations and professional and activist networks in Africa. From this exercise, a database was created of the widest possible list of organizations responding to AIDS in Africa.

¹ Sidaction’s International contacts included ANNEA for East Africa, NAM, ICASO, NAP+/GNP+, DFID, USAID, IRIN. Other contacts included Solidarité AIDS, Aides, Action Aid, AEDES, ESTHER, Act Up Paris, and ALCS.

One thousand copies of Questionnaire 1 were sent out; 285 were returned (for the geographic distribution of responses, see Annex 3. For a list of community-based organizations that responded to Questionnaire 1, see Annex 4). Based on the responses, 11 community-based organizations were excluded from further contact and use in the analysis because they were judged to fall outside the research remit. These included: public or semi-public organizations, research bodies, private organizations (private clinics, consulting groups, business coalitions), and large-scale organizations, including mission-hospital chains that were run by a faith-based body such as a church administration. Others were excluded because they did not specialize in HIV prevention and AIDS-care services, and also had the equivalent capacity of a public health programme.²

Based on responses to Questionnaire 1 indicating participation in access to care and treatment, 100 organizations were selected to receive Questionnaire 2. It contained five pages of questions and was intended to elicit more specific and detailed information on the nature and extent of care and treatment activities, particularly facilitating access to antiretroviral therapy. Of these 100 organizations, 44 responded (for a list of community-based organizations that responded to Questionnaire 2, see Annex 5).

In total, 274 responding community-based organizations fit the definition of community-based organization used in this report, and were selected as the primary sources for the descriptive accounts and analysis that follow.

Results

The research results included self-reported data collected from responses to the survey questionnaires. Combined with Sidaction's experience in and knowledge of community-based organization involvement in HIV treatment and care in Africa, these data formed the basis for the analysis that follows.

The survey identified many African community-based organizations that said they provided care and treatment, including antiretroviral therapy in some cases, to people living with HIV. The results have helped to map and describe the experience of community-based organizations in providing care and treatment in Africa.

Two databases of contacts and information have been compiled. One is an index by country of all community-based organizations contacted during the survey. The other is a catalogue of all contacts, as well as brief presentations on 200 African organizations which reported they were involved in providing care and treatment, including access to antiretroviral therapy.³

² However, these groups do constitute real potential in terms of increasing access to treatment.

³ The index of organizations and the catalogue "Community-based organizations facilitating access to antiretrovirals in Africa. A selective review. Sidaction 2004" are available on the Sidaction website: www.sidaction.org/accescommun

Key statistics emerging from Questionnaire 1

Number of countries from which at least one response was received	45
Number of community-based organizations used in the analysis	274
Total number of clients that community-based organizations reported as recipients of their services	210 400
HIV testing services – number of community organizations reporting that they:	
Conducted pre- and post-HIV testing activities	192
Provided on-site testing	96
Conducted on-site analysis of test results	75
Medical follow-up	
Number of community organizations reporting they provided medical follow-up	176
Number of clients they said received medical follow-up from them	163 000
Number of physicians/medical assistants they used	1 130
Number of nurses/health-care aides they used	11 181
The total number of medical personnel they used	12 311
Number of community organizations reporting they provided treatment for opportunistic infections	141
Number of community organizations reporting they received medications through donations	72
Number of community organizations reporting that clients did not pay entire costs	144
Access to antiretroviral drugs – number of community organizations reporting:	
They were involved in access to antiretrovirals	182
They prescribed antiretrovirals	68
They provided financial support	81
They ordered antiretrovirals in bulk	57
They provided medical follow-up of people on antiretroviral therapy	133
They provided psychosocial follow-up of people on antiretroviral therapy	156
They provided information/education sessions on antiretroviral therapy	159
Total number of persons on antiretroviral therapy who were under the auspices of the organizations	14 896
Future involvement in access to antiretroviral drugs – number of community organizations reporting:	
They were not involved in antiretroviral therapy, but intended to be	94
They expected to launch antiretroviral therapy action in the coming year	88

The number of responses received from each country reflected the number of community-based organizations included on the list of contacts. For instance, a total of 60 responses were received from Kenya, Nigeria and Uganda (Questionnaire 1 had been sent to 200 contacts in these countries). Only one or two responses were received from countries with few contacts, such as Algeria, Comoros, Eritrea, Guinea, Guinea-Bissau, Liberia, Madagascar, Mauritania, Mauritius, Namibia, Niger, Seychelles, Somalia, Sudan and Tunisia. No responses were received from Cape Verde, Djibouti, Egypt, Equatorial Guinea, Libya, Sao Tome and Principe, and Tunisia.

The survey did not focus on disparities in the number of operating community-based organizations and rate of response across countries. However, disparities that showed up could be due to several factors, including population size, the overall development of civil society, socio-political issues, the nature of the epidemic and the response to it, and government monopolies on purchasing and providing antiretroviral medicines. Some of these issues are discussed in the sections below.

The 274 community-based organizations included in the analysis reported they had a total of 210 000 clients. One hundred and thirty-seven responses were received from English-speaking Africa, 119 from French-speaking Africa and 18 from Portuguese-speaking Africa. One hundred and seventy-six organizations reported that they provided some form of medical care, including opportunistic infection prophylaxis and treatment, palliative care and, in some cases, antiretroviral therapy. All together, these organizations reported that 163 000 clients benefited from some or all of these services. Some organizations reported that they provided medical care to only a few people, while others said they provided care to thousands. For example, at the time of the survey, TASO (Uganda) reported it was offering medical care to 30 000 people, while FOPHAK (Kenya) said it was providing care to 15 000 people.

In reply to the question, “How many people are on ARVs in your organization?”, the survey showed that the organizations had 14 896 people on antiretroviral therapy “among their members and clients”. This amounted to 9% of the 163 000 people receiving medical care. Taking into account the fact that community-based organizations’ clients often might be at advanced stages of disease, this figure would appear to be low.

On the other hand, this figure was significant when compared with the total number of people reported to be on antiretroviral therapy in Africa: 100 000 people at the time of the survey, out of an estimated 4.4 million people who needed it.⁴ These responses suggested that almost 15% of HIV patients on antiretroviral therapy in Africa used the services of one of the community-based organizations surveyed.

Of the 182 community-based organizations reporting they had persons on antiretroviral therapy under their auspices, 133 said they provided some “medical follow-up for patients on ARVs”. Sixty-eight of those organizations were involved in prescribing antiretrovirals to a total of 7000 people. However, their capacity varied greatly: 91 organizations reported providing care to more than 10 people on antiretrovirals, 72 to more than 20 people, and 24 to more than 100 people. (For the extent of antiretroviral treatment coverage and need at the time of the survey, see Annex 6).

⁴ These community-based organizations were equally distributed between French-speaking (43 out of 91) and English-speaking Africa (47 out of 91). Only one Portuguese-speaking organization stated that it was treating more than 10 people with antiretrovirals.

These organizations reported they were involved in helping people obtain access to antiretroviral drugs through various activities:

- 87% said they provided psychosocial support;
- 85% said they provided information/education sessions on antiretrovirals;
- 73% said they ensured medical follow-up of patients taking antiretrovirals;
- 45% said they provided financial support to clients for purchasing antiretrovirals;
- 31% said they bulk ordered drugs for a group of people receiving antiretrovirals;
- and
- 10% said they were exclusively involved in lobbying/advocacy for access to antiretrovirals.

The survey participants also reported that 1130 “physicians and medical assistants” and 11 181 “nurses and health-care aides” were involved in medical follow-up. The survey did not specify whether these physicians offered services to the organizations a few hours a week while being employed by the public system, or were the organization’s full-time employees. In the category of nurses and health-care aides, staff ranged from qualified nursing personnel, to people making regular home-visits to members of the organization.

Of the 274 organizations that responded to Questionnaire 1, 192 said they offered pre- and post-test counselling services, 96 reported that they provided on-site testing, and 75 reported that they interpreted tests. This means that almost 30% of the organizations which replied to Questionnaire 1 said they were providing complete HIV counselling and testing services. Almost 80% of the organizations reporting that they provided HIV testing services also said they offered medical follow-up for opportunistic infections. This finding appeared significantly different from standard practices in the public or private sector where it is common to test without counselling, and where testing centres have rarely offered comprehensive medical follow-up services.

Discussion

Filling the gaps with a range of services and arrangements

During the course of the AIDS epidemic, out of necessity, dedication and compassion, community-based organizations have moved to fill gaps in prevention and care services in affected communities. The Sidaction survey confirmed that in practically all sub-Saharan African countries, community-based organizations have been founded in order to provide services that could or should have been the responsibility of public health and social services.

In fact, it appeared that many organizations were created because of shortcomings or poor public health practices. These included care, treatment and support not being available; patients being refused treatment; lack of confidentiality; and/or the public sector’s inability to respond to specific challenges such as poverty, stigma and denial. Some organizations reported a specific development pattern: a first phase during which organizations sprang up and offered services to fill gaps or answer specific problems; a second phase where, with greater resources and experience, they were able to employ a few physicians on a part-time basis and/or put their own staff at the disposal of public health services; a third phase of close and ongoing collaboration with the public health sector, and the ability to provide more extensive and varied services.

The survey confirmed that community-based organizations came in all shapes and sizes with flexible and wide-ranging arrangements that appeared to provide the basis of their strength and effectiveness—allowing them to come into existence, grow, change and respond

according to the community's needs. This diversity revealed broad regional similarities in the ways many organizations were set up. In English-speaking Africa, associations tended to be organized in a decentralized manner, and faith-based groups appeared to have a key role in providing health care. On the other hand, in West Africa it was common to find more compact community-based groups based on a standard model integrating different services around access to treatment at a single site.

The survey revealed that several types of community-based organizations are involved in some aspect of care and treatment and that there is overlap among types: (a) community centres providing medical care and treatment; (b) support groups for affected people; (c) consortiums, networks, and coalitions of people living with HIV; and (d) faith-based associations. This diversity in interests and institutional arrangements presented different opportunities and challenges for facilitating and improving access to antiretroviral medicines. Since many, if not most, organizations also conducted prevention activities, the end result appeared to be an integration of prevention and treatment and care objectives.

Providing comprehensive care, including medical care and antiretroviral therapy

About 35 community-based organizations reported they provided a complete range of conventional medical procedures and services including medical consultations; limited laboratory tests and testing partly aimed at providing clearer diagnoses of opportunistic infections; prescriptions of drugs to fight opportunistic infections; ordering pre-treatment tests and follow-up on antiretrovirals; therapeutic choice based on laboratory results and stage of HIV infection; drug purchasing; monitoring and managing possible adverse side-effects; short-stay hospitalization; nursing care; psychosocial care; home visits; and support for compliance with antiretroviral therapy treatment regimens.

Among organizations that actively engaged in medical follow-up, most had a pharmacy which stocked basic treatments for opportunistic diseases. One third of them received mainly donated supplies. As for facilitating access to antiretroviral therapy, some organizations reported they provided it themselves, others "piggybacked" their parallel services onto hospitals which provided antiretroviral therapy, and others provided essential activities that helped support antiretroviral therapy services.

In some cases, these services appeared to be an innovative way of practicing outpatient medicine, similar to services offered in a day hospital. But the community-based services were offered free of charge or on an affordable basis. Some survey respondents said their work helped ensure that hospital conditions were bearable for patients, which in turn made work more bearable for hospital staff.

AAS - Burkina Faso

"We have just set up a resource centre for persons on antiretroviral treatment (called the compliance house). This centre has four beds which can be used to house each person for a maximum of 14 days. Apart from providing rest, we look after nutrition and psychosocial aspects in relation to antiretroviral treatment."

In addition to medical care, some survey respondents said they provided other essential care and treatment services to people living with HIV. These included referencing and resource dissemination; transportation; social rehabilitation; rights advocacy; and legal,

economic, psychosocial and nutritional support. Combined with the medical services listed above, these services resulted in an approach that at times amounted to “comprehensive or total patient care”, and met clients’ medical and social needs.

This comprehensive approach appeared to be critical in introducing people living with HIV to treatment, and in convincing them to consistently follow through with it. For example, many community-based organizations reported they provided comprehensive testing services including pre- and post-test counselling and taking and analysing samples within their group. In this way, organizations were able to immediately help and counsel people distressed by a positive result. This help was also often given by people who were HIV-positive themselves.

Some community-based organizations offering this variety of services said they could follow their clients through the entire process—obtaining information and support to be tested, having the test, obtaining access to antiretroviral therapy, complying with a treatment regimen, and then sustaining compliance. Activities that helped clients enter and stay in treatment included: information campaigns, counselling, psychosocial support, formation of discussion groups, income-generating schemes for clients, training for patients and health-care workers, assistance with obtaining drugs at the lowest price, and treatment compliance follow-up.

Coping Centre – Botswana

“We realized that silence kills. To keep your HIV-positive diagnosis as your secret is not good for you, and it is not good for your loved ones. However, it is your right not to tell anybody and we respect that. But we are here to help you with breaking the news about your HIV infection to others if you are ready to disclose.”

This comprehensive approach appeared to help with access to treatment because it: (a) helped to overcome denial, silence and stigma; (b) optimized use of limited available human and financial resources; and (c) sustained clients’ positive participation over time. Anecdotal evidence suggested that many public-sector health professionals believed this comprehensive approach was important. They also depended quite openly on the voluntary sector to provide counselling, follow-up, social, financial and legal support, and to ensure conditions for good treatment compliance.

Mieux Vivre avec le SIDA – Niger

“We work with a well-known national hospital and some private clinics, whose practitioners mostly refer patients to us who were found to be HIV-positive. But they had been tested without their consent, and did not receive any counselling or psychosocial and medical care.”

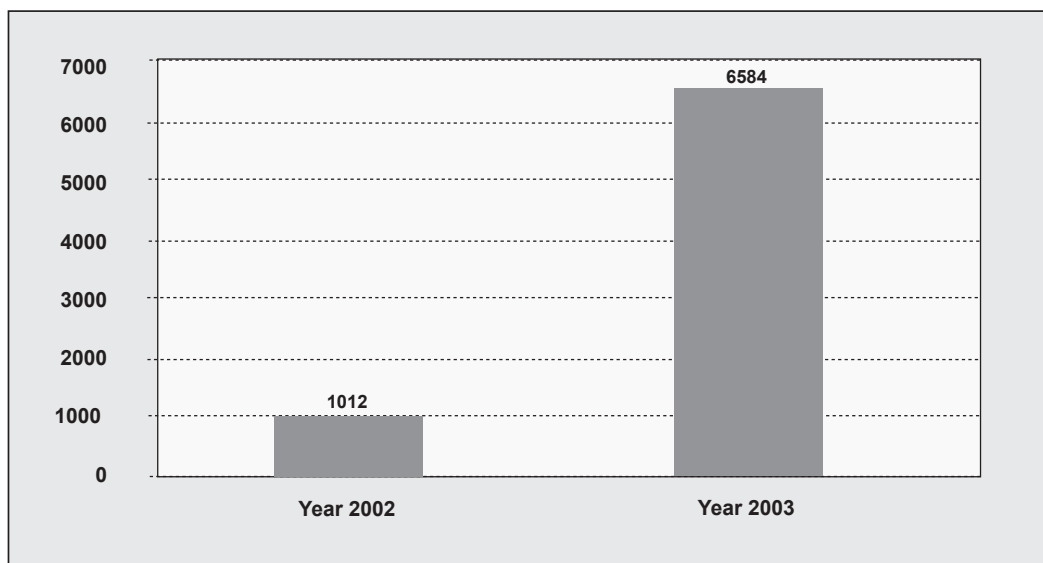
Fifty-six organizations reported they provided medical care to people living with HIV, had more than one physician and at least two caregivers in their service, were involved in the medical follow-up of patients on antiretroviral therapy, and had more than 10 clients on antiretroviral therapy. *Association Africain Solidarité (AAS)* in Burkina Faso and *Association Nationale de Soutien aux Séropositifs et Sidéens (ANSS)* in Burundi are two examples of this type of community-based organization.

According to AAS, its health facility, Oasis Centre, provided psychosocial follow-up in the form of support, counselling, and home-based care. Each month, its staff carried out more than 200 home and hospital visits. In addition, clients in need received food supply supplements, artificial milk, dietary counselling, support for children and orphans, payment of school

fees, and a summer holiday—all free of charge. Clients also received free medical examinations and drugs to fight opportunistic infections for a token price. People could be tested for HIV for less than US\$ 1.30.

During 2001, more than 100 people paid a voluntary income-based fee to receive antiretroviral therapy. From 2002, with financial support from European nongovernmental organizations, the Oasis Centre received generic antiretroviral medicines and was able to provide treatment to clients free of charge. At the time of the survey, AAS was able to employ a manager, a counter clerk and a pharmacist (on a periodic basis). At the same time demand for treatment was increasing rapidly, and in order to avoid medicine shortages AAS entered into a supply partnership with two private pharmacies.

Number of prescriptions dispensed at the AAS Oasis Centre (Ouagadougou) - Year



Source: AAS Oasis Centre, Burkina Faso, 2004

In Burundi, ANSS reported that during the first six months of 2003, almost 7000 people used its services; 3123 people were tested, and 4256 free medical consultations were provided by two full-time and six part-time physicians, including a paediatrician. There were also more than 1000 nurse consultations and 117 stays in the day hospital. Overall, ANSS provided medical follow-up for almost 1700 people, 860 of whom were on antiretroviral therapy. In addition to antiretroviral therapy, the community-run pharmacy delivered almost 4000 prescriptions for essential drugs, primarily for preventing or treating opportunistic infections.

The survey showed that antiretroviral medicine supply sources appeared to differ across countries and organizations. Some community-based organizations were set up around free access to antiretrovirals dispensed by the government. Others reported they obtained antiretrovirals from a “central medical store” at the market price (and could then only treat people who could pay), or negotiated with local generic drug distributors (Nigeria). Many reported they obtained generic antiretrovirals through various channels.

Liverpool VCT and Care – Kenya

“We are able to provide ARVs at the Hurlingham and Thika clinics. We want to make them as affordable as possible, so as many people can benefit from them as soon as possible. Right now, KES 2000 (US\$ 25.25) a month is the lowest price we can charge. This charge may become lower in the future.”

Many community-based organizations reported they started out as research groups and then eventually provided antiretroviral therapy. For example, Reach Out (Uganda) became active in 2001 in Mbuya Parish, a small town of 59 000 inhabitants, then expanded its activities, and in 2003 put its first members on antiretrovirals. Others, such as WOFAK (Kenya) or TAC (South Africa) have formed partnerships with *Médecins sans Frontières* programmes which dispense generic antiretrovirals to several hundred people at specific sites.

Reach Out – Uganda

“The possibility of collaborating with a local research programme at the Joint Clinical Research Centre therefore came as a godsend. In the period July to December 2003, a total of 85 clients were started on antiretrovirals through this programme. In addition, 26 clients were started on antiretrovirals with support from private individual sponsors and the Elton John Foundation.”

Many community-based organizations reported that they had set up group-related processes to help clients purchase antiretrovirals, including creating mutual funds, solidarity cooperatives and national fund-raising campaigns. For example, the AAS mutual fund operated through its HIV-positive members paying a minimum monthly premium of CFA 2500 (US\$ 5.15). At the same time, different partners (the Netherlands, Sidaction, UNALS, Canadian physicians and others) collected and sent antiretroviral medicines. These approaches eased access to antiretroviral therapy and helped establish a long-term fund to help ensure ongoing ARV treatment, access and compliance. In Burundi, the SWAA recently set up a solidarity cooperative to which every patient receiving ART contributes between BIF 300 and BIF 500 (US\$ 0.30 to US\$ 0.48) every month.

Based on laboratory and clinical reports, and on responses to medically-oriented questions in the survey, community-based organizations providing medical follow-up and antiretroviral therapy seemed to offer highly professional services. They reported following international recommendations on criteria for initiating treatment, for laboratory test requirements, for first and second treatment lines, and for treatment monitoring. Several organizations reported using special computer software to follow up patients (for example, Fuchia), while others used more conventional monitoring files (in Access or Excel formats).

Community-based organizations reported that both referring physicians and those they employed were specifically and regularly trained with brochures and refresher courses. Furthermore, REVS+ (Burkina Faso), ANSS (Burundi) and ALCS (Morocco) reported providing training courses for external health professionals. ANSS reported that two trained physicians regularly provided postgraduate medical education session to all medical personnel and psychologists. Once a year, the physicians attended an overseas clinical training course.

Survey responses showed that the medical care provided by these community-based organizations achieved positive therapeutic results. This was the case even in circumstances where there was little viral load data due to a lack of equipment, and patients starting treatment late. It appeared that low stocks of medicine forced teams to decide whether or not to start

patients on antiretrovirals at the last minute. Generally, they gave priority to people who were most ill at that point in time.

SWAA – Burundi

“What have you seen in terms of therapeutic results amongst people on antiretrovirals?”

“Morbidity: generally speaking, patients under antiretroviral therapy improve clinically. However, some opportunistic infections are detected, especially pulmonary tuberculosis, cryptococcal meningitis, herpes zoster.”

Mortality: Four deaths were recorded at the onset of treatment for persons who had started treatment at an advanced stage of AIDS.

The CD4 count rose slowly for some despite the viral load not being known, and for the others, results were encouraging.

Course of the viral load: This investigation is not easy to perform. For patients for whom we were able to determine the viral load, it is undetectable after six to eight months treatment in the vast majority.”

The survey also raised a thorny issue; the concern that there were dangers in allowing community-based organization to distribute antiretroviral medicines. However, the surveyed organizations rejected the idea that their involvement in distributing antiretroviral therapy would result in resistant strains of HIV developing.

ANSS – Burundi

“That doesn’t hold water. ANSS is better managed than the government. Our commitment is what is really decisive compared to practices in the public sector. And then the discussion groups and personalized follow-up mean that there is less risk of poor compliance than in the public sector. University teaching hospital physicians hesitate to begin dispensing antiretroviral drugs, claiming that they don’t have enough of anything, especially psychologists. They said to them, ‘Go to the ANSS, they have one, we will pay them’, and ever since they use our psychologist. And the university teaching hospital has started to treat 20 people; 10 of whom are children followed up by our paediatrician. Our paediatrician came to us because here he can do everything that he needs to do.”

Intercare Njinikom Project – Cameroon

“The issue of drug resistance is not unique to antiretrovirals. Communities are participating in distribution of other medications (antibiotics) where resistance is a problem. Rather than stop communities from distributing antiretrovirals, resistance-mitigating interventions should be put in place in these communities.”

Reports suggested that some community-based organizations were able to function and respond in difficult circumstances, or even in a crisis. The work of SAS Centre in Bouaké, Côte d’Ivoire illustrates this point. From September 2002, Côte d’Ivoire was divided by conflict, with refugees on either side of a front line between warring factions. Under these conditions, the national antiretroviral access programme faced major difficulties, and in Bouaké the centre’s day hospital had closed.

However, SAS Centre managed to set up a partnership with the HIV support group, Bouaké Eveil, and started up a care programme including HIV testing and medical management. Donations of antiretroviral medicines meant that patients did not have to interrupt their anti-

retroviral therapy. Another example was Stop AIDS in Liberia (SAIL) where, despite difficult conditions, staff reportedly were able to follow up 20 patients on antiretroviral therapy.

Providing support for affected people

Support groups of and for HIV-affected people appeared to play a crucial role in increasing access to antiretroviral therapy. The survey showed that groups with a large percentage of HIV-positive members were usually strong and effective. Often the staff and directors were living with HIV which created shared interests with group members. These interests included finding support, employment, shelter and treatment at the lowest cost, and improving relationships with physicians and health-care workers. The activities of these groups appeared to be organized around the real needs of people living with HIV, and seemed to help meet these needs when funding became available.

Support groups of infected and affected people were prominently represented in the survey, although in some countries there were many of these groups, and in others few. In Angola, the survey could only locate one such group. Almost all of the groups reported having people on antiretroviral therapy among their active members, but said they did not have the immediate resources to increase access to treatment. Whether or not they had the potential to dispense antiretroviral drugs, these community-based organizations appeared to make an important contribution towards greater access to treatment in other ways, such as through testing, economic activities and psychosocial support.

Fondation Tuliza – Democratic Republic of Congo

“We create awareness among clients for voluntary testing. We accompany those who are ready to the screening centre, and we defray the costs of testing. We give clients the means to carry out small-scale projects, and with the earnings from these projects, they can purchase antiretrovirals. But often it’s not easy since antiretroviral drugs are still not common in our country, and consequently tend to be more expensive at a time when clients have scant income.”

The survey confirmed that psychosocial issues, including the need for community support and solidarity, are very important for people living with HIV. These support groups reported undertaking activities that addressed related needs, such as providing emergency care, consultations with psychologists, social follow-up, economic activities, and educational literacy campaigns about HIV infection, AIDS treatment and other issues. It appeared that these organizations were filling a gap by providing psychosocial assistance that was not offered in public health services. These activities were said to be critical in bringing people living with HIV out of isolation and into treatment.

Oasis Centre - Burkina Faso

“My first challenge in counselling is to drive out despair by helping the client in front of me to understand that there is hope, and that the simple fact of saying yes to life is a winning battle against disease. Through its various services, the Oasis Centre attempts to mitigate the anxieties and worries of clients ...

Counselling creates very strong bonds between people, and one of the major difficulties is getting to know someone when that person requires their vital forces more and more, and then it is hard to see them laid low by the disease because of lack of treatment. Often one has the impression that the person fights to live, but the treatment is defective. These situations are fairly hard to bear.”

- Comments from a psychosocial counsellor

In addition to offering psychosocial support, these community-based organizations appeared to possess knowledge and motivation empowering them to be watchdogs on the community and national response, particularly for access to treatment. They reported they monitored drug prices, tariffs, women and minority group access to treatment, misuse of fees, and faulty advice from or mistreatment by health-care workers. These groups appeared to give people living with HIV, including the poor and other vulnerable populations, a public presence, and to form a base for lobbying to obtain access to care, rights and treatment. With this help, it seemed that individuals living with HIV were able to transcend their individual struggle with the disease and invest their energies in a broader fight for political change in their respective countries.

Centre for the Right to Health – Nigeria

“Most often, violation of rights in health-care institutions leads to violation of other rights such as the right to life, work, housing and education, among others. Opportunities to redress these violations are mostly lacking. Patients are reluctant to seek redress for fear of negative reprisals. The need to properly address the diverse and complex problems associated with health-care delivery in Nigeria provided the impetus to the founding in 1999, of the Centre for the Right to Health—a non-profit, nongovernmental organization. Today we provide care to 500 people, with two part-time doctors and two scientists. We would want to launch into full time ARV administration. To launch fully we would need to hire full-time doctors, [find] funding [for] ARV drug purchase, and [provide] training for medical and nursing staff.”

Ghana AIDS Treatment Access Group (GATAG) – Ghana

“Treating people living with HIV will give us hope, and by offering hope we dispel the notion that AIDS spells doom. Treatment has irreversibly broken the equation between AIDS and death. It allows us to begin to undo the social stigmas and phobias that make prevention so difficult to talk about frankly and to practice effectively. Hence, we announce to ALL, ‘Treat the people NOW!’”

Since their members desperately needed treatment and it had become more feasible, many support groups reported shifting their focus from prevention to treatment support. This included mutual antiretroviral therapy training, understanding the challenges and needs associated with taking antiretrovirals, and finding practical solutions for treatment compliance problems. Some reported that they had further evolved from support to treatment-oriented activities, including providing medical follow-up and home-based care by relying on periodic or freelance work from physicians and pharmacists. Other community-based organizations said they wanted to make this type of a shift, but lacked resources to do so.

Espoir Vie (Togo) reported that in 2001 it was a small self-support group. By the time of the survey, it provided follow-up for hundreds of patients, 70 of whom were on antiretroviral therapy. In 1999, AAS Oasis Centre in Burkina Faso mainly provided prevention and psychosocial support. By the time of the survey, it said it prescribed antiretroviral medicines to more than 150 people. Since these support groups were focusing on helping their members survive, it appeared likely that shifts in activities would continue so that organizations would increasingly provide health care and treatment.

Living Hope Organization – Nigeria

“If your thinking does not transcend figures, and all your efforts are focused only on prevention programmes that exclude care, support and treatment, then in three, five or maybe 10 years, we would become the frail, dying, skeletal image you are used to seeing on your TV screens, popularly called AIDS victims. Unless you care; we perish!”

Networking for treatment access

The survey identified other types of community-based organizations that promoted access to treatment through somewhat different activities and strategies. These included networks, coalitions and consortiums of people living with HIV. They said they acted for people living with HIV, and undertook information exchange, advocacy, and sometimes negotiations to purchase medications.

Some of these groups described themselves as a consortium and/or resource centre providing services to other nongovernmental organizations. They offered treatment literacy information, training, reference services, monitoring, resource allocation, lobbying, and joint projects. Some reported they ran an AIDS hotline, others said they had a testing centre. But few reported being directly involved in providing care. The AIDS Consortium in South Africa was a case in point. It said it was a consortium of a large network of private or voluntary services which was able to develop multiple partnerships with organizations defending the rights of people living with HIV, including treatment rights. For instance, it reported that the consortium had jointly drafted the national programme for access to antiretrovirals which was submitted to the South African Government as part of TAC’s 2003 campaign.

The survey indicated that The AIDS Information Centre (Uganda), the CIC-Doc (Burkina Faso), and to some extent JAAIDS (Nigeria) were involved in similar activities. In Kenya, a campaign for access to treatment consolidated around the Kenya AIDS NGOs Consortium (KANCO) with the backing of Médecins sans Frontières. In addition to carrying out advocacy activities, KANCO reported it helped to find funding for antiretroviral therapy.

The Kenya Coalition on Access to Essential Medicines – Kenya

The Coalition includes: Action Aid; The Association of People living with AIDS in Kenya (TAPWAK); Health Action International (HAI), Africa; Network for people living with HIV-AIDS (NEPHAK); Women Fighting AIDS in Kenya (WOFAK); Society for Woman and AIDS in Kenya (SWAK); Nyumbani; International Federation of Women Lawyers Kenya (FIDA); CARE International; Médecins sans Frontières (MSF); DACASA; Pharmaciens sans Frontières (PSF); Kenya Medical Association (KMA); Consumer Information Network; Campaigners for AIDS-Free Society.

In Swaziland, The AIDS Information and Support Centre (TASC) reported that it provided acyclovir at the lowest price to patients in its network. It also operated a mobile outreach screening service that travelled to rural communities, and noted that with more support and training, it could extend its activities to prescribing antiretroviral medicines.

The AIDS Information and Support Centre (TASC) – Swaziland

“The organization successfully initiated a mobile outreach rural community HIV VCT and education service, which by the end of 2001 reached out to 21 communities in the four regions of the country. Other substantive activities include, enhancing capacity of formal and informal institutions to incorporate AIDS education, care and support service provision to their cohorts. These include traditional healer organizations, nursing professionals, the private sector and rural-based peer educators. TASC initiated training of health professionals in the syndromic management of sexually transmitted diseases and HIV infection in 1995. In 1993, the organization made an unthinkable breakthrough in forming the first group of people living with HIV in Swaziland.”

Other groups described themselves as “PLWHA networks” which worked to support and represent people living with HIV in their dealings with national governments, UN agencies, organizations such as the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria, and at international conferences. Many of these groups seemed to have been initially created after donors said they wanted to deal with one single organization acting as a representative for PLWHA. Over time, many PLWHA groups have moved into important treatment-related activities, such as organizing campaigns for access to treatment. These include TAC through the PATAM network, RIP+ (Côte d’Ivoire), Ghana AIDS Treatment Access Group, RAME (Burkina Faso), and TAM (Nigeria). Other groups including the National Forum of PWAs (Uganda) focused on negotiating access to antiretrovirals and centralizing treatment purchases.

National Forum of PWAs – Uganda

“We provide more information on the treatment programme within the National Forum of PLWH Networks. The Forum uses two programmes to help PLWHA access treatment. One is the Treatment Fund for PLWHA Advocates which mobilizes funds and creates partnerships with various treatment centres to provide ARVs to PLWHA. The other is the AIDSETI Uganda Chapter that mobilizes obtaining drugs from partners in the United States and other parts of the world that are provided to PLWHA in partnership with the treatment centres. The organizational target is to at least provide access to treatment to 200 PLWHA per year.”

Uganda Coalition for Access to Essential Medicines – Uganda

“Policy and legal advocacy for access for essential medicines are embodied in these core objectives: (1) analysis and monitoring the implementation of the Global Fund guidelines from a consumer perspective; (2) influencing the legal process to safeguard access to essential medicines, like the Intellectual Property bill to be tabled in Parliament, and (3) local, regional, national and international activities to increase consumer participation in activities of access to essential medicines.”

Working through faith-based associations

From the survey and from Sidaction experience, many faith-based organizations appeared to have significant medical experience in general health care, but little experience in providing antiretroviral therapy. In some countries including Kenya, Malawi and Zambia, these organizations are the major health-care providers. Several groups reported they were interested in providing antiretroviral therapy, and appeared to have good potential to do so in terms of their medical experience, extensive organizational reach, and specific funding sources. Some have already begun to provide antiretroviral therapy, including Reach Out (Uganda).

Meanwhile, medical stores and supply agencies that obtain medicines for faith-based organizations are considering obtaining HIV medicines and antiretrovirals for community-based groups. In Nigeria, Chanpharm—the clearing house for all the church-related health services in the country—reported it is interested in obtaining ARVs.

Reach Out – Uganda

“By the end of 2002, we had 525 active clients enrolled with Reach Out (Uganda). During this year, we have seen our client number increase to 860 clients. Due to the increase in client numbers and services provided, we had to expand clinic days from three to four clinics per week. The average number of clients per week has over the year risen from 200 to 350 clients. Each client is seen twice a month on average. Home visits are still made once a week where five teams of medical personnel and community workers visit an average of 25 clients who are too weak to come to the clinic.

“The basic medication given involves prevention with cotrimoxazole and treatment of opportunistic infections. In June, we were able to start some of our clients on triple antiretroviral therapy through a research programme with Joint Clinical Research Centre (JCRC). In addition, we have raised sponsorships for ARV treatment for individual clients so that we now have 110 clients on ARVs ... We still have a big cry for ARVs for our clients. In November, we were assessed by the Uganda Ministry of Health for an ART centre. In late December, we got an affirmative answer, which enables us to become an antiretroviral therapy centre. Hopefully, we won't have to wait too long for the arrival of the ARVs for all clients who need them.”

Chanpharm – Nigeria

“Chan facilitates networking and information dissemination for our members. Chan member institutions provide health services to more than 40% of the 130 million Nigerian people. Many of the members are already using ARVs sourced from local suppliers at prices only a few patients can afford. Chanpharm has a well-managed distribution system to ensure access to the drugs, but has not been able to commence the programme. There is a plan to commence a separate programme on ARV distribution, but the major hindrances are: finance for bulk procurement of the drugs, and training health workers on the rational management of AIDS with ARVs. The national government has not been able to provide support and training, and there are no treatment standards for use by prescribers.”

Attending to the needs of women and children

The survey showed that several community-based organizations focused on women and children, including helping them to gain access to treatment. Many of these organizations were started and led by women. For instance, responses were received from WOFAK, an organization founded in 1993 by HIV-positive women in Kenya who decided to go public with their HIV status. These women came together to provide support to each other because they were

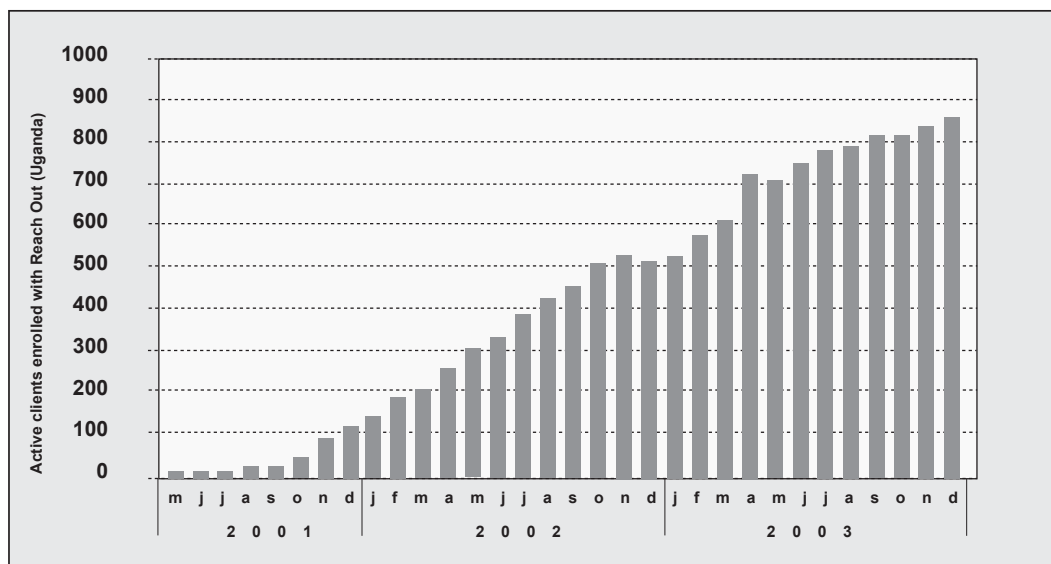
facing rejection, stigma and discrimination as a result of being affected or infected by HIV. In addition, many of their spouses had died and they had to face the burden of supporting their families alone.

WOFAK reported running two small clinics in Nairobi which provided daily medical and psychological assistance to HIV-positive women, as well as an AIDS education programme run by a nutritionist. A comprehensive orphan programme provided psychosocial support to children and arranged for them to go to school. Community meals were organized for the children, and their foster families received food coupons.

Meanwhile, the WOFAK Homa Bay office was integrated into a local Médecins sans Frontières programme for access to antiretrovirals. This merged group then went on to develop therapeutic literacy workshops that fostered information exchange between current and future beneficiaries of the initiative.

Some survey respondents appeared to be pioneers in setting up children’s health-care programmes which were almost non-existent in many settings. However, a major obstacle turned out to be difficulty in obtaining access to paediatric doses of antiretroviral drugs.

Number of Active Clients – Reach Out, Uganda – May 2001 - Dec 2003



The KidzPozitive Family Fund – South Africa

“Everyone in our organization has access to highly active antiretroviral therapy (HAART). Most of the children are already on treatment. They are the ones running around. A number of the mothers are on treatment as well, the rest are still in good health despite their HIV-positive status. Some children await the start of therapy and some are starting today. This is not a utopian vision or a pipe dream. It is a morning late in January 2004 and this antiretroviral treatment programme has been running for nearly two years. The 224th child starts treatment today. Sixty mothers are also on treatment.”

REVS+ – Burkina Faso

“Have you established techniques or specific activities for medical care of children on ARVs?”

“Yes, a paediatrician who prescribes ARVs has taken on this responsibility. Before starting them on treatment, parents and close relatives are instructed and informed so that they can be properly involved in the correct and regular administration of doses to children. We are there to answer questions from the children so that they too can be involved in their treatment and understand the need for compliance.”

Supporting free-of-charge treatment

Survey respondents unanimously felt that antiretroviral therapy should be provided free at point of service. They said they felt strongly about this issue because many people living with HIV or AIDS either could not afford to pay to start treatment, or became increasingly destitute as they sold their assets to purchase medications, ending up at a point where they could no longer cope financially. Very few were able to sustain paying treatment fees over a lifetime. Also, initial family-based support for helping HIV-positive patients pay for treatment was usually not strong enough to last over the long period required. The organizations felt that these realities meant that antiretroviral therapy needed to be offered free of charge in order to get people into treatment programmes at an appropriate time and to sustain treatment over a long period.

SWAA – Burundi

“We prefer no-charge services. Firstly, because of poverty, and because treatment is ongoing. So, at some point in time even those who earn a steady wage are not going to be able to keep up.”

The organizations also insisted that free-of-charge services did not mean that clients were less motivated to comply with their treatment regimens. They noted instead that compliance became poor when money was short. They argued that providing clients with follow-up and support was a much better way to ensure compliance than charging fees.

Mieux Vivre avec le Sida – Niger

“We don’t agree with the concept which holds that people will be less inclined to comply with ARV treatment if it’s free, since what is at issue is survival. Our patients who receive ARVs free of charge are not less compliant than others. Everything is a question of supervision and the prescriber/patient relationship. In the North, do no-charge services impair the quality of compliance?”

Espoir Vie – Togo

“No-charge services would enable those who are affected to feel themselves supported by the community. Even if the person purchases the drugs him or herself; if there’s no follow-up, it doesn’t work out. Follow-up is necessary: taking the medications has to become a habit, and that has nothing to do with cost. What cost does is to make people start a treatment at a very late juncture.”

Les Amis de Pasteur – Benin

“We hope to be able to provide no-charge services and also follow-up lab tests and assistance with other health problems. What is at issue is doing everything to reduce the circulation of HIV throughout the world by getting rid of all the impediments, especially the financial handicaps.”

CESAC (ARCAD Sida) – Mali

“Service at no charge is also a relief to the physicians and caring personnel.”

Responding to the increasing demand for treatment

Scaling up antiretroviral therapy had several positive outcomes for the community-based organizations involved. Delivering antiretroviral therapy led to an increase in their client numbers and a general increase in activities. But at the same time, with more clients to care for, the amount of time and energy per client appeared to decrease. This result seemed to stem largely from the life-prolonging attributes of antiretroviral therapy.

Overworked staff who had suffered from burnout and exhaustion from managing recurrent opportunistic diseases found “a weight lifted” because they were now able to improve their clients’ health and lives. Counselling activities became easier and the workload of physicians and caregivers already involved in medical follow-up became less of a burden because it was psychologically easier to bear.

Dispensing antiretroviral therapy did not seem to require a major revamp of professional skills. Health professionals said they could update their knowledge and skills through annual training courses and documentation. However, community-based organizations said they had to reorient their workload in two ways: first, to deal with different tasks involved in maintaining clients on antiretroviral therapy, and second, to handle the pressure to put *more* people on antiretroviral therapy.

ANSS – Burundi

“Typical reorientation of the workload: at ANSS (Burundi), nutritional and dietary activities have had to integrate new features. Laboratory follow-up is more structured and better equipped (the lab is expanding). But nurses and physicians have less work with respect to opportunistic infections. The work done by the nurse who delivers the ARV medications is also increasing because she is now involved in issues of compliance.”

LAHACO – Kenya

“Other needs have been created in the area of establishing income-generating activities in order to boost income levels of the infected and the affected.”

The ANSS (Burundi) experience revealed several features: as treatment became available, the active client caseload increased exponentially. The number of people on antiretroviral therapy doubled every year, and the organization was under continuous pressure from clients wanting access to treatment. Staff also said they were uncomfortable with “cases of conscience” when they had the difficult task of selecting which clients would receive treatment—a life-or-death choice.

Faced with enormous need and scarce antiretroviral supplies, community-based organizations reported that one of their biggest challenges was how to expand treatment and services without being overwhelmed (or taking on responsibilities rightfully belonging to the government). Some organizations were able to describe a “maximum capacity” for following up patients. But given the pressures of antiretroviral therapy demand, they seemed to doubt they could stick to these limits.

ANSS – Burundi

“How many persons do you think you will be able to put on treatment and follow up by 2005?”

“We are trying not to exceed 1500, but in view of the pressure, it is uncertain whether we will be able to hold to this figure.”

CESAC (ARCAD Sida) – Mali

“How many patients did you treat in 2002?” “250 in 2002; 400 in 2003.”

“Why not more?” “Supply of medicines, economic criteria, etc.”

“If the treatments were accessible to everyone, would you have the capacity to follow more persons on ARVs with your existing means?”

“No, not in terms of capacity. Follow-up of persons on ARVs implies a significant workload, and follow-up has to be customized if it is to be good quality. Given that we provide total medical care for patients, we cannot take on more than we have in view of our small premises and the current number of doctors. We provide close monitoring to avoid patients dropping out. And then we have other activities. To increase capacity, we would need more doctors, more space, etc. However, we wish to keep our parallel activities. The supply system would also be overrun.”

“What is your ceiling?” “Let’s say 1500; that would already be a lot.”

Expanding treatment through different growth models

Survey responses showed that community-based organizations had pursued several different growth models as they sought to expand treatment. These included creating new decentralized care centres, extending care delivery through a network of existing community services, or building partnerships with the public sector and the national treatment programme.

KidzPozitive (South Africa) reported that it was starting a spin-off programme in another part of the country. CESAC (Mali) and ANSS (Burundi) also chose this route since both had received support to form new decentralized treatment access operations: CESAC’s was at Mopti, Mali, and ANSS’s was at Kirundo, Burundi.

KidzPozitive – South Africa

“We are planning to extend our model of family-based care to other provinces in South Africa where there is a lack of political will to get going with treatment. Our funder is willing to raise the money to permit us to start up a service according to our model in Port Elisabeth in the Eastern Cape Province of South Africa.”

Some community-based organizations reported that they were able to build on an extensive network of community workers, they had strong organizational abilities, and they could represent people living with HIV. These organizations, which only recently introduced antiretroviral therapy into their programmes, appeared well-placed to provide treatment on a large scale. For instance, TASO could offer the help of its 30 000 members, its extensive experience and its considerable financial strength. TASO reported that in a matter of months it was able to expand from providing antiretroviral therapy to 60 clients to providing it to 3000 clients.

TASO – Uganda

“The ART programme is just beginning in 2004, with 3000 clients initially. There has been a staff ART programme where the organization has contributed up to 80% of cost for the staff member only and not family. A drama group (25 members) has benefited from a donation of ARVs since December 2002, and the experience has been used as a pilot to prepare TASO for a scaled up programme. A total of 100 new multidisciplinary staff are to be recruited starting in February to run the ART programme. Funding for the ART programme will be sourced through donors. Funding for the first 3000 has been approved and dispensing starts this year. It is estimated that an additional 12 000 are currently in need of ARVs.”

Other community-based organizations reported they had expanded treatment capabilities by developing partnerships with the public sector to benefit both parties and their clients. In fact, anecdotal evidence suggested that in many places the vitality of the voluntary sector had prompted the public sector to invest more in care and treatment for people living with HIV and AIDS. This was something the public sector had been avoiding in the face of stigma and lack of both political will and funding.

Some patient support groups reported that they formed links with national initiatives aimed at increasing access to antiretrovirals. *ARCAD Sida* (Mali) and TASO (Uganda) became essential components of the national AIDS programme. For example, *ARCAD Sida* reported that it was initially set up to provide home-based care because the public health sector was not doing so. By the time of the survey, it had been integrated into the national programme (which it appeared to have considerably influenced) and had become the largest of the three official antiretroviral therapy access sites.

Still other community-based organizations reported they functioned as a part of a “systems approach”. In this case, several complementary partners offered their services in a coordinated fashion in order to achieve a “global” or “complete” approach to HIV care. Clients benefited from the services of many groups and, at the same time, overall work conditions and results of the various partners improved.

Projet Enfant (Children’s Project) in Abidjan, Côte d’Ivoire, illustrates this system’s approach. It brought together several groups: the paediatric department of the Yopougon University Teaching Hospital which distributed treatment; the district health centres; a day hospital run by an association of physicians and researchers called Aconda-Cepref which put parents on antiretroviral medicines and paid for biological tests; an association of women living with HIV (Amepouh); and a self-support group of affected and infected children (Chigata) which provided financial support, nutritional aid and schooling.

The entire project reportedly followed up on 300 children (150 of them on antiretroviral therapy), from testing to care and treatment. Throughout, it provided them with support, physiotherapy, sessions with psychologists and nutritionists, and schooling. The children were said to have achieved above average school results and excellent treatment compliance.

Clearly, the reported achievements of community-based organizations in providing access to treatment show they are capable partners. However, they also reported that they faced significant challenges and constraints while seeking to provide antiretroviral therapy to their clients. These included: (a) little community involvement in care and treatment in some countries; (b) lack of funding to purchase antiretrovirals; (c) centralized or government-controlled access points; (d) difficulties in maintaining stocks of antiretrovirals; and (e) inadequate human resources and training.

Strengthening the community response

As discussed above, community-based organizations in some countries did not really respond as to whether they were providing HIV care and treatment. This was particularly true across North Africa, a region where there appeared to be few community-based organizations involved in HIV-related activities. In some countries, it was likely that low community involvement in these issues resulted from a lack of overall community and civil society development.

There were other factors that may have slowed community response: (a) few policies and programmes promoting access to treatment; (b) high levels of denial, discrimination and stigma; and (c) relatively few people living with HIV or AIDS. In these cases, support needs to be urgently extended in order to empower both infected and affected people so they can express their needs safely and be encouraged to organize community responses.

In many cases, it was reported that communities can quickly scale up treatment. For example, in the space of a few years the community response in Togo went from being virtually non-existent to having several model organizations offering care services to people living with HIV. With the support of external donors, these community-based organizations have continued to adapt and expand their activities and have encouraged the formation of new groups. According to the Togo association, *Action Contre le Sida*, setting up an internal community pharmacy revolutionized the association's everyday activities.

Action Contre le SIDA – Togo

“On the topic of medical and psychosocial management of patients, the necessary drugs have to be available for the treatment of opportunistic diseases. Rapid stabilization of the patient's immune system is also needed in order to start a course of ARV treatment. Setting up this kind of pharmacy has given confidence to the physicians who found themselves at a loss when faced with any kind of opportunistic disease.”

Funding the purchase of antiretroviral therapy

When the community response was already strong and ready for expansion, survey respondents said the biggest problem was lack of funding to buy antiretroviral drugs and to sustain treatment. This constraint was cited most often. In fact, most of the 50 respondents describing themselves as “community-based medical follow-up centres” reported identical priorities: if they had more funding for greater access to treatment, they would almost immediately triple their patient intake and follow-up rates, while providing the same quality of service. However, they reported that to accept even more patients, they would need to hire more medical assistants and provide training.

KidzPozitive – South Africa

“We need more money for purchasing ARVs. Our funder (the One to One Children’s Fund) has capped our treatment access at 225 children and 100 mothers. We will soon need access to other funds to treat more children and their mothers, because there is ongoing pressure to treat more clients. Our government roll-out is running very slowly in South Africa. It is understood that because we run on foreign funding, our regional government will not allocate us money for additional treatment slots.”

Life Line Plus Foundation – Nigeria

“We are trained to give ARVs to the PLWHAs whose CD4 count is below 200, but our handicap is access to ARVs. Only the university teaching hospitals are accessing these drugs from the national drug store. We were trained in readiness or in preparation for scaling up, but we don’t know when that will take off. As it is now, we will be very delighted to associate with any organization that will facilitate our access to ARVs.”

Zimbabwe AIDS Prevention Project – Zimbabwe

“My organization is offering ARVs, but this is for the purpose of study with a lifespan of five years. It is our primary objective to provide treatment beyond the study. What we would need most is funding for ARV drug purchase, maintaining and adding a few more employees, refresher training for current employees, administrative authorization and other HIV medicines and nutritional support.”

Fondation Tuliza – Democratic Republic of Congo

“In the country and especially in our region, the associations do not yet have access to ARVs owing to lack of interest from funders. Despite evidence that the associations are best positioned to reach the largest possible number of clients needing ARVs, they remain ineffective in this field. All the associations which have AIDS control as part of their objectives also believe that access to ARVs is an absolute priority. But they do not know how to achieve their goal because of lack of means.”

Community-based organizations reported that because they could not afford to buy antiretrovirals, many of their clients were excluded from treatment. This forced health professionals to make the intolerable choice between who received life-prolonging therapy and who did not. This same problem also meant that organizations could only offer limited treatment choices. In reply to the question, “What combinations do you prescribe most and why?” they almost unanimously said, “The fixed-dose combination of lamivudine, plus stavudine, plus nevirapine, because it is the least expensive.”

ANSS – Burundi

Comments of Dr Marie-Josee Mbuzenakamwe in the opening speech at the International AIDS Society Conference in Paris, 2003:

“Because when one has 30 treatments to dispense and more than 120 patients waiting to be treated, there are some hard choices to be made. Have you had to make this kind of choice in front of your patients, my dear colleagues?”

Decentralizing treatment

In countries where governments centrally controlled treatment programmes, survey responses were often poor, indicating that robust treatment and care community responses could not develop in this type of environment. Many respondents also said that centralized control over all aspects of antiretroviral therapy prevented organizations from obtaining and providing antiretroviral medicines to clients. Community-based organizations also said they were ready and able to put clients on antiretroviral therapy, but were hampered by the lack of official permission to distribute or prescribe antiretroviral medicines.

In some cases, legitimate concerns about public regulation of dispensing medicines appeared to have resulted in central State control which hindered decentralization and the ability of communities to provide antiretroviral therapy. The basis for the State to control antiretroviral medicine dispensing may have stemmed from initial treatment programmes. Under those programmes a national committee selected eligible patients, designated a few authorized dispensing sites, and gave accreditation to only a few prescribing physicians, often only in the capital city.

For instance, in Côte d'Ivoire, *Centre Plus*, run by the *Ruban Rouge* association, was running a small day hospital and providing financial support for antiretrovirals, but it was still not authorized to prescribe the drugs. The SAS Centre in Bouaké could not prescribe drugs either, although it had become a key player in expanding access to antiretrovirals in its region. It was reported that the situation in Côte d'Ivoire was due to improve through an upcoming policy change stipulating that physicians, rather than sites, would be authorized to prescribe. Survey respondents stressed it was important that this prescribing accreditation be broad and flexible, as was the case in Cameroon where every physician who had received training was authorized to prescribe antiretrovirals.

The move to allow physicians to prescribe antiretrovirals was said to be helpful, but still not enough to achieve serious decentralization of antiretroviral distribution. Almost all survey respondents confirmed a continuing problem: only physicians could prescribe ARVs. This was despite a WHO recommendation that prescribing should be decentralized to other levels in the health-care chain and should involve nurses.⁵

Allowing only physicians to prescribe was a particular problem in rural areas where there were few physicians. At the same time, organizations reported that their work “freed” the physician from the burden of doing medical follow-up while continuing his monopoly on prescribing. In these cases, nurses and health-care aides provided compliance support, dealt with adverse medical effects, and offered advice on the best diet for the chosen treatment. At the time of the survey, some initiatives were started in Kenya and Uganda where “clinical officers”, an intermediate level between nurse and physician, were authorized to prescribe anti-Tuberculosis drugs and sexually transmitted infection treatments, and nurses were allowed to prescribe malaria treatment.

⁵ Emergency scale-up of antiretroviral therapy in resource-limited settings: Technical and operational recommendations to achieve “3 by 5”. Report from the WHO/UNAIDS Zambia consultation. November 18-21, 2003. Lusaka, Zambia. Geneva, World Health Organization, 2004.

Kenedougou Solidarité – Mali

“In spite of the high degree of involvement of central authorities in the struggle against AIDS in Mali, only three health structures, all of which are based in the capital (two national hospitals and an association), are authorized to prescribe ARVs and to follow up patients on ARVs.

Our health centre, Cerkes, has been providing medical, psychological, social and economic follow-up for persons living with HIV in Sikasso since May 1998, but it cannot prescribe ARVs. We were obliged to send all our patients to Bamako for them to have a chance, however minimal, of having access to ARVs. This is despite all the difficulties of getting to Bamako, finding somewhere to stay in Bamako, the cost of pre-inclusion tests and the eventual cost of the ARVs. Very few patients arrived at the end of the tunnel and found the magic fleece they were all hoping for. Moreover, they did not succeed in continuing their treatment in the long-term because of the high cost of treatment, lab tests, fatigue linked to frequent travelling, and the many days off work for those still able to work.”

Managing drug supplies

Community-based organizations reported serious client-endangering problems: breakdowns and disruptions in antiretroviral supply. Organizations reported they took all possible steps to ensure that their supply channels were secure and that alternative solutions were available if a supply stoppage did occur.

They created buffer medicine stocks in anticipation of a supply problem, amalgamated stocks to make them last as long as possible, and worked in tandem to carry out an inventory of stocked drugs and to distribute them between different branches in the country while awaiting a new supply. Some community-based organizations reported that these techniques were reinforced by organizations in the North sending drugs to replenish supplies, or notifying other groups that might provide support, such as relevant government ministries, patient care centres and the World Bank.

Building client and staff capacity

Almost all survey respondents said a key priority was to strengthen both client and staff care and treatment capacities, including antiretroviral therapy. Their first priority was clients and potential clients so they could take care of their own health more effectively. Potential clients had to be willing to be tested, to acknowledge a positive result and to enter into and maintain treatment. But organizations reported that stigma often prevented people from coming forward. It also stopped people living with HIV from being involved with or leading community-based organizations.

They reported that in African communities, even in institutions or organizations which offered activities involving people living with HIV and AIDS, only a small minority of people spoke openly about their HIV-positive status. Often, people living with HIV were also not willing or did not have the specialized skills to become part of these institutions. The survey responses confirmed that if treatment access was to happen at a faster pace, people living with HIV needed to be offered a supportive environment within communities and community-based organizations.

Centre for the Right to Health – Nigeria

“At times patients are given drugs with the label peeled off, and necessary education about the drugs is denied to them, leading sometimes to adverse drug reactions and death. Youths and women seeking reproductive health care are treated with scorn and disdain depending on the disposition of the health-care provider. They are rarely consulted about their diagnosis or in making decisions about their treatment. This is more so for vulnerable groups such as the uneducated, the poor, women, children and patients with stigmatizing diseases like AIDS.”

Both clients and service providers needed additional training to be effective health agents. Respondents said that training needs should include all aspects of care and not be limited only to therapeutic components of treatment. Other issues to be addressed included providing counselling, psychological support, advice on the course of the illness, and information about antiretroviral therapy and treatment compliance.

SWAA Littoral – Cameroon

“The fall in the price of ARVs in Cameroon since 2001 has enabled many patients to be treated. The immediate consequence for care teams which had hitherto been involved in support counselling, was that they had to meet an increased demand from the patients for information about the different therapeutic possibilities resulting from research into HIV and AIDS, and on adverse drug effects. Furthermore, setting up the PMTCT programme revealed the difficulties linked to counselling the family in the event of HIV-positive status, and consequently other children in the same family when treatment proved necessary for them. The problem of compliance is also beginning to crop up, especially among patients who are poorly informed and not used to taking long-term treatments.”

Espoir Vie – Togo

“With intervention strategies changing as time passes, it is necessary to update knowledge among directors and personnel in the association, and to train future actors in the voluntary sector. This involves helping them to understand the links between different aspects of patient care, so that a hierarchy between the various services can be established in terms of priorities. On completion of training, participants should be able to identify a person’s needs, to determine the role played by different parties involved in patient management. They needed to understand the different units necessary in a health-care centre and the role played by each unit, and to marshal the resources required for them to function, and to ensure that activities in any given centre are coordinated.”

Some community-based organizations reported that their expertise in administering and following up ARV patients has enabled them to start training other public and private agencies. They also report an increasing number of South-South exchanges between organizations. Among other things, this training has included management education, how to complete applications for funding, therapeutic literacy, counselling training for active members, and additional training for medical personnel. This sort of exchange was considered crucial for strengthening and expanding community-based organizations’ involvement in treatment access. Organizations providing training included ALCS (Morocco), ANSS (Burundi) and ARCAD Sida (Mali).

The community-based survey respondents reported that 1100 “physicians and medical assistants” and 11 000 “nurses and health-care aides” were involved in HIV medical care. Despite the AIDS-provoked staffing crisis in the health-care systems of many hard-hit countries, the survey showed that a substantial number of health-care workers are participating

in community efforts to provide care and support. It also indicated that community-based organizations could be very effective in mobilizing support for community-based care.

Meeting structural needs

Community-based organizations reported that it was often difficult for them to obtain funding for operating and salary-related expenses, including obtaining office space and supplies, and salaries for coordinators, secretaries, and physicians. They pointed out that if they had funding for these basic functions, they could stabilize and sustain teams and have the ability to expand their long-term care provision.

Community-based organizations also said their own staff needed urgent access to antiretroviral therapy, since many were living with HIV and needed treatment. Clearly, an organization's well-being depended on its own staff surviving. Keeping its employees as healthy as possible preserved expertise and skills built up over time, and reduced demoralization that followed the deaths of dedicated staff members and volunteers.

TASO – Uganda

“As we go into the programme, we have categorized our need as follows: infrastructure like laboratories, consulting rooms, stores; and human resources. We need more staff to handle the extra workload and specific new services. This includes training and capacity-building for all the current staff in ART; vehicles and motorcycles; training materials; drugs and logistics; technical support; guidelines development; advocacy for the programme; organizational development to incorporate a labour-intensive new programme into the system; documentation and research; informatics; monitoring and evaluation systems development; harmonization with national and partner programmes; client involvement and training in ART literacy; community mobilization and sensitization for ART.”

“This is a long list, but it is drawn out of the issues raised under the critical path analysis for successful ART programme that the organization has compiled.”

Taking steps to support community-based access to treatment

The survey described in this report was a first attempt to map the involvement of community-based organizations in providing HIV-related care and treatment in Africa. The results include self-reported statements that were not independently verified, but the responses were detailed, consistent, and similar in tone and content. They strongly support widespread anecdotal evidence that African community-based organizations are significantly involved in providing antiretroviral therapy and care. The responses also indicate strong motivation to expand services to provide antiretroviral therapy, as well as enormous creativity in finding solutions to the challenges that this work entails. The survey results confirm that, as greater efforts are made to expand access to treatment, it becomes increasingly important to use and support the important work of community-based organizations in providing quality care and treatment.

Furthermore, the survey made it clear that not all community-based organizations can or should become involved in providing medical care, including antiretroviral therapy, and there are limits to how far they can be expected to develop in that direction. Experience has shown that community-based organizations need support in ways that take into account their different orientations and growth thresholds. This support also needs to protect them from being forced to grow in directions they do not want or cannot handle. Even good-willed donors with the best of intentions can destroy voluntary potential if they try to move too rapidly or to impose an external set of priorities. Support for expanding an organization's activities should match its

characteristics and the needs of its clients. Furthermore, efforts should be made to monitor and evaluate the care and treatment provided by community-based organizations, both in terms of the quality of care and how it relates to public and private sector care efforts.

Nevertheless, there is tremendous pressure on community-based organizations to provide care and treatment, and they will continue to expand in that direction. They represent a vital resource that should be used in a balanced manner. Community-based organizations need help to find their most effective place within an adequate overall public health response.

Based on the survey results, it is recommended that the steps listed below form the basis for strengthening, supporting and expanding community involvement in providing care and treatment, including antiretroviral therapy.

Advocacy and support

Community care, treatment and support responses should be fostered in countries where they do not exist, as well as through campaigns against stigma and discrimination. This needs to be done through North-South and South-South exchanges, networking, and funding targeted at community responses. National and international policies and programmes need to be developed for decentralizing treatment within countries, and also in relation to obtaining, providing and prescribing antiretroviral therapy. Funding is also needed for operational expenses, human resources and antiretroviral provision.

Networking

Support needs to be given to encourage and sustain networking among community-based organizations involved in care and treatment so that they can exchange information and experience, provide training, and develop and share drug procurement, supply management, funding strategies and other aspects of treatment and care. This networking needs to be a strategic component of activities undertaken by nongovernmental organizations, intergovernmental agencies and donors.

Further research

More research needs to be undertaken to better understand the opportunities and constraints to involving communities in care and treatment at country level. This should involve operational research to: (a) develop the ability to monitor and evaluate the quantity and quality of community-based organization input to care and treatment; (b) describe the activities of effective community-based organizations currently providing antiretroviral therapy, and determine the reasons for their success; (c) identify ways to provide community-based organizations with technical assistance to improve treatment quality and coverage; and (d) better understand ways to strengthen community responses while supporting primary health responses.

Mapping

Asia and the Pacific, Eastern Europe, Latin America and the Caribbean are other regions that would benefit from similar efforts to map community involvement in care and treatment. This mapping should include: (a) creating a database of those already involved in

providing care and treatment in these locations; (b) surveying achievements, lessons learned, opportunities and challenges; (c) preparing country reports to characterize the community-based organizations' response within a country; and (d) supporting networking, research and advocacy efforts.

Conclusion

Community-based organizations are providing significant HIV care and treatment in Africa, and have shown that they can provide quality activities—sometimes as a supplement to public sector services, sometimes replacing them. These community-based organizations are multiplying, creating offshoots, and even spreading their models of health care to hospitals. The broad range of services offered by these organizations brings people out of isolation and away from stigma into prevention efforts, then to HIV testing, and on to care and treatment.

Support groups of people living with HIV have set up treatment regimen compliance clubs which support and monitor treatment providers and each other. Community networks pool efforts and resources to avoid medicine stock depletion and ensure that existing antiretroviral medicine supply chains remain viable. People infected with and affected by HIV are also demanding and receiving a greater role in designing and implementing national programmes.

These community-based efforts are diverse and involve different skills, vocations and resource bases. But this diversity is one of the great strengths of the community-based response. The varied responses offer many different ways to introduce, sustain and follow up clients as they receive care and treatment. The diversity and complementary services of community organizations help clients gain access to health care that is adapted to their particular needs at the lowest cost, and is often more comprehensive than services offered in the public sector.

Community-based organizations say the greatest ongoing challenges to community-based treatment include: obtaining funding for antiretrovirals, decentralizing access to HIV treatment, maintaining continuous drug supplies, and meeting and sustaining the human and operational needs of community responses. Despite the enormous pressure to save lives and the constantly changing context of the AIDS epidemic, these challenges can and will be overcome.

However, community-based organizations should not have to overcome tremendous odds on their own. They should not be expected to shoulder full, or even major, responsibility for what is really an obligation of the State—to ensure the right to health and health care.

Relying on community responses is counter-productive if they are seen to replace building sustainable primary health-care systems that meet public health needs. Instead, the work of community-based organizations should be recognized, encouraged and supported. This work should aim to achieve the goal of community-based excellence within a strong primary health-care response—a true public-community partnership in care and treatment that is critical to survival in the AIDS epidemic.

ANNEX 1: Questionnaire 1

COMMUNITY ACCESS

When filling out this form electronically, please be sure to DELETE the INCORRECT answer

Organization	
Founded in	
City	
Country	
Contact	
Telephone	
Fax	
E-mail	
Number of members	
Number of clients	

A/ A/ Do you provide testing services?

If so	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Do you provide pre- and/or post-test counselling?	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Do you do on-site blood tests?	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Is the laboratory on site?	<input type="button" value="YES"/>	<input type="button" value="NO"/>

B/ Do you provide medical follow up to people living with HIV (prophylaxis, management of opportunistic infections, palliative care)?

If so	<input type="button" value="YES"/>	<input type="button" value="NO"/>
To how many people?	<input type="text" value="0"/>	
How many care givers are involved?	<input type="text" value="0"/>	
Number of physicians and medical assistants:	<input type="text" value="0"/>	
Number of nurses and care givers:	<input type="text" value="0"/>	

Do you provide essential treatment for most common opportunistic infections?	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Is most of this medicine donated to the organization?	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Do patients pay for the medicine at the full price?	<input type="button" value="YES"/>	<input type="button" value="NO"/>

C/ Are you involved in activities facilitating access to ARVs

If so	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Do you prescribe ARVs on site?	<input type="button" value="YES"/>	<input type="button" value="NO"/>
Do you provide financial support to individuals for ARV purchasing?	<input type="button" value="YES"/>	<input type="button" value="NO"/>

Do you regularly order ARV in bulk for your clients?

YES

NO

Do you ensure medical follow-up of patients taking ARVs?

YES

NO

Do you ensure psychosocial follow-up of patients taking ARVs?

YES

NO

Do you do treatment literacy on ARVs?

YES

NO

Other (please describe)

How many of your members / clients are currently taking ARVs?

0

D/ If your organization is not involved in giving access to ARVs

Is it one of your organization's primary objectives?

YES

NO

If so, what would you need most in order to launch such a project? (Funding ARV drug purchase, hiring more employees, training current employees, administrative authorization, other... please specify)

Do you intend to launch such a project in the year to come?

YES

NO

Is your organization facilitating access to ARVs for its clients in any way that has not been mentioned above? - If so please list all related activities

E/ Please indicate other NGOs that you think might be dealing with access to ARVs in your country

Please send your reply by e-mail or fax to the following address:

acescommun@sidaction.org / fax to 33 (0) 1 53 26 45 75

ANNEX 2: Questionnaire 2

COMMUNITY ACCESS

NAME OF THE ORGANIZATION :

Number of employees:

Number of persons paid ad hoc (for occasional work):

Address:

E mail :

Contact:

How would you describe your group (NGO, community-based organization, faith-based organization, private foundation, professional group, public health centre, private clinic, other)?

What are the main services that you provide to HIV-positive people (testing, care, psychosocial support, prevention, lobbying and representation, drugs, research, other)?

Is your organization officially linked with the your country's national programme on access to ARVs?

What other agencies or groups do you work with closely, and how do you divide the tasks; who does what?

TESTING / COUNSELLING

IF YOU DO ON-SITE TESTING

How many people were tested in 2003?

How many tested positive?

Do you do other kinds of tests for patients? If so, what?

Are there other places to get tested? In the region? In the country?

What stands out or is special about your approach when it comes to testing and counselling (advantages and disadvantages compared with other kinds of organizations)?

MEDICAL CARE

What kinds of medical care to you provide?

On-site consultation	YES	NO
Home consultation	YES	NO
Outpatient care	YES	NO
Inpatient care/hospitalization	YES	NO

What is the cost of consulting a medical doctor in your structure? What is the cost in the closest public facility?

Among those currently enrolled in your program how many people urgently need ARVs who don't have access to them? (men/women)

Are they currently on cotrimoxazole as a prophylaxis to prevent opportunistic infections?

ARV MEDICAL CARE

Have the medical staff who work for you received **specific training** to deal with ARVs?

Which testing (blood screening, CD4, etc.) do you prescribe to people on ARVs?
How often?

Do you have systematic log to keep track of these patients?

Is this follow-up backed up on a computer?

If treatment was accessible for all, and considering the means you currently have at your disposal, how many people could you follow up?

What have you seen in terms of **therapeutic results** among people on ARVs (morbidity, mortality, opportunistic infections, CD4 counts, viral load, treatment failures, side effects, overall improvement in health, or quality of life)?

(If you have additional documentation on these aspects, can you please attach it to your answers, or let us know the best way to obtain a copy?)

How long have you been prescribing ARVs?

Do nurses typically prescribe ARVs, or is this a task that only doctors can carry out?

Did your centre have to obtain special or official authorization to dispense ARVs?

Do you prescribe **brand-name** ARVs or **generic** copies? Why?

What are your criteria for placing a person on ARV treatment (for adults and for children)?

What are the laboratory tests that you recommend or require? Why?

How many patients did you treat in 2002; and in 2003 (number of adults, men/women and children)?

Why not more?

What ARV combinations do you prescribe? **Why?**

Have you established techniques or specific activities for medical care of children on ARVs?

What are the main difficulties?

PREVENTING MOTHER-TO-CHILD TRANSMISSION (PMTCT)

Are you involved in PMTCT activities?

For how many women in 2003?

What protocol do you follow when reducing mother-to-child transmission?

What specific services do you offer to mothers and their family members in terms of reducing mother-to-child transmission?

ACCESSING ARVS

Do you have a pharmacy in your organization?

How many prescriptions are filled each month?

How do your patients acquire ARVs?

If you provide ARVs to your patients:

How do you obtain them?

Are they free or must they be paid for?

If they must be purchased by the patient, are they less expensive inside your organization than elsewhere (please give examples)?

Are you a **regular source for ARVs**, or is this only in case of emergency?

Do you help your clients in their attempts to obtain ARVs? How?

What do you do to get the best price?

How do you contribute **financially** to your patients obtaining access to ARVs? Please describe how you do this on an individual or a collective basis.

What are the **main difficulties** associated with acquiring ARVs?

TRAINING, INFORMATION ON ARVs, and COMPLIANCE

Do you organize training on ARVs for **health professionals** (doctors, pharmacists, others involved)?

Have you established specific activities for patients with AIDS and their families on treatment adherence, or on tracking patients who do not adhere to treatment regimens?

Do you have other training programmes and/or information dissemination about other targets?

BUDGET

What is your organization's budget for the year 2003 (in euros or dollars)?

Please list your **main sources of funding**.

Who funds **access to medicines** and medical care (other than ARVs)?

Who funds **access to ARVs**?

Who funds the **salaries of your staff**?

Which project is the most difficult to find funding for?

What is the current situation in your country in relation to the Global Fund (opportunities, potential barriers or other issues)?

GENERAL QUESTIONS

What would you say to those who fear that when community groups are responsible for distributing ARVs, the risk of poorly managed treatment increases—resulting in the possible development of resistant strains of HIV?

Since beginning ARV treatment in your organization:

Has it brought up/created other needs?

Has it made certain tasks easier? Others harder?

Is it your opinion that ARV treatment should be free to those who need it? Can you argue for or against treatment that is free of charge?

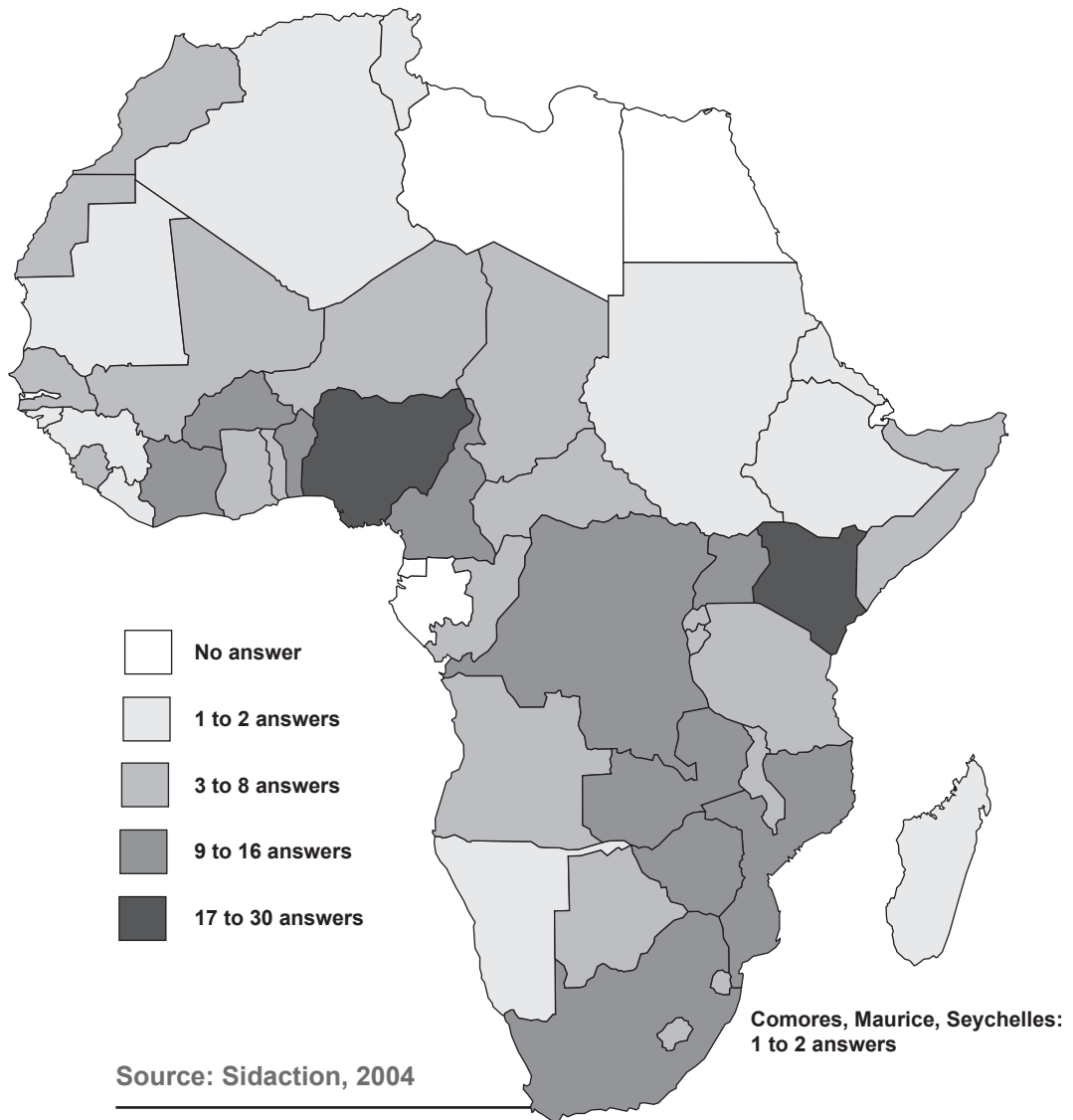
Are there other activities linked to ARVs that we haven't mentioned?

Do you agree to share the content of your answers with the other NGOs participating in this study?

ANNEX 3: Geographic distribution of responses to Questionnaire 1

Country	No. responses received to Questionnaire 1	Number of persons on ARVs
Algeria	1	10
Angola	4	40
Benin	13	106
Botswana	6	155
Burkina	12	546
Burundi	4	943
Cameroon	16	302
Central African Rep.	6	187
Chad	3	30
Comoros	2	0
Congo	7	72
Côte d'Ivoire	10	849
Dem. Rep. Congo	9	95
Eritrea	1	50
Ethiopia	5	0
Ghana	6	25
Guinea	2	30
Guinea-Bissau	1	0
Kenya	30	2573
Lesotho	4	53
Liberia	1	20
Madagascar	2	6
Malawi	5	2145
Mali	5	110
Mauritius	2	45
Mauritania	1	3
Morocco	3	387
Mozambique	13	51
Namibia	2	108
Niger	3	46
Nigeria	21	3272
Rwanda	4	78
Senegal	5	40
Seychelles	1	9
Sierra Leone	4	48
Somalia	2	0
South Africa	12	640
Sudan	1	0
Tanzania	7	127
Togo	7	164
Tunisia	2	100
Uganda	15	1247
Zambia	9	82
Zimbabwe	9	1333
Total	283	16817

Distribution of responses



ANNEX 4: Community-based organizations that responded to Questionnaire 1

Algeria	AIDS ALGERIE
Angola	ASSOCIATION MUTUEL DE L'EDUCATION GLOBAL EN ANGOLA (AMEGA) HOSPITAL DIOCESANO NOSSA SENHORA DA PAZ INSTITUTO PORTUGES DE MEDIINA PREVENTIVA MOP INTERNATIONAL
Benin	ACTION ESPOIR VIE ACTION PLUS SIDA SANTE (APSS) ARC EN CIEL ASSOCIATION JEUNESSE BENINOISE ET SIDA CENTRE DE REFLEXION ET D' ACTIONS POUR LE DEVELOPPEMENT INTEGRE ET LA SOLIDARITE (CERADIS - ONG) GROUPE D' ACTION POUR L' AUTO PROMOTION ET LE DEVELOPPEMENT DURABLE A LA BASE (GADBA) JEUNESSE AMBITION LES AMIS DE PASTEUR ONG ACTION SOCIALE (AS) PROJET SEDEKON PSI / ABMS RECHERCHES, ACTIONS COMMUNAUTAIRES, INITIATIVES POUR UN NOUVEL ESPOIR (RACINES) YWCA OF REPUBLIC OF BENIN
Botswana	BONEPWA - BOTSWANA NETWORK OF PEOPLE LIVING WITH HIV/AIDS BOTSWANA RETIRED NURSES SOCIETY CENTRE FOR YOUTH OF HOPE (CEYOHO)(PARTENAIRE BONASO) COPING CENTER FOR PEOPLE LIVING WITH AIDS (COCEPWA? PARTENAIRE BONASO) HOLY CROSS HOSPICE (PARTENAIRE BONASO) TIRISANYO CATHOLIC COMMISSION
Burkina Faso	ALAVI ASSOCIATION AFRICAN SOLIDARITE (AAS) ASSOCIATION AMMIE ASSOCIATION DES JEUNES POUR LE PROMOTION DES ORPHELINS (AJPO) ASSOCIATION POUR LE DEVELOPPEMENT DES INITIATIVES DE PREVENTION EN SANTE / SOLIDARITE BERGERIE FOI UNIVERS COMPASSION CENTRE D' INFORMATION DE CONSEIL ET DE DOCUMENTATION SUR LE SIDA ET LA TUBERCULOSE ESPOIR ET VIE INITIATIVE PRIVEE ET COMMUNAUTAIRE DE LUTTE CONTRE LE VIH/SIDA (IPC/BF) RESEAU ACCES AUX MEDICAMENTS ESSENTIEL (RAME) REVS+ UNION DES ROUTIERS BURKINABE DE LUTTE CONTRE LE SIDA (URBLS)
Burundi	ASSOCIATION DE PRISE EN CHARGE DES ORPHELINS DU SIDA (APECOS) ASSOCIATION NATIONALE DE SOUTIEN AUX SEROPOSITIFS ET SIDEENS (ANSS) CED CARITAS SWAA BURUNDI

Cameroon	<p>AFSUPES ASSOCIATION DES FEMMES ACTIVES ET SOLIDAIRES (AFASO) ASSOCIATION DES FRERES ET SŒURS UNIS (AFSU) BANS SELF SUPPORT GROUP FOR WOMEN LIVING WITH HIV AIDS BELO SELF SUPPORT GROUP FOR WOMEN LIVING WITH HIV AIDS CENTRE D'ANIMATION SOCIALE ET SANITAIRE COLIBRI ESPOIR + HOPE IS RISING ASSOCIATION (HIRASSO) INTER CARE NJINIKOM PROJECT HOPE CATHOLIC HEALTH SERVICES MBINGO SELF SUPPORT GROUP FOR WOMEN LIVING WITH HIV AIDS MUCATAS NDU SELF SUPPORT GROUP FOR WOMEN LIVING WITH HIV AIDS RESEAU ETHIQUE DROIT ET SIDA (REDS) SUNAIDS SWAA</p>
Central African Republic	<p>AMIS D'AFRIQUE CARITAS CONGRES NATIONAL DES JEUNES FEMMES VIVANT AVEC LE VIH RECAPEV RONALSI SOLISIDAC (SOLIDARITE CONTRE LE SIDA EN CENTRAFRIQUE)</p>
Chad	<p>CENTRE AL NADJMA CENTRE DIOCESAIN D'INFORMATION SUR LE SIDA ET D'ACCOMPAGNEMENT DES MALADES (CEDIAM) RESEAU NATIONAL TCHADIEN DES PVVIH (RNTP+)</p>
Comores	<p>ASSOCIATION COMORIENNE POUR LE BIEN ETRE DE LA FAMILLE (ASCOBEF) CROISSANT ROUGE COMORIEN</p>
Congo	<p>ASSOCIATION DONNONS LE SOURIRE ASSOCIATION FEMMES PLUS DU CONGO ASSOCIATION HALTE SIDA ASSOCIATION JEUNES POSITIFS DU CONGO ASSOCIATION VIVRE PLUS CONGO (AVPC) AZUR DEVELOPPEMENT ESPACE SEROPOSITIFS ET AUTRES PERSONNES ORGANISEES POUR UN INTERET REEL (ESPOIR)</p>
Côte d'Ivoire	<p>ACONDA VS CI BOUAKE EVEIL CENTRE SOLIDARITE ACTION SOCIALE CHIGATA CLUB DES AMIS GROUPE D'AUTO ASSISTANCE DE PERSONNES VIVANT AVEC LE VIH SIDA ET PROMOTION SOCIALE (GAP+PS) LUMIERE ACTION RENAISSANCE SANTE BOUAKE (RSB) RIP + RUBAN ROUGE CI</p>

UNAIDS

Democratic Republic of Congo

- ASSOCIATION POUR LA PROMOTION DES INITIATIVES COMMUNAUTAIRES
- CERCLE DE RECHERCHE DES ETUDIANTS EN MEDECINE DE BUKAVU (CREM)
- COMITE DIOCESAIN DE LUTTE CONTRE LE SIDA (CODILUSI)
- ESPOIR, VIE & SOLIDARITE (EVIS)
- FONDATION FEMME PLUS
- FONDATION TULIZA
- GROUPE ANTI SIDA DE BUTEMBO
- KATALIKO ACTIONS FOR AFRICA
- SIDAACCESS

Eritrea BIDHO, PLWHAS, ERITREA

Ethiopia

- CARE ETHIOPIA
- FAMILY GUIDANCE ASSOCIATION
- NORWEGIAN CHURCH AID ETHIOPIA
- PLAN ETHIOPIE
- TESFA INTEGRATED RURAL DEVELOPMENT & SOCIAL SERVICES (TIRDSS)

Ghana

- AFRICAN TURNING POINT FOUNDATION
- AFRIWEB FOUNDATION
- GHANA AIDS TREATMENT ACCESS GROUP
- LIFE RELIEF FOUNDATION
- LYNX AFRICARE NETWORK
- MUSLIM RELIEF ASSOCIATION OF GHANA (MURAG)
- YOUTH FOR ACTION ORGANIZATION

Guinea

- ASFEGMASSI
- FONDATION ESPOIR GUINNE (FEG)

Guinea Bissau ASSOCIATION GUINEENNE D'ETUDES ET ALTERNATIVES - CENTRE D'INFORMATION DEPISTAGE, CONSEIL ET APPUI EN SIDA

Kenya

- ACTION NOW KENYA
- AFRICA INLAND CHURCH
- AFRICAN MEDICAL AND RESEARCH FOUNDATION
- APOSTOLES OF JESUS AIDS MINISTRIES (AJAM)
- AWARENESS GROUP ON AIDS PREVENTION (AGAP)
- BORABORA INNOVATIONS
- CAMPAIGNER FOR AN AIDS FREE SOCIETY (CAFS)
- CARE FOR ORPHANS COMMUNITY DEVELOPMENT PROJECT
- GRACE CENTRE INTERNATIONAL
- HARVEST OF HOPE SELF HELP COMMUNITY CENTRE
- HEALTH MANAGEMENT AGENCY
- HEALTH PARTNERS
- KENYA AIDS NGOS CONSORTIUM
- LAIKIPIA HIV AIDS CONTROL ORGANIZATION
- LIVERPOOL VCT & CARE
- MOP KENYA
- MOTHER'S RURAL CARE FOR AIDS ORPHANS (MORCAO)
- MOVEMENT OF MEN AGAINST AIDS (MMAAK)
- MSF ESPAGNE KENYA
- MUSLIM YOUTH DEVELOPMENT
- NEW LIFE HOME TRUST

Expanding access to HIV treatment through community-based organizations

Kenya	<p>OECUMENICAL PHARMACEUTICAL NETWORK ORGANIZATION FOUNDATION OF PEOPLE LIVING WITH HIV AIDS IN KENYA (FOPHAK) PENDEKEZO LETU RURAL AWARENESS AND DEVELOPMENT SERVICES (RADES) TAPWAK WOMEN FIGHTING AIDS IN KENYA (WOFAK) YOUTH EMPOWERED TO SUCCEED PROJECT</p>
Lesotho	<p>HOPE OF THE WORLD LESOTHO CATHOLIC BISHOP'S CONFERENCE POPULATION SERVICES INTERNATIONAL THE N.U.L HIV AIDS COORDINATING COMMITTEE</p>
Liberia	<p>STOP AIDS IN LIBERIA (SAIL)</p>
Madagascar	<p>ASSOCIATION PHILADELPHIE FIFAFI (FINOANA FANANTENANA FITIAVANA) OU (FOI ESPOIR AMOUR)</p>
Malawi	<p>CHRISTIAN HEALTH ASSOCIATION DEVELOPMENT AID FROM PEOPLE TO PEOPLE (DAPP) FAMILI MSF FRANCE MALAWI PARTNERS IN HOPE</p>
Mali	<p>ARCAD SIDA ASSOCIATION POUR LA PROMOTION DE LA FEMME ET DES ENFANTS DU MALI (APROFEM) KENEDOUGOU SOLIDARITE TOMBOUCTOU KOIRO HINSA (TKH) WALE ACTION SANTE POPULATION</p>
Morocco	<p>ASSOCIATION DE LUTTE CONTRE LE SIDA (ALCS) ASSOCIATION DE LUTTE CONTRE LE SIDA, SECTION AGADIR ORGANISATION PAN AFRICAINE DE LUTTE CONTRE LE SIDA (OPALS - MAROC)</p>
Mauritius	<p>PREVENTION INFORMATION ET LUTTE CONTRE LE SIDA (PILS) SWAA</p>
Mauritania	<p>AMALTUS</p>
Mozambique	<p>ADPP-TCE MOZAMBIQUE AFRICAN MEDICAL RESEARCH FOUNDATION (AMREF) ASSOCIAÇÃO KINDLIMUKA ASSOCIAÇÃO NIVENYEE ASSOCIAÇÃO TINEHENA KULIMA KUVUMBANA KUYAKANA MONASO DE SOFALA SAVE THE CHILDREN UK SOUTHERN AFRICAN AIDS TRUST TCHAVELELO YOLAKA</p>

Namibia	CATHOLIC HEALTH SERVICES MOP INTERNATIONAL NAMIBIA
Niger	LUTTE CONTRE LA PAUVRETE (LUCOP) MIEUX VIVRE AVEC LE SIDA (MVS) ACTION FAMILY NETWORK (AFN)
Nigeria	AFRICAN BOOK TRUST AIDS ALLIANCE NIGERIA CENTER FOR DEVELOPMENT SUPPORT INITIATIVES CENTER FOR THE RIGHT TO HEALTH CHRISTIAN HEALTH ASSOCIATION CHRISTIANS CONCERNED ABOUT AIDS GLOBAL HEALTH AND AWARENESS RESEARCH FOUNDATION (GHARF) GOODWORKER MOVEMENT INTERNATIONAL HEALTH CARE CONCEPTS HEALTH COMMUNICATION AND RELIEF NETWORK INC. HOPE FOR AIDS OUTREACH JOURNALISTS AGAINST AIDS (JAAIDS) LIFE LINE PLUS FOUNDATION LIVING HOPE ORGANIZATION NETWORK OF PEOPLE LIVING WITH HIV AIDS IN NIGERIA (NEPHWAN) NETWORK ON ETHIC, LAW, HIV AIDS PREVENTION SUPPORT AND CARE (NELA PSC) POSITIVE LIFE ASSOCIATION OF NIGERIA (PLAN) SAVE VISIONS AFRICA THE PRESBYTERIAN AIDS ACTION WOMEN'S ACTION RESEARCH ORGANIZATION (WARO)
Rwanda	AFXB RWANDA ASSOCIATION FEMMES MUSULMANES POUR LE DEVELOPPEMENT (AFMD) BAMPOREZE RESEAU FEMME LEVE TOI
Senegal	ASSOCIATION SENEGALAISE POUR LE DEVELOPPEMENT DE LA PSYCHOLOGIE APPLIQUEE RESEAU NATIONAL DES PVVIH SIDA SERVICE SYNERGIE POUR L'ENFANCE
Seychelles	FAITH AND HOPE ASSOCIATION (FAHA)
Sierra Leone	FLASK COMMUNITY DEVELOPMENT ORGANIZATION INTERNATIONAL EDUCATION AND RESSOURCE NETWORK (IEANR) KENEMA DIOCESAN HEALTH OFFICE UMC KISSY HEALTH AND MATERNITY CENTER
Somalia	FAMILY ECONOMY REHABILITATION ORGANIZATION SAMO DEVELOPMENT ORGANIZATION

Sudan	PATIENTS HELPING FUND
South Africa	BLESSED GERARD'S CARE CENTRE HIV AIDS PREVENTION GROUP HOLY CROSS HOME (FRAIL CARE AND HOSPICE) HOPE WORLDWIDE SA LIFE LINE RAPE CRISI PIETERMARITZBURG PROJECT GATEWAY SINOSIZO HBC OVC & TRAINING THE HOUSE OF RESURECTION HEAVEN THE KIDZPOSITIVE FAMILY FUND TOPSY FOUNDATION
Swaziland	SWAZILAND AIDS SUPPORT ORGANISATION (SASO) SWAZILAND HOSPICE AT HOME THE AIDS INFORMATION & SUPPORT CENTRE (TASC) THE FAMILY LIFE ASSOCIATION OF SWAZILAND (FLAS)
Tanzania	CHAWAVUMA TANZANIA NETWORK OF ORGANIZATIONS FOR PEOPLE LIVING WITH HIV AIDS (TANOPHA) TUMAINI CENTRE - HURUMA HOSPITAL VUKA TANZANIA WAMATA ARUSHA WAVUMO
Togo	ACTION CONTRE LE SIDA AIDE MEDICALE ET CHARITE ASSOCIATION TOGOLAISE DES JEUNES POUR LE DEVELOPPEMENT ESPOIR VIE TOGO LONLOYO SAUVONS LA VIE VIVRE DANS L'ESPERANCE
Tunisia	ASSOCIATION TUNISIENNE DE LUTTE CONTRE LES MST ET LE SIDA (ATL MST / SIDA) ASSOCIATION TUNISIENNE DE LUTTE CONTRE LES MST ET LE SIDA SECTION TUNIS
Uganda	AIDS INFORMATION CENTRE ASSOCIATION FRANÇOIS XAVIER BAGNOUD (AFXB) BUDIOPE WELFARE ACTION INITIATIVE (BUWAI) FRIENDS OF CHRIST REVIVAL MINISTRIES HEALTH RIGHTS ACTION GROUP MARIAM FOUNDATION CENTRE MARIE STOPES NATIONAL COMMUNITY OF WOMEN LIVING WITH HIV AIDS IN UGANDA (NACWOLA) NATIONAL FORUM OF PEOPLE LIVING WITH HIV AIDS IN UGANDA REACH OUT MBUYA HIV AIDS INITIATIVE THE AIDS SUPPORT ORGANISATION (TASO) UGANDA COALITION FOR ACCESSTO ESSENTIAL MEDICINES UGANDA NETWORK OF AIDS SERVICE ORGANIZATION (UNASO)

UNAIDS

Zambia

CHINIKA HOUSE SACRED HEARTS SISTERS
CHURCHES HEALTH ASSOCIATION OF ZAMBIA
FAITH ORPHANAGE FOUNDATION
FAMILY HEALTH TRUST
HOMECARE SERVICES
LOLOMA
MOP INTERNATIONAL
NCHELENGE DISTRICT HIV AIDS TASK FORCE
ZAMBIA RED CROSS SOCIETY

Zimbabwe

BATSIRAI GROUP
FAMILY AIDS CARING TRUST
GAYS AND LESBIANS OF ZIMBABWE+
LUISA GUIDOTTI HOSPITAL
SOUL'S COMFORT
THE CENTRE
YOUTH IN FOCUS
ZIMBABWE AIDS PREVENTION PROJECT
ZIMBABWE NATIONAL FAMILY PLANNING COUNCIL

ANNEX 5: Community-based organizations that responded to Questionnaire 2

Angola	ASSOCIATION NATIONALE POUR L'ACTION COMMUNAUTAIRE
Benin	LES AMIS DE PASTEUR ONG ACTION SOCIALE (AS)
Burkina Faso	ALAVI REVS+
Burundi	ASSOCIATION DE PRISE EN CHARGE DES ORPHELINS DU SIDA (APECOS) ASSOCIATION NATIONALE DE SOUTIEN AUX SEROPOSITIFS ET SIDEENS (ANSS) SWAA BURUNDI
Cameroon	ASSOCIATION DES FRERES ET SŒURS UNIS (AFSU) INTER CARE NJINIKOM PROJECT HOPE CATHOLIC HEALTH SERVICES SUNAIDS SWAA
Congo	ESPACE SEROPOSITIFS ET AUTRES PERSONNES ORGANISEES POUR UN INTERET REEL (ESPOIR)
Cote d'Ivoire	CENTRE SOLIDARITE ACTION SOCIALE RENAISSANCE SANTE BOUAKE (RSB) RUBAN ROUGE CI
Eritrea	BIDHO, PLWHAS, ERITREA
Guinea	ASFEGMASSI
Kenya	HEALTH MANAGEMENT AGENCY LAIKIPIA HIV AIDS CONTROL ORGANIZATION WOMEN FIGHTING AIDS IN KENYA (WOFAK)
Mali	ARCAD SIDA KENEDOUGOU SOLIDARITE
Morocco	ORGANISATION PAN AFRICAINE DE LUTTE CONTER LE SIDA (OPALS - MAROC)
Namibia	CATHOLIC HEALTH SERVICE
Niger	MIEUX VIVRE AVEC LE SIDA (MVS)
Nigeria	LIVING HOPE ORGANIZATION
South Africa	HOPE WORLDWIDE SA THE KIDZPOSITIVE FAMILY FUND

UNAIDS

Swaziland	SWAZILAND HOSPICE AT HOME
Tchad	CENTRE AL NADJMA
Togo	ACTION CONTRE LE SIDA AIDE MEDICALE ET CHARITE ESPOIR VIE TOGO VIVRE DANS L'ESPERANCE
Zambia	FAMILY HEALTH TRUST

ANNEX 6: Antiretroviral treatment coverage and need at the time of the survey

Coverage of adults in low- and middle-income countries on antiretroviral treatment, by WHO Region, situation as of November 2003			
Region	Number of people on treatment	Estimated need	Coverage
Africa	100 000	4 400 000	2%
Americas	210 000	250 000	84%
Europe (Eastern Europe, Central Asia)	15 000	80 000	19%
Eastern Mediterranean	5 000	100 000	5%
South-East Asia	60 000	900 000	7%
Western Pacific	10 000	170 000	6%
All WHO Regions	400 000	5 900 000	7%

Source: "3 by 5" Progress Report, December 2003-June 2004, World Health Organization, 2004 (available from www.who.int)

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together ten UN agencies in a common effort to fight the epidemic: the Office of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Children's Fund (UNICEF), the World Food Programme (WFP), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its ten cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV/AIDS on all fronts. UNAIDS works with a broad range of partners – governmental and nongovernmental, business, scientific and lay – to share knowledge, skills and best practices across boundaries.

Produced with environment-friendly materials

UNAIDS • BEST • PRACTICE • COLLECTION

The UNAIDS Best Practice Collection

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV/AIDS, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the HIV/AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact- alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the HIV/AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

Find out more about the Best Practice Collection and other UNAIDS publications from www.unaids.org. Readers are encouraged to send their comments and suggestions to the UNAIDS Secretariat in care of the Best Practice Manager, UNAIDS, 20 avenue Appia, 1211 Geneva 27, Switzerland.

Expanding access to HIV treatment through community-based organizations

This UNAIDS Best Practice Collection publication is intended as a resource for civil society, groups of people living with HIV, national programme managers, international and national policy-makers and donors to better appreciate and support the concept of involving more community-based organizations in national plans for providing HIV care and treatment.

In 2004, the nongovernmental organization, Sidaction, with support from UNAIDS and WHO, conducted a survey of the community response to HIV treatment needs in Africa. The document describes the self-reported experiences and achievements of community-based organizations already involved in providing care; this Best Practice provides strategic information on some of the needs, challenges and opportunities that are specific to community-based organizations in scaling up access to care and treatment; it demonstrates the current and potential value of their work and suggests ways forward to assess, support, and enlarge the scope and impact of that work. It is hoped that this Best Practice will inspire other countries and regions to replicate the untiring work of African community-based organizations, as well as demonstrate to both policy makers and donors the valuable contributions of civil society to the response to the AIDS epidemic, especially with regards to provision of care and treatment.

This survey was the first attempt to map and describe the contributions made by community groups, including those founded by persons living with HIV, in increasing access to antiretroviral therapy. Urgent and ongoing support to their efforts, in the context of a viable public health response, is a critical part of an effective and comprehensive response to HIV.



Joint United Nations Programme on HIV/AIDS

UNAIDS

UNHCR • UNICEF • WFP • UNDP • UNFPA
UNODC • ILO • UNESCO • WHO • WORLD BANK