

National Community Home-Based Care Standards



National Community Home-Based Care Standards



National Community Home-Based Care Standards

This document is published as part of the Government of Zimbabwe's continuing effort to make the best possible health care available to its citizens.

The publication of the document was made possible through the support of the UK Department for International Development (DFID) under the Zimbabwe HIV and AIDS Programme (ZHAP), managed by John Snow International (UK) under contract number dfRC/ZW 023844. The opinions expressed herein are those of the authors and do not necessarily reflect the views of DFID or the organizations the authors represent.

Any part of this document may be freely reviewed, quoted, reproduced or translated in full or in part, provided the source is acknowledged. It may not be sold or used in conjunction with commercial purposes or for profit.

Published by: Ministry of Health and Child Welfare
Government of Zimbabwe
PO Box CY1122
Causeway
Harare, Zimbabwe

Edited by: Margaret Crouch
PO Box 61538 - 0200 City Square
Nairobi, Kenya

Printed by: Commercial Printers (Pvt) Ltd

Contents

Abbreviations	vi
Acknowledgements	vii
Foreword	ix
Definitions for Home-Based Care Standards	xi
Introduction	1
Why Home-Based Care?	1
Why This Guide?	2
Why Standards?	3
Structure of the Guidebook	3
Summary of the Standards	4
Standard 1 – Care and Support for Patients and Family	4
Standard 2 – Team Service Provision	4
Standard 3 – Governance and Management	4
Standard 4 – Training, Information and Education	4
Standard 5 – Monitoring and Evaluation	4
Data and Information Collection	4
A Word about Monitoring and Evaluation	5
Standard 1: Care and Support for Patient and Family	7
Needs Assessment and Situation Analysis	7
Objective 1.1: To provide holistic care for physical, emotional, spiritual and socio-cultural needs of the patient and the family through care teams	7
Joint Development of an Appropriate Care Plan	9
Objective 1.2: To ensure that patients and their families are involved in planning and decision making about their care	9
National Community Home-Based Care Standards	iii

Objective 1.3: To mobilize adequate resources for HBC together with community leaders and stakeholders	9
Objective 1.4: To ensure that care teams provide pre and post bereavement support to those affected	10
Care of Infected and Affected Children and Youth	10
Objective 1.5: To ensure that care teams cater for the needs and rights of infected and affected children	10
Confidentiality, Privacy and Dignity	12
Objective 1.6: To ensure the patient's right to privacy, dignity and confidentiality in the home	12
Skills Sharing	15
Objective 1.7: To ensure that primary caregivers have practical caring skills	15
Standard 2: Team Service Provision	16
Networking and Team Building	16
Objective 2.1: To strengthen collaboration among support networks involved in home-based care	16
Objective 2.2: To establish criteria for home-based care team membership	17
Objective 2.3: To conduct regular collaborative multi-disciplinary team/stakeholder meetings	17
Objective 2.4: To coordinate HBC resources from all sectors	17
Objective 2.5: To create an enabling environment for volunteers	19
Objective 2.6: To assure comprehensive and holistic care by ensuring appropriate staffing levels at all times	19
Objective 2.7: To ensure a continuum of care through discharge planning	19
Service Delivery	21
Objective 2.8: To ensure equitable access to HBC services and information by everyone in need of home-based care	21
Objective 2.9: To create an awareness of ethical issues among HBC team members so that PLWHAs are able to exercise their fundamental human rights and freedoms (such as privacy, informed choice, decency, personal integrity and dignity), and to benefit from all HBC services and activities without discrimination	21
Objective 2.10: To provide essential drugs, medical and surgical sundries, through joint resource mobilization strategies by HBC programme managers/supervisors, care teams, stakeholders, families and communities	23
Objective 2.11: To provide psycho-social support to home-based care clients including infected and affected children	24
Standard 3: Governance and Management	25
Objective 3.1: To adopt home-based care policies and standards, including professional principles and standards	25

Objective 3.2: To provide periodic technical supervision and support to care teams	26
Objective 3.3: To maintain confidentiality of patient records	27
Objective 3.4: To ensure that up-to-date records are kept for ordering and distributing supplies and equipment to avoid surpluses or shortages	29
Objective 3.5: To implement innovative strategies to finance home-based care activities through families, stakeholders and community initiatives	29
Standard 4: Training, Information and Education	31
Objective 4.1: To develop and strengthen home-based care teams	31
Standard 5: Monitoring and Evaluation	33
Objective 5.1: To ensure timely, accurate tracking of progress of home-based care programmes so as to ensure that they are on course to achieve their goals	33
Annex: Data Collection Tools	37
References and Further Reading	47

Abbreviations

AIDS	Acquired immune-deficiency syndrome
BCC	Behaviour change communications
CBO	Community-based organization
CDC	Centers for Disease Control
CHBC	Community home-based care
DAAC	District AIDS Action Committees
DFID	Department for International Development
HBC	Home-based care
HIV	Human immunodeficiency virus
HOSPAZ	Hospice Association of Zimbabwe
IEC	Information, education and communication
JSI ^{UK}	John Snow International - UK
M&E	Monitoring and evaluation
MOH&CW	Ministry of Health and Child Welfare
NAC	National AIDS Council
NGO	Non-government organization
PLWHA(s)	Person(s) living with HIV/AIDS
PMTCT	Prevention of mother to child transmission (of HIV)
TB	Tuberculosis
UK	United Kingdom
UNAIDS	United Nations Joint Programme on HIV/AIDS
UPs	Universal precautions (WHO)
WHO	World Health Organization
ZACH	Zimbabwe Association of Church-related Hospitals
ZHAP	Zimbabwe HIV and AIDS Programme

Acknowledgements

The Ministry of Health and Child Welfare wishes to thank the standards Technical Working Group members listed below for their individual and collective contribution towards this handbook. The Ministry extends deepest appreciation to John Snow International - United Kingdom (JSI^{UK}) for providing financial, material and technical assistance in developing the community home-based care standards. The Ministry also greatly appreciates the efforts of the Hospice Association of Zimbabwe (HOSPAZ) for spearheading the process of developing the standards.

We also wish to acknowledge the authors of these previous policy documents: National Policy for Community Home-Based Care and the National Discharge Planning Guidelines. Many other stakeholders and professionals representing various organizations provided well thought comments on various drafts and to them we are grateful. Many home-based care organizations not named, from whom we solicited information, were very forthcoming with suggestions and

offered various materials relating to their home-based care work, most of which benefited our efforts to develop these standards. These organizations are also hereby sincerely appreciated.

Standards Technical Working Group

Paul S.S. Shumba, JSI^{UK} – *Group Leader*

Group Members:

Ms. Carla Lamadora, Hospice Association of Zimbabwe
Mrs. Julieth Musengi, Hospice Association of Zimbabwe
Mrs. Eunice Garanganga, Hospice Association of Zimbabwe
Mrs. Janet Muteiwa, Ministry of Health and Child Welfare
Mr. Denmark Mavesere, Zimbabwe Association of Church-related Hospitals
Mr. David Matanhire, National AIDS Council
Mrs. Sambulo Mkwanzani, Island Hospice Service, Harare

Foreword

These National Community Home-Based Care Standards are part of the ongoing effort to bring together an enabling environment for care and support of patients and their families in Zimbabwe. The National Community Home-Based Care Policy and Discharge Planning Guidelines, developed by a multi-disciplinary team in consultation with relevant stakeholders, highlight the priorities and policies to be adopted by government and partners, including communities, to ensure quality of care for patients and their families.

The standards are intended to guide us to a more concerted and unified response to providing quality care in our communities, especially in light of the impact of the HIV/AIDS pandemic. While recent figures reveal that we may be making progress in retarding the rate of infection in the country, the percentage of those infected still remains at 24.6%. Until people living with HIV and AIDS have greater access to antiretroviral treatment, many families in our communities will continue to face the difficult challenge of caring for a family member at home.

Individuals, families and communities are playing a vital role in assisting families to cope with the care required for patients. However, the quality of care and effort are hampered by lack of knowledge, coordination and resources. These standards will give the nation a useful instrument by which to measure efforts and progress in providing quality holistic care. It is my hope that with the implementation of these standards the desired supportive environment will be created for the patients and their families throughout the continuum of care.



Dr. Elizabeth Xaba
Secretary for Health
Ministry of Health and Child Welfare
Republic of Zimbabwe
March 2004

Definitions for Home-Based Care Standards

Alternative nursing care measures – The use of techniques such as dietary regimes, massage, aromatherapy and other approaches that are not part of the conventional medical approach.

Bereavement support – Provision of counselling and practical assistance to those who are anticipating the death of a family member or have had a family member die.

Care plan – The document of planned activities that outlines the manner in which the needs of the patient and family are to be addressed continually.

Caregiver – A trained person, often a volunteer, who works with communities and families to share information about health practices, provide some simple treatments and refer sick people to clinics/medical centres for other necessary treatment.

Caring skills – The ability to provide for the holistic needs of a patient and the family.

Continuum of care – A comprehensive multi-level response from the hospital to the home and vice versa, covering a wide range of medical, emotional and social support needs of chronically ill patients and their families. To establish a

continuum, a diagnosis has to be made that provides for further care and support.

Counselling – A one-on-one process by which a trained person assists a client to examine the client's situation and assess options for resolving problems and making decisions about future actions. In the home-based care context, counselling often has to do with issues such as HIV testing, life-style considerations and coming to terms with loss.

Discrimination – Takes place when a prejudicial thought or attitude leads to a distinction being made against a person, or persons, that results in the person or persons being treated unfairly on the basis of their belonging, or being perceived to belong, to a particular group. Where appropriate laws exist that protect the equal rights of all, these actions are unlawful.

Evaluation – The systematic process of conducting quantitative and qualitative data collection and analysis activities in order to assess actual progress towards programme goals. Evaluations should be participatory and scheduled to cover specific periods or aspects of programme implementation to judge value and/or effectiveness. For example, a process evaluation assesses both qualitative and quantitative aspects of programme inputs, outputs and service quality.

Holistic – An approach that looks at the complete person, physically, psychologically, spiritually and socially.

Home-based care – Any form of care given to sick people in their own homes (MOH&CW Home-Based Care Guidelines).

Informed consent – Decision made on the basis of information provided to the patient and/or family on the best options of care, and a mutual understanding of the implications of those options of care and treatment, medication side effects, and a mutual agreement to pursue the options available.

Logistics system – System of procurement, storage, dispensing/distribution and inventory management of HBC drugs, equipment, supplies and relevant materials.

Monitoring – The continuing process or set of actions to review planned activities in order to assess whether they are carried out in a manner that will facilitate the ultimate achievement of the goals and objectives of the HBC intervention, by keeping the HBC programme on track.

Ongoing recognition – Motivational tools that provide incentives and facilitate the regular, formal appreciation of the work of caregivers.

Patient health assessment – A process of evaluating the current status of a person’s health.

Primary caregiver(s) – Person (or people) with the ultimate responsibility of caring for the sick person on a routine basis in the home.

Reference materials – Information intended to serve as a resource during the provision of care.

Stigma – The imposition of a special, discrediting and unwanted “label” on a person, or group of persons that indicates that they are looked upon as fundamentally and in most cases shamefully different from “normal” persons. The label is imposed on persons who are believed to be deviant or to have a status that distinguishes them. The effects of such a label are currently experienced by a majority of those infected or affected by HIV/AIDS.

Universal precautions (UPs) – World Health Organization (WHO) standard measures accepted and promoted worldwide to prevent infection promptly.

Introduction

Zimbabwe has been hit hard by HIV and AIDS, and there is every sign that the impact will get worse in the next few years. The prevalence of HIV infection among adults in Zimbabwe is estimated at 24.6%, with an estimated 2,000 people dying per week (MOH&CW/CDC, 2003). Obviously many of these people are parents, and they are leaving behind an ever-larger population of children who will grow up without their love and guidance. The number of Zimbabwe's children who have lost one or both parents to the virus is estimated to exceed 780,000 (UNAIDS, 2002), and is increasing.

Children orphaned by AIDS face numerous problems, many of them devastating. They know the trauma of witnessing the sickness and death of one or both of their parents. They are likely to be poorer and less healthy than non-orphans. They endure damage to both their cognitive and their emotional growth, have less access to education, are frequently forced into child labour, and are at risk of various forms of abuse by adults.

Many children are also infected by the virus at birth, and face a short, uncertain future. The estimated number of Zimbabwe's children who have died of AIDS-related illness is 240,000 (UNAIDS, 2001), while the number of children below 15 years infected by HIV stands at around 56,000

(UNAIDS, 2001). Infected children face similar patterns of disadvantage, particularly stigma and discrimination, and are often denied their fundamental rights to parental love, proper health care, nutrition and education. Many infected and affected children and youth require special attention.

Why Home-Based Care?

Even as the HIV/AIDS pandemic plays havoc with families and communities, so too is it putting serious pressure on the capacities of the health care and other welfare systems in Zimbabwe. The number of HIV and AIDS patients is ever increasing, and most of these individuals must be cared for at home or in their respective communities. The caregivers who tend them often have no or very limited training in caring for the terminally ill and may not know at all how to protect themselves from infection. For home-based care to be effective, essential support services need to be developed or strengthened to assist relatives and communities to provide quality care for patients in the most cost-effective manner.

HIV/AIDS patients face bouts of often life threatening illness, interspersed with periods of reasonably good health. They and their families need to know how to protect themselves from opportunistic infections, such as tuberculosis. Eventually, however, the virus begins to take

HIV infected children face stigma and discrimination and are often denied their fundamental rights to parental love, proper health care, nutrition and education.

**Home care,
home-based
care,
community
home-based
care, palliative
care, hospice
care – all
these are
aspects of
caring for a
person at
home.**

its toll and the infected person may be bedridden. Here is where home-based care is most demanding on family and community caregivers. Before many of the patients die, they will need intensive, long-term medical care.

As a result of many adverse socio-economic factors, most citizens cannot afford or do not have access to public and private health care. The HIV/AIDS pandemic and the adverse socio-economic environment have given our country no choice except to encourage home-based care. The World Health Organization (WHO) defines home-based care as “a programme that through regular visits, offers health care services to support the care process in the home environment of the person with HIV infection. Home visits may be the only service provided or be part of an integrated programme which offers the patient and his/her family services in the home, hospital and community”.

But home-based care should not be viewed only as a third rate option for poor people. It has many advantages. These standards are part of the ongoing participatory development of a more formal system of supporting home-based care in Zimbabwe in order to increase the quality and effectiveness of this mode of care. The standards form the foundation from which to advocate for resources to support home care, to recognize when we have met our targets, to determine whether our care is effective and if we have achieved the goal of providing the best quality of life.

The design and operational basis of these standards is the Community Home-Based Care Policy for the Republic of Zimbabwe (MOH&CW, 2001). The compilation of these standards has been a collaborative effort by home-based care stakeholders, donors, non-government organizations (NGOs)

and representatives of the Government of Zimbabwe.

The standards, as “work in progress”, are intended to be a useful tool. As such, they must be kept relevant, updated periodically with input from all sectors, adjusted when the environment changes, and used to regularly re-evaluate the way we work in home-based care. In developing these standards, the Technical Working Group relied on current research reports, guidelines, handbooks and policy documents drawn from local, regional and international sources that touch on the various aspects of clinical and palliative community home-based care of HIV and AIDS patients.

Why This Guide?

In Zimbabwe, home-based care has been practised for many years. Nursing an ill relative at home is not unusual. As the extent of the need for such care has grown uncontrollably, however, with nearly every family in an area nursing a terminally ill person, individual families are no longer able to cope. Communities and organizations serving them are aware of the problem and are looking for optimal ways to address it.

Home care is care for chronically ill people in the home. Home care, home-based care, community home-based care, palliative care, hospice care – all these are aspects of caring for a person at home. What does it entail? What does it need? What makes it work? How should it link up with other health care services? To answer these questions, we must develop a set of standards – answers that help us reach a common understanding and speak the same language. An ideal home-based care programme offers many advantages to the patient, family and community. These are:

- Patients are cared for in a familiar home environment until they die, as opposed to being isolated during hospitalization.
- The entire family works together to support the patient.
- Families and communities begin to understand HIV and AIDS better, helping to make prevention initiatives more effective and providing experience and skills for coping with future cases in the family and community.
- Communities adopt more supportive attitudes and an awareness that AIDS in Africa is a family disease.
- A comprehensive home care programme facilitates planning by identifying households where orphans and other dependents will be left behind to fend for themselves.
- Home care frees up hospital beds and reduces the cost to the conventional health care system, while maintaining a strong link with it.

The beginning of a process is always a good time to reflect on its purpose.

Why Standards?

Why standards for home-based care in particular? The answers lie in the working environment. Stakeholders are concerned about the diversity and quality of services home-based care groups provide. The lack of standardization has led to some care being compromised. Most home-care programmes and services fall far short of the ideal quality and effectiveness of service provision. Among the main issues of concern are that:

- Activities are not coordinated
- Resources are not allocated appropriately
- HBC groups are working in isolation
- Caregivers receive limited training and support
- Appropriate programme monitoring and evaluation plans are lacking

Uniform guidelines or standards make it possible to design programmes that deliver services effectively – and the indicators for determining whether the programmes are on track. The absence of national HBC monitoring and evaluation systems, with appropriate standardized tools, has limited the capacity of HBC programmes to identify and disseminate best practices for replicating and sharing lessons learned. Without proper monitoring and evaluation, it is difficult to improve current programmes on the basis of assessing resources, outputs, outcomes, coverage, effects and impact of HBC efforts.

These standards are intended to give programme managers and home-based care providers a foundation from which to identify gaps in their service and to seek the training and support they need. This capacity building requires people to share skills, information and best practices.

Structure of the Guidebook

This guidebook presents the home-based care standards in five sections covering the following areas: Care and Support for Patient and Family; Team Service Provision; Governance and Management; Training, Information and Education; and Monitoring and Evaluation. Sample Data Collection Tools are included in the Annex.

Uniform guidelines or standards make it possible to design programmes that deliver services effectively – and the indicators for determining whether the programmes are on track.

As much as possible monitoring and evaluation of HBC services and activities must be participatory.

The presentation is organized in the following way: Each standard is treated in its own section beginning with the purpose and goal of the standard and a brief statement of how the standard is expected to work. These are followed by the specific objectives for the standard. The description of each objective includes who is responsible for the activities, the type of activities, the indicators, data sources or tools, and the frequency of collection or reporting monitoring and evaluation information. The various elements are summarized in table form for easy reference.

Summary of Standards

The paragraphs below quickly highlight the main features of each of the standards. These are followed by a summary of the data collection tools and information that will be used in tracking the implementation of the standards.

Standard 1 – Care and Support for Patients and Family

This section takes a holistic approach to care - from the type of care on offer to the composition of the care teams, and including the development of a care plan that identifies needs and resources. The standard incorporates information, skills sharing, equipment, counselling and medical support. A primary objective within this standard is care for children and youth infected and affected by HIV/ AIDS.

Standard 2 - Team Service Provision

This standard focuses on home-based care as a community effort, involving different disciplines and including people from different sectors of civil society. It deals with the competencies and functions of home care teams. Collaboration, networking, linkages and resource coordination all strengthen and enhance care provision.

Standard 3 – Governance and Management

Adopting community home-based care standards, other policies and professional principles of home-based care assures quality care management. Ongoing technical supervision and support keep home-based care teams from operating in isolation, while record keeping, meetings and documentation bring a systematic approach that helps maintain high standards of care. And finally, ensuring financial support for home-based care activities in the community, combined with good management of resources, produces an enabling environment for quality care.

Standard 4 – Training, Information and Education

The strengthening of care teams is vital to improving the quality of care. Providing information to families and patients allows them to make appropriate decisions and empowers them to complement care providers throughout the continuum of care. Ongoing development of staff and volunteers will also assure the future of home-based care in the country.

Standard 5 – Monitoring and Evaluation

Continually reviewing and assessing home-based care programmes by monitoring activities such as supervisory visits and case and record reviews will keep home-based care implementation on track. Participatory monitoring and evaluation ensure that guidelines and standards are followed, and that programme managers develop solutions to problems. M&E is the component that brings standards into action, ultimately reaching the patients and their families.

Data and Information Collection

The Annex provides a number of data collection tools geared towards the monitoring, evaluation and feedback system

described in Standard 5 – Monitoring and Evaluation. Organizations may already have their data collection tools, but perhaps they do not cover all the aspects of care presented in the standards. Thus, these tools guide providers to identify what information and/or services need to be initiated, expanded or improved.

Sources of data and the frequency of collection vary according to the indicators. A needs assessment and situation analysis should ideally be conducted at the start of a programme to provide benchmarks that define the baseline indicators, scope of coverage of the programme, required resource inputs, and appropriate programme strategies and activities. This should also define the indicators that will be used for measuring success. Patient data should be obtained and records securely kept after each patient visit, while patient observations can be made during a supervisory visit. Caregiver, patient and family feedback can be obtained during monthly programme reviews.

Feedback should be a continuous process at all levels and home-based care programmes need to have formal reviews of inputs, processes, outcomes, effects and impacts of the programme. All stakeholders, including family and community, must be involved in the feedback process at the appropriate levels. Confidential patient data must be made accessible only to those who need it for care of the patient. Where information from monitoring and evaluation suggests a change of course or corrective action, such action should be taken in consultation with all appropriate stakeholders, with particular consideration for the rights of patients and their families.

A Word about Monitoring and Evaluation

Because monitoring and evaluation of care of PLHWAs is relatively new, the development of effective monitoring tools, methodologies and indicators is currently being field-tested. WHO, UNAIDS and the MEASURE project have suggested indicators of care to guide national programmes and donors. Additional tools and indicators are needed to monitor and evaluate patient care and support activities at the local level. Using locally relevant indicators and tools for M&E makes it easier to use the results to refine, adapt and strengthen care and support activities.

Some definitions may be in order here. **Monitoring** is the day-to-day process of ensuring that programme activities are carried out in a way that will allow the programme to achieve its goals and objectives. In other words, monitoring helps keep the HBC programme on track. Monitoring can be achieved through spot checks, scheduled reviews at regular intervals, and activities such as formal supportive supervision using checklists, follow up of volunteers/caregivers, daily case-by-case reviews and monthly reviews of service records.

Evaluation is the more formal process of systematic collection and analysis of quantitative and qualitative programme data. Evaluation intends to assess **actual** progress toward programme goals. Evaluations generally cover specific periods or aspects of programme implementation, for example a midterm or end of project evaluation, or an evaluation of service quality or cost-effectiveness.

Continual review and assessment of home-based care programmes will keep home-based care activities on track.

Evaluation results may also be used to suggest potential directions, including reallocation of resources, replication of successful interventions that can be scaled-up or adapted to new project phases, or phasing out of less successful activities. The entire M&E system needs regular review to ensure that results are valid, informative and helpful for improving the quality of work.

Those who implement HBC activities must participate in collecting and analysing the data and in making decisions that promote improvement of care. Building capacity among caregivers to monitor and evaluate their work is a required component of the HBC programme. An understanding of the local environment is essential for interpreting M&E results that may be influenced by contextual factors at the local level. Caregivers also need to be able to use M&E information as a management tool for routine activity/ programme planning and ongoing self-assessment.

M&E by programme implementers will help assure that the results from internal M&E processes are reliable and unbiased and that programme adjustments or changes are based on reality and objectivity. External personnel may be required to monitor and evaluate a programme as part of an agreement between the implementing agency and donor. External evaluators normally have no personal stake in the programme, and the results of their evaluations are often more objective, reliable, believable and unbiased.

As much as possible, however, monitoring and evaluation of HBC services and activities must be participatory. When regular team members and the community are involved, the M&E activities and findings become more acceptable to patients, their families and caregivers.

Standard 1: Care and Support for Patient and Family

PURPOSE: *Provision of a support system through the development of strong partnerships with the community, family and patient, home-based caregivers, and the health system, thus assuring patients an acceptable quality of life until death, particularly including safeguarding the rights of infected and affected children and youth, their access to information, emotional, spiritual and other psychosocial support, bereavement counselling, and other appropriate assistance that meets their special needs*

GOAL: **To improve the quality of holistic care for the patient and support for the family, including orphans and vulnerable children and youth**

In this standard, caregiver teams and programme managers/supervisors will address all aspects of improving the quality of holistic care. The standard focuses on how the objectives and activities relate to support the quality of care. This entails initial and ongoing assessment and participatory development of a care plan that identifies needs and resources. Information, skills sharing, equipment, counselling and medical support are all elements of the care surrounding the patient and the family. Players in the circle include professionals and

community members, as well as the too-often-ignored family members. Infected and affected children and youth should also be assessed to ensure that they get support as and when they need it.

Needs Assessment and Situation Analysis

Objective 1.1: To provide holistic care for physical, emotional, spiritual and socio-cultural needs of the patient and the family through care teams

What should be done?

At the start of the programme, the caregiver teams, with support from management and supervisors, should assess:

- Status of capacity of local groups for planning and collaborating in provision of care
- Status of the patient's physical, emotional, spiritual and socio-cultural needs including: medical stage, last wishes, mental status, number and ages of own children
- The community health care and social support required during the terminal stages of illness and after death
- The patient's family primary caregivers including: family structure, emotional status, interaction patterns

Information, skills sharing, equipment, counselling and medical support are all elements of the care surrounding the patient and the family.

- within and outside the family, decision making processes surrounding the terminal illness, problems and resource needs, experience in caring for the terminally ill
- The capacity of the community to understand the nature of the HIV/AIDS related illness, providing care, mobilizing resources and responding to patient needs: including socio cultural environment and coping mechanisms during illness and at the time of bereavement

How will it be done?

- Involve community leaders and groups, local NGOs engaged in HBC, health care workers and other care providers
- Enlist the participation of community leaders and other key people at community level to participate as key informants and participants in the care of terminally ill patients, from planning stages of care, to death and bereavement including orphan care

- Identify affected households with terminally ill patients, infected and affected children at community level
- Adapt appropriate tools and methods for information collection and documentation
- Use assessment information for continuous patient care planning and review

How will we measure success?

Reference to the patients' records and observations made by supervisors during visits and from family, patient and caregiver feedback will indicate:

- Number of patients and families assessed
- Number of health issues/problems identified
- Number of patients cared for in their homes
- Number of affected families served in their homes
- Number of infected children served
- Number of affected children served
- Number of patients and families who express satisfaction with care provided

STANDARD 1: Goal – Improved quality of care through holistic patient and family support				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p><i>1.1: To provide holistic care for physical, emotional, spiritual and socio-cultural needs of the patient and the family through care teams</i></p> <p>(CAREGIVER)</p>	<p>ASSESSMENT</p> <ul style="list-style-type: none"> Conduct initial and follow-up health assessment of the patient and family, i.e.: <ul style="list-style-type: none"> - Physical needs - Emotional needs - Spiritual needs - Social/cultural needs 	<ul style="list-style-type: none"> Initial and follow-up assessments conducted and documented Number of health issues/problems identified Number of patients served Number of affected families served Number of patients and families who express satisfaction with care provided Number of infected and affected children served 	<ul style="list-style-type: none"> Assessment reports Patient records Patient observation Patient feedback Caregiver feedback Follow-up evaluation reports 	<ul style="list-style-type: none"> Start of programme After each patient visit During supervisory visits Monthly programme reviews Semi-annually

Joint Development of an Appropriate Care Plan

Objective 1.2: *To ensure that care teams involve patients and their families in planning and decision making about their care*

What should be done?

Caregiver teams will develop a comprehensive care plan with the patient and family that addresses their needs and the special needs of chronically sick children.

How will it be done?

- By advising on appropriate dietary and nutritional interventions for patients and chronically sick children
- By educating team members about alternative measures of health care, and guaranteeing “informed consent”
- By reviewing implementation of care plans
- By establishing an effective referral system

How will we measure success?

We should be able to determine if the comprehensive care plan is in use by reviewing documentary evidence of a care plan, patient records, observations made by supervisors during visits, and patient feedback from monthly programme reviews. These information sources will indicate:

- Number of children, families and patients provided dietary guidance
- Number of caregivers providing alternative health care
- Number of patients who received alternative health care in the last month
- Number of referrals of discharged patients from institutions to voluntary counselling services at the local level and vice versa

- Number of joint meetings conducted to review care plans
- Number of patients referred and receiving services

Objective 1.3: *To mobilize adequate resources for home-based care together with community leaders and stakeholders*

What should be done?

At the start of the programme, managers and supervisors will:

- Conduct a participatory assessment/inventory of resources available for home-based care
- Identify the various public and private groups engaged in home-based care
- Mobilize adequate and appropriate resources for effective patient care, including equipment, basic drugs, materials and supplies
- Provide the caregiver or patient with health care equipment and supplies
- Provide home-based caregivers with skills for the proper use of basic drugs, equipment and supplies
- Ensure an effective logistics system is in place to prevent shortages and stock outs of critical drugs and supplies

How will we measure success?

- Participatory HBC resource analysis conducted and disseminated at community level
- Supplies distributed to patients and families by type
- Equipment distributed to patients and families by type
- Number of families who report having received HBC supplies for patient care by type in the last month
- Number of community groups participating in resource mobilization
- Number of community leaders taking responsibility for resource mobilization for HBC activities

Players in the home-based care circle include professionals and community members, as well as the too-often-ignored family members.

Infected and affected children and youth should also be assessed to ensure that they get support as and when they need it.

- Amount of locally mobilized financial and informational resources for HBC
- Impact of social mobilization efforts for HBC at community level (Evaluation)

Objective 1.4: To ensure that care teams provide pre and post bereavement support to those affected

How should it be done?

Caregivers will discuss the patient's and family's fears and anxieties about death and dying focusing on:

Emotional issues:

- Resolving old quarrels
- Mobilizing local support groups
- Reassuring patients and providing pain relief
- Telling patients and family members or friends that they are loved
- Sharing hopes for future especially for spouses and children left behind
- Saying farewells to family, caregivers and providers
- Respecting patient's choice of burial site

Practical issues:

- Arrangement for visits by a priest/other spiritual person
- Custody/guardianship of children
- Family support: for partners and children
- Preparing a will
- Memory books
- Funeral costs
- Future support for children's needs especially school fees and health care

How will we measure success?

Patient records will indicate:

- Number of whole families and patients who have received psychological and bereavement support
- Number of affected families whose future support is planned for
- Number of affected children and youth whose rights to education, health and welfare are secured
- Number of patients who receive a satisfactory quality of life till death at home
- Number of caregivers who have received motivational psychological support

Care of Infected and Affected Children and Youth

Objective 1.5: To ensure that care teams cater for the needs and rights of infected and affected children

What should be done?

At the start of the programme, or on initial contact, caregiver teams will be trained to:

- Use a checklist of infected and affected children's needs
- Jointly develop a registry of children and youth infected and affected by HIV/ AIDS
- Provide education and referral for mothers on antenatal and postnatal care, prevention of mother to child transmission of HIV
- Jointly determine infected and affected children's needs, together with the families and communities
- Describe the nature of stigma and discrimination faced by infected and affected children and youth

STANDARD 1: Goal – Improved quality of care through holistic patient and family support				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/ reporting
<p><i>1.2: To ensure that care teams involve patients and their families in planning and decision making about their care</i></p> <p>(CAREGIVER)</p>	<p>CARE PLAN</p> <ul style="list-style-type: none"> ▪ Develop and implement a comprehensive care plan with the patient and family ▪ Address the special needs of chronically sick children ▪ Educate teams on principle of “informed consent” ▪ Educate teams on use of alternative measures of health care ▪ Give advice on appropriate dietary interventions ▪ Provide appropriate equipment and supplies for health care to the caregiver and/or patient ▪ Educate teams on proper use of equipment and supplies ▪ Identify resources available and accessible within the family and community 	<ul style="list-style-type: none"> ▪ Resource analysis conducted and documented ▪ Comprehensive care plan in place (documented) and in use ▪ Number of families and patients provided psychosocial and bereavement support ▪ Number of patients and families provided dietary guidance ▪ Number of patients and families provided appropriate care equipment and supplies ▪ Equipment provided for care by type ▪ Supplies provided for patient care by type ▪ Number of caregivers providing alternative health care ▪ Number of patients who received alternative health care in the last month ▪ Number of joint meetings conducted to review care plans 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Patient records ▪ Patient observation ▪ Patient feedback ▪ Supplies inventory ▪ Provider training reports/follow-up ▪ Caregiver feedback ▪ Evaluation reports 	<ul style="list-style-type: none"> ▪ Start of programme ▪ After each patient visit ▪ During supervisory visits ▪ Monthly programme reviews ▪ Semi-annually
<p><i>1.3: To mobilize adequate resources for HBC together with community leaders and stakeholders</i></p> <p>(CAREGIVER)</p>	<ul style="list-style-type: none"> ▪ Discuss anxieties/fears of death and dying through counselling patient/family ▪ Assist patient/family with both emotional (e.g., farewells) and practical (e.g., wills, memory books) concerns ▪ Establish an effective referral system ▪ Review implementation of care plans 	<ul style="list-style-type: none"> ▪ Effective referral system and tools in place ▪ Number of patients who are referred and receive services (effective referrals) 		
<p><i>1.4: To ensure that care teams provide pre and post bereavement support to those affected</i></p> <p>(CAREGIVER)</p>				

Families and communities work together to jointly identify infected and affected children's needs.

- Jointly address mechanisms for dealing with stigma and discrimination faced by children and youth infected and affected by HIV/ AIDS
- Create awareness about the human, health, education and welfare rights of children and youth infected and affected by HIV/ AIDS
- Jointly develop operational plans to counsel and follow up infected and affected children and youth
- Assist families to plan for the children's future (guardianship, succession planning, survival and development)

How will we measure success?

Feedback from the families during home/patient visits, supervisory visits and semi-annual evaluation reports will indicate:

- Total number of infected and affected children and youth served
- Number of children counselled or referred
- Number of infected and affected children and youth
- Number of infected and affected children and youth of school going age who are in school
- Number of infected and affected children and youth of school going age who are aware of their human, health, education and welfare rights
- Number of infected and affected children and youth who have access to counselling, basic health care and safe environments
- Number of those who are monitored and followed up

Patients have the right to privacy, dignity and confidentiality in home-based care.

Confidentiality, Privacy and Dignity

Objective 1.6: To ensure the patient's right to privacy, dignity and confidentiality in the home

What should be done?

At each contact or visit caregivers will:

- Explain the right to confidentiality, privacy and dignity to the patient and family
- Ensure that patient records are securely kept
- Engage families, patients, caregivers and communities on stigma and discrimination
- Ensure that patients give consent to all forms of medical treatment, and may also refuse consent
- Ensure that patients are cared for in privacy and with dignity

Caregivers will release only the information that is necessary for patient care.

How will we measure success?

Monthly patient and family feedback, caregiver feedback, caregiver training reports and semi-annual supervisory follow-up reports will indicate:

- % of patients and families who are aware of their rights to confidentiality
- % of patients who are satisfied with the privacy and dignity they are accorded during care
- % of families who are satisfied with the privacy and dignity accorded their patients during care
- % of patients and families indicating satisfaction that their case has been kept confidential
- % of caregivers who provide care in confidence (supervisor follow up/evaluation)

STANDARD 1: Goal – Improved quality of care through holistic patient and family support				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>1.5: <i>To ensure that care teams cater for the needs and rights of infected and affected children</i></p> <p>(CAREGIVER)</p>	<p>CHILD CARE</p> <ul style="list-style-type: none"> ▪ Jointly develop a registry of children and youth infected and affected by HIV/AIDS ▪ Jointly assess needs of infected and affected children, together with the families and communities ▪ Jointly develop plans for counselling and follow up ▪ Provide age-appropriate information ▪ Provide counselling to the affected children ▪ Provide education and referral for mothers on ante-natal and post natal care, PMTCT of HIV ▪ Jointly create mechanisms to address stigma and discrimination faced by HIV/AIDS infected and affected children ▪ Create awareness about rights of children and youth infected and affected by HIV/AIDS ▪ Conduct regular follow up of affected children ▪ Assist families to plan for the children's future 	<ul style="list-style-type: none"> ▪ Children's needs assessed and documented ▪ Needs checklist developed ▪ Age-specific child information developed, documented and disseminated ▪ Plans for children's future developed and implemented ▪ Total number of infected and affected children and youth served ▪ Number of infected and affected children counselled or referred ▪ Number of infected and affected children and youth of school going age who <ul style="list-style-type: none"> > are in school > are aware of their human, health, education and welfare rights ▪ Number of infected and affected children and youth who <ul style="list-style-type: none"> > have access to counselling, basic health care, and safe environments > are monitored and followed up ▪ Number of children covered by follow up 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Caregiver feedback ▪ Children's and family feedback ▪ Provider reports ▪ Evaluation reports 	<ul style="list-style-type: none"> ▪ Start of programme ▪ After each patient visit ▪ During supervisory visits ▪ Patient and family feedback ▪ Semi-annually

STANDARD 1: Goal – Improved quality of care through holistic patient and family support				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p><i>1.6: To ensure the patient's right to privacy, dignity and confidentiality in the home</i></p> <p>(CAREGIVER)</p>	<p>CONFIDENTIALITY</p> <ul style="list-style-type: none"> ▪ Explain to the patient and family the policy of confidentiality and privacy ▪ Release only information necessary for patient care ▪ Ensure patients/family are aware of informed consent and their right to choose to accept or not to accept ▪ Train patients and families to keep medical records confidential ▪ Store closed patient records in secure area of HBC office ▪ Ensure active patient records are accessed only by HBC team members involved in the case ▪ Ensure only care team members, supervisors or management have access to confidential programme information ▪ Keep names of patients private and confidential ▪ Release information requested by other health authorities only with consent of the patient or guardian ▪ Maintain confidentiality throughout the HBC organization 	<ul style="list-style-type: none"> ▪ % patients and families indicating satisfaction with confidentiality and privacy of care ▪ Evidence of secure storage and restricted access to patient records ▪ % team members reporting adherence to confidentiality of client records ▪ % patients and families reporting satisfaction with confidentiality of HBC information ▪ % patients and/or guardians who report ever having seen consent release forms ▪ % patients who report having provided consent for release of their diagnostic/medical information ▪ % patients and/or guardians who report that they understand the standard consent release forms ▪ Evidence of confidentiality throughout the HBC organization ▪ % caregivers who provide confidential and private care 	<ul style="list-style-type: none"> ▪ Patient and family feedback ▪ Caregiver feedback ▪ Caregiver training reports ▪ Supervisor follow-up reports ▪ Evaluation reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly ▪ Semi-annually ▪ Annually

Skills Sharing

Objective 1.7: To ensure that primary caregivers have practical caring skills

What should be done?

At the start of the programme, programme managers and supervisors will:

- Inform caregiver teams about universal precautions (UPs) and the transmission of HIV
- Impart practical caring skills to primary caregivers

How will we measure success?

Primary caregiver, patient and family feedback, observation of care delivered, and supervisor's follow-up reports will indicate:

- The number of trained caregivers
- The number of caregivers who know about UPs and HIV transmission modes
- The number of caregivers demonstrating practical caring skills according to UPs
- Caregivers demonstrate physical and psychosocial motivation in their work
- Caregivers demonstrate skills in addressing the special needs of children

STANDARD 1: Goal – Improved quality of care through holistic patient and family support				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>1.7: To ensure that primary caregivers have practical caring skills</p> <p>(PROGRAMME MANAGER/SUPERVISOR)</p>	<p>SKILLS SHARING</p> <ul style="list-style-type: none"> ▪ Inform caregiver teams about universal precautions and the transmission of HIV ▪ Impart practical caring skills to primary caregivers 	<ul style="list-style-type: none"> ▪ Number of trained caregivers ▪ Number of caregivers who know about UPs and HIV transmission modes ▪ Number of caregivers demonstrating practical caring skills according to UPs ▪ Caregivers demonstrate physical and psychosocial motivation in their work ▪ Caregivers demonstrate skills in meeting special needs of children 	<ul style="list-style-type: none"> ▪ Caregiver feedback ▪ Caregiver training reports ▪ Supervisor follow-up reports ▪ Evaluation reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly ▪ Semi-annually ▪ Annually

Caregivers will have practical skills necessary for patient care.

A home-based care team might include community health workers, nurses, IEC officers, counsellors, social workers, spiritual advisors, or local priests and clinical officers.

Standard 2: Team Service Provision

PURPOSE: *Implementation of community home-based care involving teams made up of professionals from a wide range of interests, volunteers and critical community members networking with various sectors, communities and stakeholders*

GOAL: **To improve the quality of holistic care by providing services through various stakeholders, networks, civil society, government and private sector, often as home-based care teams**

This standard focuses on the need for home-based care to become a community effort, using different disciplines and sectors to form home-based care teams with community involvement. Collaboration, networking, linking and coordinating resources all strengthen and enhance care

Networking helps build home-based care teams with community involvement.

provision. In this standard, programme managers/supervisors will oversee the implementation of home-based care activities to improve the quality of care.

Networking and Team Building

Objective 2.1: To strengthen collaboration among support networks involved in home-based care

What should be done?

Every quarter programme managers/supervisors will:

- Assess services and networks working in home-based care
- Develop various linkages among them
- Organize network meetings

How will we measure success?

Programme reports and documents and caregiver feedback will indicate:

- Number of care teams established
- Number of multi-agency/sector home-based care plans developed for care and support
- Presence of joint home-based care tools
- Number of joint planning and review meetings held

- Number of technical support and supervisory visits to care teams

Objective 2.2: To establish criteria for home-based care team membership

What should be done?

At the beginning of the programme, and to be reviewed periodically, programme managers will:

- Create and adopt selection criteria with stakeholders
- Develop tools for team member selection
- Assist in the formation, training and maintenance of home-based care teams

How will we measure success?

- Existence of standard criteria for team member selection
- Clear terms of reference for care teams
- Number of team members identified
- Number of joint teams established
- Number of members trained and oriented in HBC
- Joint team supervisory checklists developed

Objective 2.3: To conduct regular collaborative multi-disciplinary team/stakeholder meetings

What should be done?

Every three months, programme managers/supervisors will:

- Schedule regular team meetings to discuss and review care plans
- Share caring skills
- Update care team members with reference materials
- Assess care team skill gaps and address them through formal training

How will we measure success?

Quarterly HBC programme documents, reports, minutes of meetings and M&E documents will indicate:

- Number of collaborative meetings, meeting schedules
- Number of team members with access to up-to-date reference materials for HBC by type
- Number of workshops by type and duration, for updates/ongoing training of teams
- Total number of care teams and members

Objective 2.4: To coordinate HBC resources from all sectors

What should be done?

Every three months, programme managers/supervisors will:

- Hold meetings with all HBC stakeholders, families and communities
- Conduct an inventory of available resources at community level
- Update the resource databases regularly
- Participate in optimal resource allocation for patient care
- Participate in decision making on care teams' resource needs

How will we measure success?

Programme documents, M&E reports, and minutes of meetings will indicate:

- Number of joint meetings
- Inventory of available resources
- Existence of an up-to-date resource database
- Optimal allocation of resources for patient/family care and support

Every three months, programme managers/supervisors will hold meetings with all HBC stakeholders, families and communities.

STANDARD 2: Goal – Improved quality of care through multi-sector service provision				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
2.1: <i>To strengthen collaboration among support networks involved in home-based care</i> (PROGRAMME MANAGER/SUPERVISOR)	<ul style="list-style-type: none"> ▪ Identify and assess existing service networks ▪ Develop multi-sector/multi-disciplinary linkages for home-based care ▪ Organize network meetings 	<ul style="list-style-type: none"> ▪ Number of multi-agency HBC plans developed for care and support ▪ Presence of collaborative HBC tools 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Caregiver feedback 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly
2.2: <i>To establish criteria for home-based care team members</i> (PROGRAMME MANAGER)	<ul style="list-style-type: none"> ▪ Create and adopt selection criteria with stakeholders ▪ Develop tools for team member selection ▪ Constitute and train HBC teams 	<ul style="list-style-type: none"> ▪ Existence of standard criteria for team member selection ▪ Existence of job descriptions for team members ▪ Number of team members identified ▪ Number of joint teams established ▪ Number of members trained and oriented in HBC ▪ Joint team supervisory checklists developed 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Follow-up reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly
2.3: <i>To conduct regular collaborative multi-disciplinary team/stakeholder meetings</i> (MANAGER/SUPERVISOR)	<ul style="list-style-type: none"> ▪ Schedule regular team meetings ▪ Discuss and review care plans ▪ Facilitate sharing of caring skills ▪ Provide up-to-date reference materials to team members 	<ul style="list-style-type: none"> ▪ Minutes of collaborative meetings, meeting schedules ▪ Number of joint meetings ▪ Number of team members who have access to up-to-date reference materials for HBC ▪ Clearly defined objectives 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ M&E reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly
2.4: <i>To coordinate resources from all sectors</i> (PROGRAMME MANAGER/SUPERVISOR)	<ul style="list-style-type: none"> ▪ Hold meetings with stakeholders ▪ Conduct an inventory of available resources ▪ Ensure optimal resource allocation ▪ Update resource databases regularly 	<ul style="list-style-type: none"> ▪ Minutes of meetings ▪ Number of joint meetings ▪ Inventory of available resources ▪ Up-to-date resource database 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ M&E reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly

Objective 2.5: To create an enabling environment for volunteers

What should be done?

Every three months (quarter), programme managers/supervisors will:

- Collaborate with stakeholders/communities to develop standard incentive packages for volunteers
- Motivate volunteers by providing clear job descriptions and guidelines
- Jointly review policy/framework of work conditions
- Provide basic allowances and good working conditions for volunteers

How will we measure success?

Programme documents, caregiver feedback, supervisors' reports and evaluations will indicate:

- Existence of an incentives package for volunteers
- % of volunteers who report satisfaction with their work
- % of volunteers who display up-to-date HBC skills
- % of volunteers who report confidence in care provision
- Number of HBC providers/teams continuing in programme

Objective 2.6: To assure comprehensive and holistic care by ensuring appropriate staffing levels at all times

What should be done?

At the start of the programme, and on an ongoing basis, programme managers will:

- Establish a standard staff-to-patient/client ratio
- Recruit staff to maintain the ratio
- Regularly monitor patient caseloads of team members
- Provide ongoing training/updates of staff
- Provide staff motivation

How will we measure success?

Every quarter, programme documents, caregiver feedback and supervisors' reports will indicate:

- Number of staff/volunteers involved in care provision
- % of patients satisfied with care provided
- Average patient-caregiver ratio
- Standard staff-to-patient ratio defined and maintained
- Number of staff trained
- Proportion of staff who indicate that they are motivated

Objective 2.7: To ensure a continuum of care through discharge planning

What should be done?

Every three months, programme managers/supervisors will:

- Ensure adherence to the national discharge planning policy and procedures
- Review/ update roster of referral agencies, institutions, etc.
- Conduct timely follow-up on discharged patients
- Provide written feedback to referring agencies

How will we measure success?

Programme documents, caregiver feedback and supervisors' reports will indicate:

- % of HBC providers who report use of discharge planning policy and procedures
- Number of discharged patients followed up by HBC team
- Number of agencies reporting referral feedback
- Number of caregivers who have access to discharge plans each quarter
- Number of caregivers trained and aware of discharge plans each quarter

The psycho-social and physical progress of the patient and family are indicators of the progress of the care programme.

STANDARD 2: Goal – Improved quality of care through multi-sector service provision				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>2.5: <i>To create an enabling environment for volunteers</i></p> <p>(MANAGER/ SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Collaborate to develop standard packages for volunteers ▪ Motivate volunteers on a continuous basis ▪ Clear job descriptions ▪ Clear guidelines ▪ Jointly review policy/framework of work conditions ▪ Provide allowances and good working conditions for volunteers ▪ Develop skills of volunteers through ongoing skills sharing 	<ul style="list-style-type: none"> ▪ Standard package for volunteers developed and documented ▪ % of volunteers who report satisfaction with their work ▪ % of volunteers who display up-to-date HBC skills ▪ % of volunteers who report confidence in care provision ▪ Number of HBC volunteers continuing in year 2 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Caregiver feedback ▪ Supervisors' reports ▪ Evaluation reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly ▪ Semi-annually
<p>2.6: <i>To assure comprehensive and holistic care by ensuring appropriate staffing levels at all times</i></p> <p>(MANAGER)</p>	<ul style="list-style-type: none"> ▪ Establish a standard staff-to-patient/client ratio ▪ Recruit staff to maintain the staff-to-patient/client ratio ▪ Regularly monitor the patient caseloads of team members ▪ Train staff 	<ul style="list-style-type: none"> ▪ Number of staff/volunteers involved in care provision ▪ % of patients satisfied with care provided ▪ Actual average patient-caregiver ratio ▪ Standard staff-to-patient ratio defined ▪ Number of staff trained/month 	<ul style="list-style-type: none"> ▪ Programme reports ▪ Caregiver feedback ▪ Supervisors' reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly
<p>2.7: <i>To ensure a continuum of care through discharge planning</i></p> <p>(MANAGER/ SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Ensure adherence to the national discharge planning policy and procedures ▪ Review/update roster of referral agencies/institutions ▪ Conduct timely follow-up on discharged patients ▪ Provide written feedback to referring agencies 	<ul style="list-style-type: none"> ▪ % of HBC providers who report use of discharge planning policy and procedures ▪ Number of discharged patients followed up by HBC team ▪ Number of agencies reporting receipt of referral feedback ▪ Number of discharge plans per quarter ▪ Number of caregivers trained and aware of discharge plans/quarter 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Caregiver feedback ▪ Supervisors' reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly

Service Delivery

Objective 2.8: To ensure equitable access to HBC services and information by everyone in need of home-based care

What should be done?

Every three months, programme managers/supervisors will:

- Identify gaps in access to HBC services
- Develop team strategies for equitable provision
- Periodically update community needs and service provision

How will we measure success?

Programme reports and documents will indicate:

- Completion of needs assessments in all target communities
- Development of joint strategies based on real needs
- Development and implementation of care plans
- Number of joint review meetings
- % of target populations provided HBC

Any discussion about home-based care patients must be kept confidential.

Objective 2.9: To create an awareness of ethical issues among the HBC team members against, are able to exercise their fundamental human rights and freedoms (such as privacy, informed choice, decency, personal integrity and dignity) and benefit from all HBC services and activities without discrimination

What should be done?

Every three months, programme managers/supervisors will:

- Discuss ethical issues with care teams and communities
- Discuss ethical issues with patients and families
- Disseminate appropriate documents and information
- Provide team members with ongoing education on ethical issues

How will we measure success?

Programme reports, caregiver feedback and observation of care will indicate:

- Number of key HBC ethical issues outlined and disseminated
- % of HBC team members who report knowledge of HBC ethical issues
- % of HBC team members who report adherence to ethical issues in care provision, such as ensuring that a sick person is bathed and dressed in private, or ensuring that any discussion about the patient is kept confidential
- Number amount of IEC community meetings held on ethics each quarter
- Estimated coverage/impact (evaluation)

A sick person's dignity can be protected for example by ensuring that the person is bathed and dressed in private.

STANDARD 2: Goal – Improved quality of care through multi-sector service provision				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
2.8: <i>To ensure equitable access to HBC services and information by everyone in need of home care</i> (PROGRAMME MANAGER/ SUPERVISOR)	<ul style="list-style-type: none"> ▪ Identify gaps in access to HBC services ▪ Develop team strategies for equitable service provision ▪ Conduct community needs and service provision updates periodically 	<ul style="list-style-type: none"> ▪ Needs assessments conducted in all target communities ▪ Joint strategies developed based on needs ▪ Care plans developed and implemented ▪ Number of joint review meetings ▪ % of target populations provided HBC 	<ul style="list-style-type: none"> ▪ Programme reports and documents 	<ul style="list-style-type: none"> ▪ Monthly
2.9: <i>To create an awareness of ethical issues among HBC team members</i> (MANAGER/ SUPERVISOR)	<ul style="list-style-type: none"> ▪ Document and disseminate ethical issues widely ▪ Discuss ethical issues with team members ▪ Provide team members with ongoing education on ethical issues 	<ul style="list-style-type: none"> ▪ Critical ethical issues outlined and disseminated ▪ % of team members who report knowledge of HBC ethical issues ▪ % of team members who report adherence to ethical issues in care provision ▪ Number of IEC activities held on ethics per quarter 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ Caregiver feedback ▪ Observation of care 	<ul style="list-style-type: none"> ▪ Monthly

**Every three months, programme managers/
supervisors will discuss ethical issues
with care teams, communities,
patients and families.**

Objective 2.10: *To provide essential drugs, medical and surgical sundries, through joint resource mobilization strategies by HBC programme managers/supervisors, care teams, stakeholders, families and communities*

- Assess and document adequacies and gaps
- Ensure adequacy of HBC supplies
- Ensure care teams are equipped to handle necessary drugs and supplies

How will we measure success?

Programme reports and M&E documents will indicate:

- Supplies in stock by type
- Supplies distributed by type
- Any stock outs and reasons
- Efficiency of logistics system
- Competence of care teams in handling drugs and supplies
- Number of patients receiving appropriate supplies

What should be done?

Every three months, programme managers/supervisors will:

- Maintain an inventory of all drugs, medical and surgical equipment, and supplies
- Distribute drugs and medical/surgical supplies equitably
- Monitor use of supplies for patient care

STANDARD 2: Goal – Improved quality of care through multi-sector service provision				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>2.10: <i>To provide essential drugs, medical and surgical sundries, through joint resource mobilization strategies by HBC programme managers/supervisors, care teams, stakeholders, families and communities</i></p> <p>(PROGRAMME MANAGER/SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Maintain inventory of all drugs, medical/surgical supplies ▪ Train care teams to use the logistics record-keeping system to order and maintain appropriate supplies ▪ Train care teams/caregivers in the use of appropriate drugs and supplies ▪ Record all utilization (loans, repairs and returns) ▪ Maintain adequate buffer stock to avoid stock outs ▪ Distribute drugs and medical/surgical supplies equitably ▪ Monitor use of supplies for patient care 	<ul style="list-style-type: none"> ▪ Supplies in stock by type ▪ Supplies distributed by type ▪ Appropriate supplies logistics system in place ▪ Appropriate asset registers in place ▪ % of stakeholders reporting surplus of supplies in the last month ▪ % of stakeholders reporting stock outs in the last month ▪ Effect/impact of adequacy of all supplies, equipment, medicines on HBC (Evaluation) ▪ Number of patients served and given appropriate supplies 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ M&E reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly

Objective 2.11: To provide psychosocial support to home-based care clients including infected and affected children

What should be done?

Every three months, caregiver teams will:

- Hold formal and informal debriefing sessions with all team members and supervisors
- Back up team support through regular technical supervision
- Provide psychosocial support to PLWHAs, caregivers and families including children and youth affected by HIV and AIDS

How will we measure success?

Programme reports and documents will indicate:

- Number of meetings
- Existence of supervisory reports
- Number of supervisory visits conducted
- Number of patients and families provided support
- Number of patients, families, including children and youth affected by HIV and AIDS
- Satisfaction with support provided

STANDARD 2: Goal – Improved quality of care through multi-sector service provision				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>2.11: <i>To provide psychosocial support to home-based care clients including infected and affected children</i></p> <p>(SUPERVISOR/ PROGRAMME MANAGER)</p>	<ul style="list-style-type: none"> ▪ Train multidisciplinary team members in principles and practices of palliative care ▪ Ensure teams give clear information related to diagnosis, progress of illness, care options and support services to the patient and immediate family ▪ Hold formal and informal debriefing sessions with all team members and supervisors ▪ Provide appropriate IEC for all levels, disciplines and sectors ▪ Provide backup team support through supervision ▪ Provide psychosocial support to care teams 	<ul style="list-style-type: none"> ▪ Number of meetings ▪ Number of training courses conducted and evaluated ▪ Number of team members trained ▪ % of team members who report satisfaction with training received ▪ % of team members who report confidence in provision of palliative care ▪ % of affected families who report they are fully informed of their patient's status ▪ % of affected families who report satisfaction with caregiver teams ▪ Existence of supervisory reports ▪ Number of supervisory visits conducted ▪ Number of patients and families provided support 	<ul style="list-style-type: none"> ▪ Programme reports and documents ▪ M&E reports 	<ul style="list-style-type: none"> ▪ Monthly ▪ Quarterly

Standard 3: Governance and Management

PURPOSE: *Ensuring that all home-based care services and resources are effectively planned, governed, managed and implemented*

GOAL: **To improve the quality of life through appropriate governance and management**

Adoption of the community home-based care standards, other policies and professional principles by home-based care stakeholders assures good care management. Ongoing technical supervision and support keep home-based care teams from operating in isolation. Record keeping, meetings, and documentation bring a systematic approach to home-based care that helps maintain standards of care. Ensuring financial support for home-based care activities in the community combined with good management of resources creates an enabling environment for quality care.

Objective S: *To articulate and adopt home-based care policies and standards, including professional principles and standards*

What should be done?

At the start of the programme and every six months thereafter, programme managers will:

- Document and disseminate up-to-date HBC standards,

procedures and policies to all stakeholders and care teams

- Adopt through the governing body of the home-based care programme, policies that support home-based care
- Disseminate professional principles and regulations to all stakeholders including universal precautions
- Ensure that care is provided according to professional principles and regulations

How will we measure success?

An examination of stakeholder programme reports and documents, caregiver feedback, supervisors' reports, and internal or external evaluation will indicate:

- Number of caregiver teams who have access to up-to-date HBC standards, policies and procedures for daily use
- Number of caregivers who adhere to professional principles and regulations
- Adherence to professional principles, regulations and procedures by care teams
- Existence of supervisory checklists and monitoring tools
- Availability of a multidisciplinary committee team on HBC standards that meets quarterly
- Effective technical supervision, monitoring and evaluation

Ongoing technical supervision and support keep home-based care teams from operating in isolation.

Programme managers/supervisors will ensure that only care team members, supervisors or management have access to confidential programme information.

- Use of technical supervision, monitoring and evaluation information for HBC programme decision making

Objective 3.2: To provide periodic technical supervision and support to care teams

What should be done?

Every month, HBC management/supervisors will:

- Develop weekly field and home follow up visit schedules
- Conduct weekly supervision visits to the home-based care team members
- Answer questions and address concerns from care teams
- Provide regular supportive technical supervision to teams in between scheduled visits as necessary
- Establish policy and procedures to address technical supervision and support

- Maintain accurate records of supervisors' visits/issues addressed and any action taken
- Refer to caregiver reports for making decisions

How will we measure success?

Reference to stakeholder program reports, caregiver feedback, supervisors' reports; internal or external evaluation reports will indicate:

- Written supervision schedules for supervisory visits
- Number of technical supervision visits to teams conducted per month
- % of HBC team members who report receiving a supervisory visit in the last month
- % of HBC team members reporting satisfaction with frequency and depth of supervision
- % of HBC team members reporting satisfaction with technical support supervision

STANDARD 3: Goal – Improved quality of life through appropriate governance and management				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>3.1: To articulate and adopt home-based care policies and standards, including professional principles and regulations</p> <p>(PROGRAMME MANAGER)</p>	<ul style="list-style-type: none"> ▪ Document, produce and disseminate HBC standards, procedures and policies to all stakeholders ▪ Adopt policies that support home-based care through the governing body of the home-based care programme ▪ Widely disseminate professional principles and regulations to all stakeholders ▪ Ensure that care is provided according to professional principles and regulations 	<ul style="list-style-type: none"> ▪ Number of stakeholders who have access to HBC standards, policies and procedures for daily use ▪ Number of stakeholders who adhere to professional principles and regulations ▪ Documentary evidence of professional principles and regulations (dissemination) ▪ Existence of supervisory checklists and monitoring tools ▪ Existence of multi-disciplinary task force on HBC standards that meets quarterly 	<ul style="list-style-type: none"> ▪ Stakeholder programme reports and documents ▪ Caregiver feedback ▪ Supervisors' reports ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Quarterly ▪ Monthly ▪ Semi-annually/Annually

- Number of supervisors reporting satisfaction with policies and procedures
- Number of scheduled supervision reports produced
- Number of new initiatives taken by supervisors
- Number of caregivers reporting corrective action based on supervisory reports
- Number of supervisors reporting satisfaction with policies and procedures
- Number of technical supervision visits to teams conducted per month
- % of HBC team members who report receiving a supervisory visit in the last month
- Programme effectiveness/impact (Evaluation)

Objective 3.3: To maintain confidentiality of patient records

What should be done?

- Every month, programme managers/supervisors will ensure that:
- Patients are aware of informed consent and choose to accept or not to accept
 - Patients and families keep medical records confidential
 - Closed patient records are stored in a secure area of the HBC office
 - Active patient records are accessed only by the home-based care team members involved in the case

STANDARD 3: Goal – Improved quality of life through appropriate governance and management				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>3.2: <i>To provide periodic technical supervision and support to care teams</i></p> <p>(SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Conduct weekly supervisory visits to the home-based care team members ▪ Address questions, problems and concerns of the home-based care team members on time ▪ Provide regular supportive supervision to teams between scheduled supervision visits ▪ Establish policy and procedures for addressing technical supervision and support ▪ Maintain accurate records of supervisory visits/issues addressed and any action taken ▪ Use reports for decision making 	<ul style="list-style-type: none"> ▪ Documented evidence of supervision schedules ▪ % of HBC team members who report satisfaction with supervision frequency and intensity ▪ % of HBC team members who report satisfaction with technical support supervision provided ▪ Number of scheduled supervision reports produced ▪ Number of new initiatives ▪ Proportion of stakeholders who report corrective action based on supervisory reports ▪ Number of supervisors who report satisfaction with policies and procedures ▪ Number of technical supervision visits to teams conducted per month ▪ % of HBC team members who report receiving a supervisory visit in the last month 	<ul style="list-style-type: none"> ▪ Stakeholder programme reports and documents ▪ Caregiver feedback ▪ Supervisors’ reports ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Quarterly ▪ Monthly ▪ Semi-annually/Annually

- Only care team members, supervisors or management have access to confidential programme information
- The names of patients are kept private and confidential
- Patients and their guardians understand consent release forms
- Any information requested by other health authorities is released only with consent from the patient or guardian
- Confidentiality is maintained throughout the HBC organization

How will we measure success?

Reference to stakeholder programme reports, caregiver, patient and family feedback, supervisors' reports, observation of care provision, and review of records and internal or external evaluation reports will indicate:

- Evidence of secure storage and restricted access to patient records
- % of team members reporting adherence to confidentiality of client records

STANDARD 3: Goal – Improved quality of life through appropriate governance and management				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>3.3: <i>To maintain confidentiality of patient records</i></p> <p>(PROGRAMME MANAGER/SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Store closed patient records in a secure and closed area of the HBC office ▪ Allow active patient records to be accessed only by the HBC team members involved in the care or supervision of that case ▪ Ensure all programme information is accessed only by team members, supervisors and/or management ▪ Keep names of patients private and confidential ▪ Release any information requested by other health authorities only with consent from the patient or guardian ▪ Explain consent release forms to patients and their guardians ▪ Maintain confidentiality as a professional principle throughout the HBC organization 	<ul style="list-style-type: none"> ▪ Evidence of secure storage of patient records ▪ Evidence of restricted access to patient records ▪ % of team members who report adherence to confidentiality of client records ▪ % of patients and families who report satisfaction with confidentiality of HBC information ▪ % of patients who report to have provided consent for release of their diagnostic/medical information ▪ Evidence of consent release forms ▪ % of patients and/or guardians who report to have ever seen consent release forms ▪ % of patients and/or guardians who report they understand the standard consent release forms ▪ Evidence of confidentiality throughout the HBC organization 	<ul style="list-style-type: none"> ▪ Stakeholder programme reports and documents ▪ Caregiver feedback ▪ Supervisors' reports ▪ Observation of care provision and review of records ▪ Patient and family feedback ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Quarterly ▪ Monthly ▪ Semi-annually/Annually

- % of patients and families reporting satisfaction with confidentiality of HBC information
- % of patients and/or guardians who report to have ever seen consent release forms
- % of patients who report having provided consent for release of their diagnostic/medical information
- % of patients and/or guardians who report that they understand the standard consent release forms
- Evidence of confidentiality throughout the HBC organization

Objective 3.4: *To ensure that up-to-date records are kept for ordering and distributing supplies and equipment to avoid surpluses or shortages*

What should be done?

Every month, programme managers/supervisors will:

- Use the logistics record-keeping system to order and maintain appropriate supplies
- Register all equipment purchased for the programme
- Record all utilization (loans, repairs and returns)
- Keep stock inventories of all supplies and reorders made in advance of predicted needs
- Maintain adequate buffer stock to avoid stock outs

How will we measure success?

Reference to the logistics management information system, supervisors' reports, records and stock cards, and internal or external evaluation reports will indicate:

- Appropriate supplies logistics system in place
- Appropriate asset registers in place
- % of stakeholders reporting supply surplus in last month
- % of stakeholders reporting stock outs in the last month
- Effect/impact of adequacy of all supplies, equipment, medicines on HBC (Evaluation)

Objective 3.5: *To implement innovative strategies to finance home-based care activities through families, stakeholders and community initiatives*

What should be done?

Every month, programme managers will:

- Create an awareness of the need for financial support of home-based care activities within the community
- Establish advocacy groups for resource mobilization
- Facilitate training of community and traditional leaders in resource
- Conduct cost/benefit analyses of HBC activities
- Prioritize financial needs
- Establish community fund raising committees and train in basic marketing, accounting/book keeping/reporting
- Implement projects with specific budget line items for home-based care activities
- Ensure accountability and equitable distribution of resources for HBC, patient care and families including children and youth affected by HIV and AIDS

How will we measure success?

Quarterly programme reports, and internal and external evaluation reports will indicate:

- Documented evidence of resource mobilization strategy
- Documented financial and resource priorities
- The number of income-generating projects established by type/income raised
- % of HBC programme budget locally supported
- Adequacy of financial resources to support ongoing HBC activities
- Number of families including children and youth affected by HIV and AIDS who are benefiting from locally mobilized resources (Evaluation)

Advocacy groups can help mobilize community resources for home-based care programmes.

STANDARD 3: Goal – Improved quality of life through appropriate governance and management				
Objective	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>3.4: <i>To ensure records are kept for ordering and distributing supplies and equipment to avoid surpluses or shortages</i></p> <p>(PROGRAMME MANAGER/ SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Use the record-keeping system to order supplies ▪ Keep an asset register of all equipment and record all utilization (loaning, servicing, returns) ▪ Maintain an efficient logistics system (stock inventories kept of all supplies and reorders made in advance of predicted needs) 	<ul style="list-style-type: none"> ▪ Appropriate supplies logistics system in place ▪ Appropriate asset registers in place ▪ % of stakeholders who report surplus of supplies in the last month ▪ % of stakeholders who report stock outs in the last month 	<ul style="list-style-type: none"> ▪ Logistics management information system ▪ Supervisors' reports ▪ Review of records, stocks ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Quarterly ▪ Monthly ▪ Semi-annually/Annually
<p>3.5: <i>To create and implement innovative strategies for financing home-based care activities through community initiatives</i></p> <p>(PROGRAMME MANAGER)</p>	<ul style="list-style-type: none"> ▪ Create an awareness of the need for financial support of home-based care activities within the community ▪ Conduct cost analyses of home-based care activities ▪ Prioritize financial needs ▪ Establish and work with a community fund raising committee ▪ Establish advocacy groups for resource mobilization ▪ Conduct viability studies of various income-generating ideas/projects ▪ Select and implement projects with budget line items for home-based care activities 	<ul style="list-style-type: none"> ▪ Evidence of resource mobilization strategy ▪ Cost analyses conducted and disseminated ▪ Documentation of financial priorities ▪ Appropriate viability studies conducted and disseminated among stakeholders ▪ Number of income-generating projects established by type ▪ % of HBC programme budget locally supported 	<ul style="list-style-type: none"> ▪ Stakeholder programme reports and documents ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Quarterly ▪ Semi-annually/Annually

Standard 4: Training, Information and Education

Providing information to families and patients allows them to make appropriate decisions.

PURPOSE: *Provision of ongoing training and learning support for HBC team members, family members, community and health care professionals*

GOAL: **To improve the quality of care through ongoing training and support**

The strengthening of care teams is vital for improving the quality of care. Providing information to families and patients allows them to make appropriate decisions and empowers them to challenge or question care providers throughout the continuum of care. Ongoing development of professional staff and volunteers also will assure the future of home-based care in the country.

Objective 4.1: To develop and strengthen multi-disciplinary HBC teams

What should be done?

At the start of the programme and every three months thereafter, programme managers/supervisors will:

- Implement and evaluate multi-disciplinary team training and skills sharing on a regular basis
- Provide appropriate information, education and communication materials for all levels, disciplines and sectors

- Provide ongoing staff and volunteer development programmes
- Train multidisciplinary team members in principles and practices of palliative care
- Give clear information related to diagnosis, progress of illness, care options and support services to the patient and immediate family

How will we measure success?

Stakeholder programme reports, feedback from caregivers, patients and families, supervisors' reports, and observations of care provision and internal or external evaluations will indicate:

- Number of training courses conducted and evaluated by type (basic, refresher)
- Number of team members trained
- % of team members who report satisfaction with training received
- % of team members who report confidence in provision of palliative care
- % of affected families who report they are fully informed of their patient's status
- % of affected families who report satisfaction with care giver teams

STANDARD 4: Goal – Improved quality of care through ongoing training and learning support				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p><i>4.1: To develop and strengthen multi-disciplinary care teams</i></p> <p>(PROGRAMME MANAGER/SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Continually train and evaluate multi-disciplinary care teams ▪ Conduct regular refresher training and skills sharing ▪ Provide appropriate information, education and communication for all levels, disciplines and sectors ▪ Provide ongoing staff and volunteer development programmes 	<ul style="list-style-type: none"> ▪ Number of training courses conducted and evaluated ▪ Number of team members trained ▪ % of team members who report satisfaction with training received ▪ % of affected families who report satisfaction with patient care and own handling 	<ul style="list-style-type: none"> ▪ Stakeholder programme reports and documents ▪ Caregiver feedback ▪ Supervisors' reports ▪ Observation of care provision and review of records ▪ Patient and family feedback ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Quarterly ▪ Monthly ▪ Semi-annually/Annually

Standard 5: Monitoring and Evaluation

PURPOSE: *Development of an integral monitoring and evaluation system within the home-based care program as a planning and management tool for all levels*

GOAL: **To improve the quality of home-based care through routine assessment of the efficiency and effectiveness of service delivery**

This standard applies mainly to the monitoring and evaluation (M&E) process within home-based care programmes in order to set the stage properly for periodic formal assessments. With direct support from programme management, those who implement HBC will be trained and participate in assessments, monitoring and evaluation.

Objective 5.1: To provide for timely, accurate tracking of progress of HBC programmes so as to ensure that they are on course to achieve their goals

Why we evaluate

M&E is a tool that enables us to:

- Collect and use information for planning, resource mobilization, resource allocation, review and management

- Identify problems and potential solutions
- Enhance accountability and transparency at all levels
- Identify, disseminate and replicate best practices
- Incorporate programme experiences into decision making at all levels

What we evaluate

Among other things, M&E helps measure:

- Effectiveness of HBC services, cost-effectiveness and community demand
- Level of acceptance of HBC by patients, family and community
- Adequacy of preparation and effectiveness of caregivers
- Psycho-social/physical progress of the patient and family
- Number of patients, families and communities benefiting
- Effectiveness of referral networks
- Short-term effects/long-term impacts of HBC activities
- Community responsiveness and potential sustainability

What should we do?

Programme management will:

- Ensure that guidelines and standards are being followed
- Ensure that records are kept properly and consistently
- Review the viability of the home-based care programme
- Establish proper organizational structures for management and supervision purposes

An appropriate M&E plan generates indicators mutually agreed to by all stakeholders and involves them in the activities.

- Conduct regular joint programme process reviews, monitoring and evaluation focusing on standards, objectives and indicators
- Apply M&E findings in programme design, management and supervision

How should we do it?

As part of their routine work and at appropriate regular intervals, programme managers will:

- Carry out a participatory baseline survey/needs assessment/situation analysis of existing home-based care interventions at the community level
- Generate monitoring and evaluation indicators agreed to by all stakeholders
- Establish and maintain an accurate patient and family management information system
- Develop/adapt appropriate tools for regular data collection, analysis, reporting and feedback

- Train teams and volunteers in the use of monitoring and evaluation tools and systems

How will we measure success?

- Baseline survey conducted
- M&E indicators in place
- Data collection tools in place
- Thoroughness and consistency of supervisors' reports
- Number of teams/caregivers trained in appropriate aspects of M&E

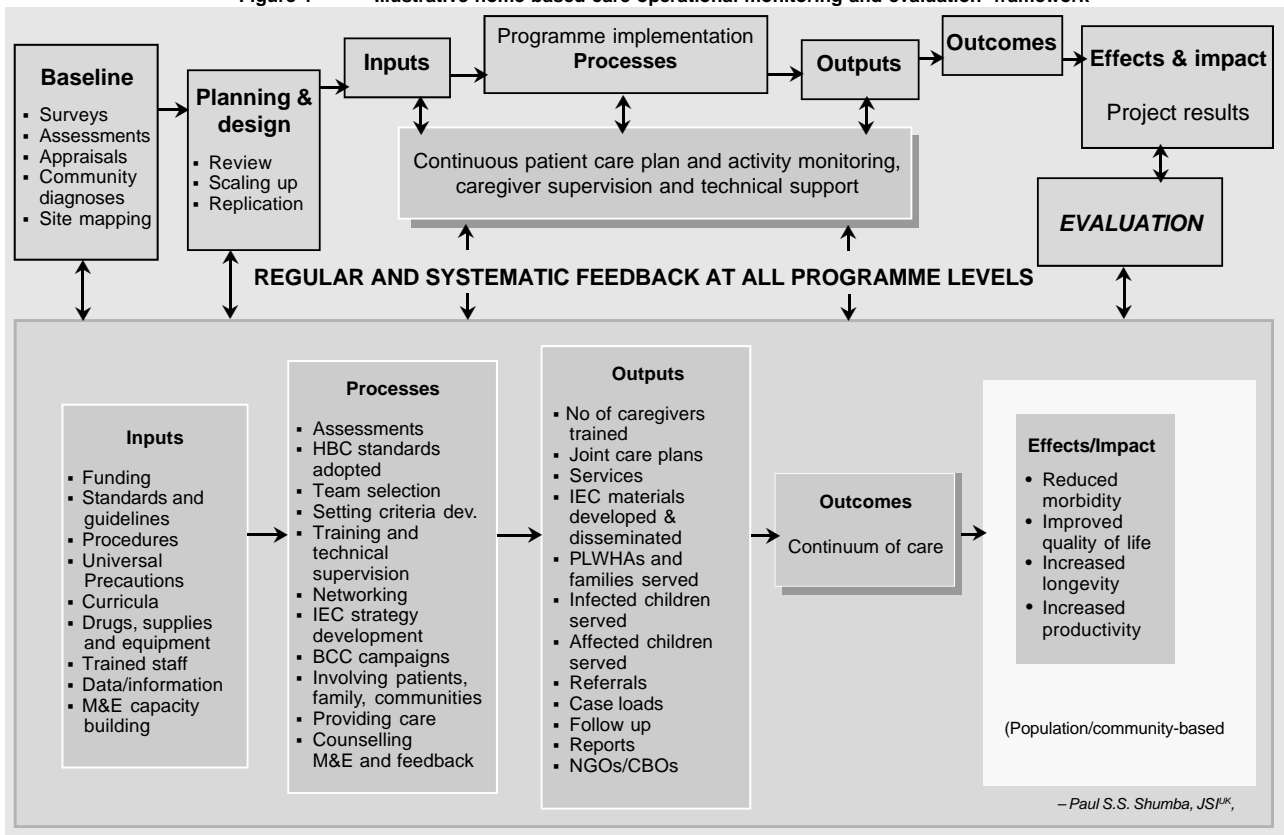
The table on the next page lists some of the principal evaluation types and the core questions that can be used to ensure that HBC services are adequately monitored and evaluated. The M&E framework in Figure 1 illustrates some of these critical elements for guiding HBC programmes as they respond to the needs of PLHWAs and their families.

STANDARD 5: Goal – Improved quality of care through ongoing assessment of service delivery				
Objectives	Activities	Indicators	Data sources/Tools	Frequency of collection/reporting
<p>5.1: <i>To provide for timely, accurate tracking of HBC programmes so as to ensure that they are on course to achieve their goals</i></p> <p>(PROGRAMME MANAGER/SUPERVISOR)</p>	<ul style="list-style-type: none"> ▪ Carry out a participatory baseline survey/needs assessment/situation analysis of existing HBC at the community level ▪ Generate monitoring and evaluation indicators agreed to by all stakeholders ▪ Maintain an accurate patient and family management information system ▪ Develop/adapt appropriate tools for regular data collection, analysis, reporting ▪ Train teams and volunteers in the use of monitoring and evaluation tools and systems 	<ul style="list-style-type: none"> ▪ Baseline survey conducted ▪ M&E indicators in place ▪ Data collection tools in place ▪ Thoroughness and consistency of supervisors' reports ▪ Number of teams/caregivers trained in appropriate aspects of M&E 	<ul style="list-style-type: none"> ▪ Baseline data ▪ Supervisors' reports ▪ Observation of care provision and review of records ▪ Patient and family feedback ▪ Internal and/or external evaluation reports 	<ul style="list-style-type: none"> ▪ Start up ▪ Quarterly ▪ Monthly ▪ Semi-annually/Annually

Evaluation models for home-based care programmes

Evaluation type	Core questions to be answered by the evaluation
<p>Formative Evaluation Determine the programme concept, scope and design. Should be conducted during the planning or redesign of the HBC programme to resolve intervention and M&E issues before wide implementation. Defines scope, realistic goals and objectives of the interventions. Helps decide on feasible interventions and how to implement them, and estimates the potential number of beneficiaries and caregivers/volunteers needed for successful implementation.</p>	<ul style="list-style-type: none"> ▪ Is an HBC intervention needed? ▪ How many patients and families would benefit from the intervention? ▪ How should the intervention be implemented? ▪ Where should it be implemented and by whom? ▪ What resources would be required?
<p>Process Evaluation Designed to assess the inputs for the HBC programme, the outputs (e.g., staff / volunteers trained) generated and the quality of services provided to PLHWAs, families and communities. Looks at ongoing HBC programme activities, whether they are carried out correctly, on time and within the limited resources budgeted for them. Facilitates realignment of programme interventions, goals and objectives during implementation. Appropriately uses both qualitative and quantitative methods and tools.</p>	<ul style="list-style-type: none"> ▪ To what extent are all the planned HBC activities being implemented? ▪ How well are the services and information provided to PLHWAs, families and communities? ▪ Are the services equitably accessible to those in need? ▪ Are volunteers, supervisors and teams appropriately skilled to provide quality services? ▪ Is the patient caseload appropriate for volunteers? ▪ Are patients and families satisfied with the quality services provided?
<p>Effectiveness Evaluation Designed to assess the extent to which HBC programme objectives are achieved over a defined implementation period. Measures short-term (outcomes) and long-term (impact) programme effects at the target population level. Avoiding wrong conclusions about the effectiveness of HBC interventions requires assessment of outcome/impact indicators along with programme implementation.</p>	<ul style="list-style-type: none"> ▪ What outcomes have been observed in the HBC programme? ▪ What are their implications/meaning? ▪ Has the programme made a difference (impact) as intended? ▪ By what magnitude has the programme made a difference among the affected/served/target population? ▪ To what extent are standards of care maintained? ▪ To what extent does the programme maintain the continuum of care? ▪ Has the quality of life of the PLWHA improved? <ul style="list-style-type: none"> > Reduced morbidity > Increased longevity > Enhanced productivity
<p>Programme Cost Analysis Relates results and the costs of various interventions in order to assist in setting priorities, allocating resources, making decisions and designing a programme. Can be complicated in a HBC programme setting. Should probably be considered only when HBC programmes have been tried and tested over time, and definite outcomes and impacts standardized. For most donor-dependent programmes, basic cost analyses that look at sustainability issues can be conducted with appropriate external technical expertise.</p>	<ul style="list-style-type: none"> ▪ Do programme priorities need change or expansion? ▪ Is there a need to reallocate resources to achieve optimal programme operations? ▪ Does the programme need to be scaled up or scaled down? ▪ What is the level of community involvement/ ownership of the programme in terms of resource mobilization and caregiver incentives? ▪ Is the programme sustainable beyond external donor support?

Figure 1 Illustrative home-based care operational monitoring and evaluation framework



Annex – Data Collection Tools

The tools presented in this Annex support the system described in Standard 5 – Monitoring and Evaluation. They relate directly to the regular and systematic feedback at all programme levels described in Standard 5. The tools help providers to identify what information or services may need to be enhanced or initiated.

Home-based care monitoring and reporting are critical for strengthening programming and planning resources. Ideally, information from the HBC programme should be incorporated into the mainstream national, provincial and district level M&E and/or health management information system. The monitoring forms should be reviewed regularly and updated to capture important information relevant to HBC implementation. As much as possible, it is important to avoid duplication and the development of irrelevant data collection forms.

The Ministry of Health and Child Welfare provides the forms in this Annex as illustrative samples of the kinds of tools needed to collect consistent data on home-based care services. Individual programmes may design their own forms as needed, but the forms must provide for the collection of data illustrated here.

Everyone Must Participate

All participating and core stakeholders in HBC, especially home-based care teams, must have input into the application of reporting forms.

The specific HBC team members responsible for collecting and reporting information on a regular basis must be trained in the use of the tools. Competency-based training is the recommended approach to ensure that emphasis is placed only on what the provider has to know and accomplish to deliver quality care while ensuring adequate HBC management.

Reports Must Be Made Regularly

It is recommended that caregiver teams provide up-to-date patient progress reports on a monthly basis, and that managers and supervisors produce quarterly follow-up reports that collate and combine the information from caregivers. Multi-stakeholder reviews should also be conducted at regular intervals where filed reports are discussed, lessons documented and the way forward mapped out jointly. When resources allow, formal participatory evaluations may be conducted twice a year, at 6 and 12

Once complete, the form becomes a confidential document and must be carefully and respectfully secured.

ample forms

months of implementation, respectively. Internal or external programme evaluation reports that may be commissioned by donors should always be made available as home-based care planning and review inputs.

As much as possible, forms 1 and 2 in this section should be used in conjunction with the WHO community home-based care guidance kits. Caregivers must be required always to record how they have dispensed the medicines and supplies collected from the community, supervisor or district health centre. The form must be signed and returned to the respective HBC supervisor or coordinator at the end of each month or according to the MOH&CW guidelines.

How To Use the Forms

The caregiver must complete two forms:

- Form 1: Client Profile Form
- Form 2: Client Management Form

There are also two forms that must be used by supervisors:

- Form 3: Supervisory Checklists for Monitoring and Service Delivery
- Form 4: Supervisor's Monthly Report

Form 1: Client Profile Form

This form is completed when the caregiver makes the initial contact with the client. The completed form is returned to the Regional HIV/AIDS Coordinator through the appropriate management channels. Once complete, this form becomes a confidential document and must be carefully and respectfully secured, and not in any way accessible to unauthorized persons. Any information recorded on this form must be kept in a secure database held by the NGO or clinic responsible

for overseeing the HBC services in the respective HBC programme catchment area.

Form 2: Client Management Form

This form has four parts for recording four types of data: general information, observation of patient's condition, medicines and supplies dispensed, and patient's complaints/comments. For each of these categories there is space for recording the observation made or action taken for weekly visits over the course of 12 weeks. On the first and follow-up visits to the patient's home, the caregiver will assess the patient's overall condition, record observations of the patient's total condition and note any complaints the patient reports.

Where a clinical referral is the option, the caregiver must inform the family members and the patient to go to the nearest health center or hospital for clinical attention. The supervisor must also be informed immediately when a patient is in serious condition needing clinical attention.

The caregiver will then tick the appropriate conditions observed or noted in the spaces on the form. After 12 weeks, or as recommended by WHO, the form should be lodged at the clinic or handed over to the supervisor. This might occur when the caregiver is receiving medical and other supplies.

The caregiver will also use the patient assessment findings to decide what supplies the patient needs and what training and instructions should be given to a primary caregiver/family member on how to administer the requisite medicines and other items to the patient.

The caregiver may also need to suggest referrals for non-clinical services, such as legal advice or spiritual guidance. In

addition, the caregiver is expected to provide health education to family members about hygiene and healthy sexual practices. At each mutually pre-arranged visit, the caregiver must counsel the patient and family members, recording these sessions on the form.

Form 3: Supervisory Checklists for Monitoring and Service Delivery

This form is to be completed by the supervisor during regular visits to the teams and caregivers at the community level. The district-level supervisor will use this checklist during regular monthly or scheduled supervisory visits to the community.

The sources of information for the form include: District/ community level HBC coordinator, community leaders, clinic supervisors, or, as needed, other sources, e.g., TB registers, HBC activity reports, drugs and supplies stock records, etc.

The district-level supervisor may also collate information from the Patient Management Form (FORM 2). The supervisor is required to complete the checklist during monthly or scheduled visits to the caregivers, DAACs or the local body responsible for HIV & AIDS activities in the catchment area.

Form 4: Supervisor's Monthly Report

This form contains three sections: Service information, medicines dispensed and recommendations. The information required to fill the form is derived from the reports developed and submitted by each caregiver. (Number of clients assisted by volunteers this quarter means total seen by all caregivers for the reporting period.)

The sources of information for supervisory checklists include: District/community level HBC coordinator, community leaders, clinic supervisors, or, as needed, other sources, e.g., TB registers, HBC activity reports, drugs and supplies stock records, etc.

Sampl
Form:

HBC FORM 1: CLIENT PROFILE

This form is to be filled in when the caregiver makes the first contact with the client. The completed form is then returned to the Regional HIV/AIDS Coordinator through the appropriate management channels. *The completed form immediately becomes a confidential document. It must be*

carefully and respectfully secured. It must not be accessible to any unauthorized persons. Any information recorded on this form must be kept in a secure database held by the NGO or clinic responsible for overseeing the HBC services in the respective HBC programme catchment area.

CLIENT BACKGROUND

1. NAME OF CLIENT: _____
SEX: _____
2. DATE OF BIRTH: ____/____/____
3. NAME OF VILLAGE/TOWN/CITY: _____
4. REFERRED BY: _____
5. HEAD OF HOUSEHOLD: _____
(e.g., client, wife, husband, aunt, children, grandparents)
6. NUMBER OF CHILDREN IN THE HOUSEHOLD: _____
7. NUMBER OF ORPHANS: _____
8. DATE PATIENT RECEIVED
FIRST CARE BY CAREGIVER: ____/____/____
9. NAME OF PRIMARY CAREGIVER: _____
10. AGE OF PRIMARY CAREGIVER: _____
11. NAME OF VOLUNTEER GROUP/NGO: _____

CLIENT BRIEF CONFIDENTIAL MEDICAL HISTORY

1. HIV TEST DONE? NO [] YES [] WHEN? [____/____/____]
 2. HIV STATUS +[] -[]
 3. IS THE CLIENT BEDRIDDEN? YES [] NO []
FOR HOW LONG? _____
 4. CLIENT COMPLAINTS: _____

 5. OTHER ILLNESSES REPORTED: _____

 6. OTHER COMMENTS: _____

- NAME OF INTERVIEWER: _____
- DATE: ____/____/____

HBC FORM 2: CLIENT MANAGEMENT FORM

Date form was started: __/__/__

PART 1: GENERAL INFORMATION

1. Name of patient: _____ 6. Referred by: _____
2. Name of district: _____ 7. Marital status: Married [] Single [] Widowed [] Divorced [] Student []
3. Period of care in months: _____ 8. Age: _____ years
4. Name of caregiver: _____ 9. Sex: Male [] Female []
5. Name of community: _____ 10. Occupation: _____

PART 2: OBSERVATION OF PATIENT'S CONDITION

Tick the condition(s) that best describe your OBSERVATION of the patient on the visit indicated. In the box labelled (INV), record any referral made by placing (R) in the box. If an intervention other than referral was made, abbreviate the intervention as appropriate. For example: Sponged (SP), Counselling (CL), Assisted (AS). For all other common options, abbreviations should be drawn up, standardized and used consistently by all caregivers.

DATE	WEEK 1			WEEK 2			WEEK 3			WEEK 4			WEEK 5			WEEK 6			WEEK 7			WEEK 8			WEEK 9			WEEK 10			WEEK 11						
	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	
Weakness																																					
Cannot sit alone																																					
Cannot walk alone																																					
Cannot turn in bed																																					
Sweating a lot																																					
Feeds self																																					
Chest Infection																																					
Non productive cough																																					
Productive without blood																																					
Productive with blood																																					
Difficulty breathing																																					
STI																																					
Vaginal discharge foul																																					
Non foul vaginal discharge																																					
Urethral discharge																																					
Sores on penis																																					
Vaginal sores																																					

HBC FORM 2: CLIENT MANAGEMENT FORM – PART 2: OBSERVATION OF PATIENT'S CONDITION (CONTINUED)

DATE	WEEK 1			WEEK 2			WEEK 3			WEEK 4			WEEK 5			WEEK 6			WEEK 7			WEEK 8			WEEK 9			WEEK 10			WEEK 11				
	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N
CONDITION																																			
Dermatological																																			
Skin rash																																			
Itching																																			
Psychosocial																																			
Anxious																																			
Depressed																																			
Confused																																			
Cheerful																																			
Hungry																																			
Environment																																			
Safe drinking water																																			
Clean linen																																			
Toilet facilities																																			
Toiletries																																			

PART 3: MEDICATION AND MEDICAL SUPPLIES DISPENSED
 Use this part of the form to record any medicines and medical supplies you provide the client/patient. This form should list only those medicines and supplies the caregiver is allowed to dispense.

DRUGS AND SUPPLIES	WEEK 1			WEEK 2			WEEK 3			WEEK 4			WEEK 5			WEEK 6			WEEK 7			WEEK 8			WEEK 9			WEEK 10			WEEK 11					
	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv

ample forms

HBC FORM 2: CLIENT MANAGEMENT FORM (Continued)

PART 4: PATIENT COMPLAINTS/COMMENTS

Tick the condition(s) COMPLAINED OF OR MENTIONED by the patient on the visit appropriate. For example: Sponged (SP), Counselling (CL), Assisted (AS). For all indicated. In the box labelled (INV), record any referral made by placing (R) in the other common options, abbreviations should be drawn up, standardized and used consistently by all caregivers.

DATE	WEEK 1			WEEK 2			WEEK 3			WEEK 4			WEEK 5			WEEK 6			WEEK 7			WEEK 8			WEEK 9			WEEK 10			WEEK 11					
	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv	Y	N	Inv
CONDITION																																				
Difficulty swallowing																																				
Vaginal discharge																																				
Urethral discharge																																				
Vomiting																																				
Pain																																				
Diarrhoea																																				
Weight loss																																				
Productive cough																																				
Non productive cough																																				
Profuse sweating																																				
Cheerful																																				
Hungry																																				
Need for contraceptives																																				
Lonely																																				
Confused																																				

Sample Form:

HBC FORM 3: HBC SUPERVISORY CHECKLISTS FOR MONITORING AND SERVICE DELIVERY

This form is to be completed by the supervisor during regular visits to the teams and caregivers at the community level. Please tick in the appropriate spaces provided. The district-level supervisor will use this checklist during regular monthly or scheduled supervisory visits to the community. The sources of information for the form include: District/community level HBC coordinator, community leaders, clinic super-

visors, or, as needed, other sources, e.g., TB registers, HBC activity reports, drugs and supplies stock records, etc. The district-level supervisor may also collate information from the Patient Management Form (FORM 2). The supervisor is required to complete the checklist during monthly or scheduled visits to the caregivers, DAACs or the local body responsible for HIV & AIDS activities in the catchment area.

Period: _____ Name of supervisor: _____
 District: _____ Province: _____

INDICATORS	NUMBER	FUNCTIONALITY		COMMENTS
		YES	NO	
Number of NGO/CBO partners providing HBC				
Number of business partners supporting HBC activities				
Number of ministries involved				
Number of AIDS committees				
Number of partners				
Number of supervisors				
Number of care groups				
Number of caregivers				
Number of replenishment centres				
Number of clients receiving HBC services				
Number of individuals counselled				
Number of clients on DOTS				
Number of orphans				
Number of families supported				
Number of kits replenished				
Number of referrals made/served				
Number of client deaths recorded				

HBC FORM 4: SUPERVISOR'S MONTHLY REPORT

This form has three sections: *Service information*, *medicines dispensed* and *recommendations*. The information required to fill the form is derived from the reports developed and submitted by each caregiver.

Number of clients assisted by volunteers this quarter means total seen by all caregivers for the reporting period.

Report date: _____ Name of district: _____
 Prepared by: _____ Name of community: _____
 Reporting period: Month: _____ To: _____ Population: _____

PART 1. SERVICE INFORMATION

Number of trained HBC volunteers in the community:	[]
Number reporting this quarter:	[]
Number of patients assisted by volunteers this quarter:	[]
Number of families benefiting from HBC this quarter:	[]
Number of AIDS related/long-term deaths this quarter:	[]
Number of patients referred to HBC provider this quarter:	[]
Number of patients referred by HBC provider this quarter	[]

Sampl
Form:

PART 2. RECOMMENDED KIT OF MEDICINES AND NURSING CARE SUPPLIES	
Types and quantity of medicines and supplies dispensed by HBC providers/volunteers this quarter	
MEDICINES/SUPPLIES	QUANTITIES
PART 3. SUMMARY AND RECOMMENDATIONS	
Number of person-hours of HBC provided this quarter []	
Number of NGOs supporting HBC in the district this quarter []	
What types of services did they provide?	
a. _____	
b. _____	
c. _____	
General comments on caregivers' activities:	

Recommendations: _____	

ample
forms

References and Further Reading

- Burns, A. August, Ronnie Lavish, Jane Maxwell, and Katharine Shaper. 1997. *Where Women Have No Doctor: A Health Guide for Women*. Berkeley, California USA: The Hesperian Foundation. Publishers of Where There is No Doctor, by David Werner. Contact Hesperian Foundation, PO Box 1157, Berkeley, California 94712-2577 USA.
- Centers for Disease Control (CDC), FHI, Horizons, HRSA, Macro, Measure, USAID, WHO, UNICEF and UNAIDS. 2002. "National AIDS Programmes: A guide to monitoring and evaluating HIV/AIDS care and support". Draft. Atlanta, Georgia USA.
- Evan, Clive. 1995. *Primary AIDS Care: A Practical Guide for Primary Health Personnel in the Clinical and Supportive Care of People with HIV/AIDS*. Johannesburg, South Africa: Jacana Education. Distributors for East Africa: Family Planning Private Sector, PO Box 46042, Nairobi, Kenya.
- Department of Health, RSA. 2001. *National Guideline on Home Based Care and Community Based Care*. Republic of South Africa.
- International HIV/AIDS Alliance. 2002. *HIV/AIDS NGO/CBO Support Toolkit*. London, UK.
- Kisubi, Wilson, Elizabeth Lule, Charles Omondi, Pamela Onduso, Paul S.S. Shumba, Francessa Farmer and Margaret Crouch. 2000. *Integrating STD/HIV/AIDS Services into MCH/FP Programs: A Guide for Policy Makers and Program Managers*. Nairobi, Kenya: Pathfinder International. Africa Regional Office.
- Lucas, Sue and Hospice Information. 2002. *Palliative Care and HIV/AIDS*. London, UK.
- MOH&CW. 2001. *Community Home-Based Care Policy for The Republic of Zimbabwe*. Harare, Zimbabwe: Ministry of Health and Child Welfare.
- Ministry of Health, Kenya. 2002. *National Home Based Care Programme and Service Guidelines*. Nairobi, Kenya: National AIDS/STD Control Programme. Ministry of Health.
- NAC. 1999. *National HIV/AIDS Strategic Framework (2000-2004)*. Harare, Zimbabwe: Government of Zimbabwe, National Aids Council.
- Narain, Jai P., Clement Chela and Eric van Praag. 1998. *Planning and Implementing HIV/AIDS Care Programmes: A Step-by-Step Approach*. No. SEA/AIDS/106. WHO Project ICP OCD 041. New Delhi: World Health Organization, Regional Office for South-East Asia.
- Rehle, T., T. Saidei, S. Mills and R. Magnani, eds. 2001. *Evaluating Programs for HIV/AIDS Prevention and Care in Developing Countries. A Handbook for Program Managers and Decision Makers*. North Carolina, USA: Family Health International.
- Russell, Michele and Helen Schneider. 2000. *A Rapid Appraisal of Community-Based HIV/AIDS Care and Support Programmes in South Africa*. Durban: Health Systems Trust, 401 Maritime House, Salmon Grove, Victoria Embankment, Durban 4001, South Africa.
- Sanei, Linda. 1998. *Palliative Care for HIV/AIDS in Less Developed Countries*. Discussion Paper No. 3. Discussion Papers on HIV/AIDS Care and Support. US Agency for International Development, Health Technical Services

- Project, 1601 North Kent Street, Suite 1104, Arlington, Virginia 22209-2105 USA.
- Save the Children (UK) South Africa Programme. 2002. *The Rights of Children and Youth Infected and Affected by HIV and AIDS: Trainers' Handbook*. South Africa.
- Save the Children (UK). 2003. "Responding to the HIV/AIDS Challenge in Africa". CD-ROM. ICASA.
- TASO and WHO. 1995. *TASO Uganda – The Inside Story: Participatory evaluation of HIV/AIDS counselling, medical and social services 1993–1994*. WHO/TCO/HCS/95.1. The AIDS Support Organization (TASO), PO Box 10443, Kampala, Uganda, and Global Programme on AIDS, Documentation Centre, World Health Organization, CH-1211 Geneva 27, Switzerland.
- UK Forum for Hospice Care World Wide. 2003. *Palliative Care – An Information Document*. London, UK.
- UNAIDS. 1999. *From Principle to Practice*. GIPA. Geneva: Joint United Nations Programme on HIV/AIDS.
- UNAIDS. 2000a. *National AIDS Programmes: A Guide to Monitoring and Evaluation*. Geneva: Joint United Nations Programme on HIV/AIDS.
- UNAIDS. 2000b. "Technical Update: AIDS: Palliative Care". Geneva: Joint UN Programme for HIV/AIDS.
- UNAIDS. 2002a. "Epidemiological Fact Sheets, 2002 Update". Geneva: Joint United Nations Programme on HIV/AIDS.
- UNAIDS. 2002b. Library CD-ROM (Standard Version). Geneva: Joint UN Programme for HIV/AIDS.
- UNAIDS. 2002c. *Report on the Global HIV/AIDS Epidemic*. Geneva: Joint United Nations Programme on HIV/AIDS.
- UNICEF. 2003. *Africa's Orphaned Generations*. New York: United Nations Children's Fund.
- UNICEF. 2002. "Situational Assessment of Children in Zimbabwe, Update". Harare, Zimbabwe: United Nations Children's Fund.
- USAID. 2000. *Handbook of Indicators for HIV/STI Programs*. Washington, D.C.: United States Agency for International Development.
- USAID. 2002. *Expanded Response Core Indicators for Monitoring and Reporting on HIV/AIDS Programs*. Washington, D.C.: United States Agency for International Development.
- USAID. 2003. *Zimbabwe. Country Profile: HIV/AIDS*. Washington, D.C.: United States Agency for International Development.
- WHO. 1993. *AIDS Home Care Handbook*. Geneva: World Health Organization.
- WHO. 2002. *Regional Guidance Kit for Planning and Implementing HIV/AIDS and Tuberculosis Community and Home-Based Care Activities*. Harare, Zimbabwe: World Health Organization Regional Office for Africa.
- Woelk, G., et al. 1997. *Do We Care? The Cost and Quality of Community Home-Based Care for HIV/AIDS Patients and Their Communities in Zimbabwe*. Harare, Zimbabwe: University of Zimbabwe, SAFAIDS, Ministry of Health and Child Welfare.
- World Education/NANASO. 1997/98. *HIV/AIDS Community Education Initiative – Training of Trainers*. Windhoek, Namibia.