Strengthening Communities' Responses to HIV/AIDS

Standardized Quality Assurance Manual for CSO's Palliative Care Activities

QA and Operations Manual

September, 2010

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Foreword

With the generous support from USAID/PEPFAR, the Strengthening Communities' Responses to HIV/AIDS Project (SCRHA) (one component of the Program for Appropriate Technology in Health (PATH)), is working towards improving communities' capacities so that they can access comprehensive and integrated HIV/AIDS services. This includes care and support that encompasses palliative care, capacity building, HIV counseling and testing, and economic strengthening services in eight regional states in Ethiopia.

Palliative care is an essential component of a comprehensive package of care and support for people living with HIV because it is a means of relieving symptoms that would otherwise lead to undue suffering and frequent visits to the hospital or clinic. Lack of palliative care services may hamper an individual's ability to continue his or her daily life activities.

This operations manual is, therefore, intended to address the implementation protocol and procedures for both non-clinical and clinical palliative care services provided at the household or community level. In addition, this manual will address how linkages are developed with facility-based clinical services. This operations manual will guide both programmers planning community care as well as direct implementers, community health workers, and community volunteer providers so that they are aware of their responsibilities in providing care.

The SCRHA project wishes to acknowledge the Dawn of Hope Ethiopia Association for initiating the preparation of this manual and HESA Health and Social Development Consultants for developing it. This manual was the result of a concerted effort by different partners working in the area of HIV/AIDS care and support. Gratitude is expressed to key informants, health extension workers, community care and support volunteer providers, PLHIV associations, and others who contributed their valuable input in identifying gaps and suggesting possible solutions. Special thanks also goes to SCRHA technical staff members for their

technical input, participation, leadership, and support throughout the manual development process.

This operations manual will significantly contribute to the improvement of palliative care service delivery both locally and nationally.

Chief of Party

Dr. Zelalem Gizaw

Acknowledgements

This operations manual was developed for the Strengthening Communities' Responses to HIV/AIDS (SCRHA) project, led by PATH (Program for Appropriate Technology in Health), through the generous support of the United States Agency for International Development (USAID). The contents of this guide are the sole responsibility of the SCRHA project and do not necessarily reflect the views of USAID or the United States Government.

PATH would like to thank international partner I-TECH (International Training and Education Center for Health), national implementing partner Dawn of Hope Ethiopia Association, as well as Hesa Health and Social Development Consultants of Hesa Inter Enter PLC - Ethiopia for leading the development of this manual. In addition, PATH would like to extend its gratitude to the Federal Ministry of Health, Federal HIV/AIDS Prevention and Control Office and all other stakeholders and individuals for their constructive contribution in the development of this manual. We pay special tribute to those participants who are living with HIV (PLHIV) and orphans and vulnerable children (OVC); we hope the contents of this manual will contribute to improving their health and the quality of all their lives.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARC	AIDS Resource Center
ART	Antiretroviral Treatment
BCC	Behavior Change Communication
CBO	Community-Based Organization
CC	Community Conversation
CCS	Community Care and Support
CDC	Centers for Disease Control and Prevention
CHBC	Community and Home-Based Care
CPC	Community-based Palliative Care
CSA	Central Statistics Authority
CSO	Civil Society Organization
DHEA	Dawn of Hope Ethiopia Association
EIFDDA	Ethiopian Interfaith Forum for Development Dialogue and Action
ES	Economic Strengthening
FBO	Faith-Based Organization
FBP	Food by Prescription
FGEA	Family Guidance Ethiopia Association
FHI	Family Health International
HAPCO	HIV/AIDS Prevention and Control Office
HBC	Home-Based Care
HC	Health Center
HEW	Health Extension Workers
HFC	Hope for Children

HIV	Human Immunodeficiency Virus
HP	Health Post
ICESCR	International Covenant on Economic, Social and Cultural Rights
IEC	Information, Education and Communication
IIP	International Implementing Partner
IRD	Institute for Research and Development
M&E	Monitoring and Evaluation
MFI	Micro Finance Institution
MoFED	Ministry of Finance and Economic Development
MoH	Ministry of Health
MoU	Memorandum of Understanding
MoWA	Ministry of Women's Affairs
MSG	Mothers' Support Group
NEP+	Network of Ethiopian HIV Positives
NGO	Non-Governmental Organization
NIP	National Implementing Partner
OI	Opportunistic Infection
OM	Operations Manual
ORDA	Organization for Rehabilitation and Development for Amhara
PATH	Program for Appropriate Technology in Health
PC	Palliative Care
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	Person/People Living with HIV
PMP	Performance Monitoring Plan
PMTCT	Prevention of Mother-to-Child Transmission of HIV
RH	Reproductive Health

RHB	Regional Health Bureau
SCRHA	Strengthening Communities' Responses to HIV/AIDS
SLOT	Strength, Limitations, Opportunity and Threat
SoW	Scope of Work
STI.....	Sexually Transmitted Infection
TB.....	Tuberculosis
TWG	Technical Working Group
USG	United States Government
UHEW.....	Urban Health Extension Worker
UNAIDS	Joint United Nations Program on HIV/AIDS
USAID.....	United States Agency for International Development
VCT	Voluntary Counseling and Testing
WFP.....	World Food Program
WHO	World Health Organization

Operational Definitions

Capacity Building: All key stakeholders involved in providing service and support to PLHIV and their families at the household level should ensure that users of the Operations Manual, at all levels including federal, regional and kebele/local, are trained in the application of the Operations Manual. The stakeholders should also ensure that implementers have the technical, financial and managerial capacities necessary to successfully utilize the Operations Manual.

Civil Society Organization (CSO): Any sort of not-for-profit, non-state organization or community-based association/group that advance a collective or public good.

Clinical Services: Services provided by certified professionals i.e. nurses, physicians and medical personnel at the health facility level. In the context of community/home based palliative care these services are carried out jointly with urban health extension workers (UHEWs) at the household level.

Community Care and Support Volunteer Providers: Community members who provide non-clinical care and support (educational, social, spiritual, and psychological support), and conduct broader HIV awareness and promotional activities.

Comprehensive Care and Support: Comprehensive care for people living with HIV/AIDS (PLHIV) requires both clinical care based at the health facility as well as community or home based care and support involving the patient, family, friends, community health workers, other community-based caregivers, trained traditional healers, and community-based organizations such as CSOs and faith-based organizations (FBOs) (source: SCRHA, PMP, December 2009). Also, comprehensive care involves a network of resources and services that provide holistic, comprehensive, wide-ranging support for PLHIV and their families.

Confidentiality: The SCRHA team, NIPs and/or CSOs and staff or volunteers with knowledge of a patient's personal or private information should make every effort to ensure that that information remains confidential, unless they have a client's and/or family's written, recorded or witnessed consent.

Coordination: The needs of PC services clients may not be met by a single organization or individual. In order to fulfill the vast needs of PC clients, all implementing partners

including PC service providers should identify and address service gaps by coordinating locally available resources and efforts.

Ekub: A traditional local way of saving whereby each group member contributes an equal amount of money to a central person or "pot" which is collected monthly or weekly. At the end of the agreed upon time period, one group member receives the entire collection, and the practice continues so that each member receives the collection by turn.

Evaluation: A systematic process of data collection, analysis and interpretation about the activity and implementation progress of a given program. In the context of palliative care, an evaluation will assess characteristics and effects of a palliative care services implementation process, looking to answer standard evaluation questions. An evaluation will assess the effectiveness of those activities as well as outcomes (short-term effects) and impacts (long term effects).

Generalists: Nurses or social workers based in the CSOs who facilitate, coordinate and oversee the delivery of quality community level PC services.

Health Care Services: These services include the provision of primary care, immunization, treatment for ill children, ongoing treatment for HIV positive children, and HIV prevention.

Idir: A local social gathering organized by community elders aimed at assisting community members with resource mobilization mainly during funeral and mourning time when losing family members. Members of the *idir* contribute money monthly.

Indicator: Indicators are measurable or tangible signs that services have been provided or that results have been achieved. For example, common indicators for overall health in a community include the infant/child/maternal mortality rate, the birth rate, nutritional status change, and birth weights.

International Implementing Partners (IIP): International organizations that have legal entity in Ethiopia and work on the SCRHA project. These include: PATH, I-TECH, International HIV/AIDS Alliance, Westat and IRD.

Monitoring: An ongoing and continuous process for checking on the progress of activities. Monitoring tasks include making sure that activities are being implemented as planned and looking at inputs, process and outputs. It involves continuous day-to-day or routine

ongoing tracking for a project or program activities in order to determine whether they are moving forward and making progress as planned.

National Implementing Partners (NIPs): National implementing partners (NIPs) are CSOs that have a good amount of capacity, coverage, and experience working with multiple CSOs and government counterparts in addition to proven experience in SCRHA project areas at the community level. For this specific project these include: Dawn of Hope Ethiopia Association (DHEA), Mekdim National Association, Hope for Children, Family Guidance Association-Ethiopia (FGAE), Organization for Rehabilitation and Development for Amhara (ORDA), Pro-Pride ESSWA and others.

Non-clinical services: Services provided by a multi disciplinary team including bereavement support and follow-up to people living with HIV and their families as well as social, spiritual and psychological support for PLHIV. In the SCRHA context, non-clinical services are services specifically provided by trained community care and support volunteers at the household level.

Psychosocial Support: These services aim to provide PC clients with the human relationships necessary to improve the quality of their lives. The provision of psychosocial support also aims to promote and encourage the acquisition of life skills that facilitate social interactions. With these skills, PLHIV will be more able to participate in activities such as public gatherings, recreation, and work and eventually live exemplary lives.

Social Mobilization: A strategy which primarily involves organizing and engaging community members around a specific issue. Social mobilization involves informing and empowering communities, and equipping them with the knowledge and skills they need to effect the changes that their community needs. In the case of HIV, social mobilization can be used to inform communities about HIV and what they can do to fight the pandemic. It is a process through which the community capitalizes on its assets and capacities to prevent and control HIV/AIDS by taking ownership and action at the forefront with a shared sense of urgency to reduce and reverse the spread of the pandemic, provide care and support to infected, affected and vulnerable people. (Source: FHAPCO, SM Guideline, 2007).

Chapter One: Introduction

1.1. Rationale for the Operations Manual

SCRHA and its international and national implementing partners, aim to improve Ethiopian communities' abilities to respond to the HIV epidemic through the enhancement of access to HIV/AIDS prevention, care and treatment services. The main task of this operations manual is to guide palliative care service providers who engage in improving the quality of life of people and families living with HIV.

In order to provide quality and comprehensive palliative care services to the targeted beneficiaries, development and use of a PC operations manual for SCRHA was deemed necessary. This operations manual will clearly map channels of services, outline and clarify the roles of service providers at different levels, and explain effective service quality assurance and control mechanisms that guide the provision of quality care and support services at the community and household level. It also describes how to integrate palliative care services within different care and support services as well as other HIV/AIDS prevention and control interventions.

1.2. Objectives of the Operations Manual

This manual is intended to support SCRHA project implementation of both clinical and non-clinical palliative care activities. The manual is designed to facilitate the systematic and unified implementation process of community-based care and support activities in SCRHA target towns as well as to answer questions related to how to implement palliative care services effectively and efficiently. Hence, the information in this operations manual will provide guidance for two major types of activities:

a. **Clinical palliative care services** - provided by urban health extension workers; involve the coordination and management of clinical services under the leadership of the nearby health facility and government health offices.

b. **Non-clinical palliative care services** - provided by community care and support volunteer providers; targeted to 300 urban and peri-urban towns and involve the coordination and engagement of multiple CSOs under the leadership of NIPs.

The guidance in the manual may need to be tailored to specific regions, woredas and towns where CSOs operate. It can also be used to facilitate referrals by community promoters and urban health extension workers to organizations or institutions that provide wider services.

In addition to this, the operations manual is intended to guide program designers and coordinator son how to plan, implement, supervise, and ensure quality palliative care services provision at the household level. Specific objectives are shown in Table 1 below.

Table 1: Specific Objectives of the PC Service Operations Manual by Major Actors

Major Actors	Specific Objectives
Policy makers/ Coordinating bodies	• Help facilitate informed palliative care policy related decisions. • Help define the roles and responsibilities of each stakeholder. • Provide guidance on coordination and collaboration mechanisms for stakeholders.
Program managers and/or planners	• Give guidance for the implementation of integrated and harmonized palliative care services at all levels. • Integrate PC services with the existing health system, involving all levels of care. Place special emphasis on home-based care, and integration and networking with the ongoing strategies and those that provide comprehensive care and support services. • Define and illustrate monitoring and evaluation mechanisms including integrated supportive supervision. • Define the roles and responsibilities of each implementing partner throughout the implementation process. • Show the referral and referral audit tracking mechanisms.
Community/home -based palliative care service providers (both	• Create awareness of PC services and other community support services. • Provide services for selected beneficiaries in their areas. • Network between community care organizations, support volunteers and

CCS volunteers and UHEWs)	UHEWs, and other workers in the operational areas. • Identify, document and communicate good practices at the community level pertaining to PC. This can include developing case studies and writing periodic reports.
Intended beneficiaries of palliative care services	• Standardize the continuum of palliative care services across different target areas based on their specific service needs. • Get meaningfully involved and contribute to the success of the palliative care activities implemented in their vicinity. • Access existing service providers through referral and linkages created by service providers based on prepared formats and mechanisms. • Get practical experience on the implementation of community/home-based palliative care services through direct involvement based on strategies outlined in the manual.

1.3. Intended Users of the Operations Manual

The intended users of this manual include:

- SCRHA Project team members;
- National implementing partners;
- Civil society organizations; and
- Palliative care service providers: community care and support volunteer providers and UHEWs.

Chapter Two: Background

2.1. HIV/AIDS Situation in Ethiopia

HIV/AIDS has rapidly become one of the most devastating pandemics ever seen. It has spread quickly to every country in the world. It does not discriminate; it affects people of any race, sex, color, occupation, profession, socioeconomic class, age, territory, religion or ideology. HIV/AIDS is not only a major public health problem, but has threatened and damaged various levels of societal functioning and development. Some examples of its reach include harm to individual health and well-being, reduced household income, ruined families, reduced organizational productivity and increased healthcare costs. HIV/AIDS has increasingly become a development problem, requiring the concerted efforts of various partners.

The HIV/AIDS pandemic continues to spread worldwide. In 2009, some 33.4 million [31.1 – 35.8 million] were living with the virus, which killed about 2.0 million [1.7 million–2.4 million] in 2008. Sub-Saharan Africa region is the most affected region in the global AIDS epidemic. 22.4 million [20.8 million–24.1 million] people, which is more than two-thirds (68%) of all HIV-positive people, live in Africa where more than three quarters (76%) of all AIDS deaths in 2008 occurred. Unlike other regions, the majority (61%) of people living with HIV in sub-Saharan Africa are women (UNAIDS and WHO, December 2009).

Ethiopia is one of the most highly affected nations in the world. According to the combined national single point estimates for the year 2009[1], the adult HIV incidence was 0.28% and the prevalence was 2.3%. Over 1.1 million people live with HIV in Ethiopia, 59% of whom are female. The estimated number of Ethiopians who needed ART in 2009was 336,160, and 44,751 people died of AIDS that year. All of these people could have benefited from palliative care services.

Ethiopia has poor health status relative to other low-income countries, even within Sub-Saharan Africa, which is largely attributed to preventable infections and

[1] Federal Ministry of Health (FMOH): Single Point HIV prevalence Estimate, 2009.

nutritional problems. Infectious and communicable diseases including HIV/AIDS, malaria and tuberculosis (TB) account for about 60–80% of the health problems in the country.

A number of underlying factors have contributed to the spread of HIV in Ethiopia including poverty, illiteracy, stigma and discrimination of those affected by HIV/AIDS; high rates of unemployment; widespread use of sex work; gender disparities; population movement including rural to urban migration; and harmful cultural and traditional practices. HIV/AIDS, in turn, has worsened the economic situations of individuals, families, communities, and the nation at large. This has led to the development of a vicious cycle that increases individual and community vulnerability to infection.

According to the Ethiopian Federal Ministry of Health (MOH) report of 2006–07, there are a total of 143 hospitals, 690 health centers, 1,376 health stations and nucleus health centers, and 9,914 health posts run by the Ethiopian Government which provide health care services. Likewise, 2,153 private clinics are run by private institutions and non-governmental organizations (NGOs). In addition, there are 2,489 pharmaceutical retail outlets owned by the government, private owners and NGOs. Health care services, mainly clinical care with respect to HIV/AIDS, are inevitably linked to the national responses to HIV/AIDS.

The practice of modern medicine, traditional medicine, and holy water treatment run side-by-side even in Addis Ababa. PLHIV tend to go first to modern health facilities, but when their sickness is not effectively managed at the health facilities, patients consider seeking out assistance from traditional medicine or holy water treatment to fill in the gap.

The SCRHA project and its partners will improve the Ethiopian Community's ability to respond to the HIV epidemic by improving access to HIV/AIDS prevention, care and treatment services and strengthening the quality of community and home based services.

2.2. *The SCRHA Project*

2.2.1. *Establishment of the SCRHA Project*

SCRHA is a new initiative funded by USAID, implemented by PATH and its national and international partners. SCRHA is a three-year contract project with one-year optional extension periods. The goal of the project is to strengthen the capacity of civil society organizations to improve the access and quality of HIV care and support services, including counseling and testing and treatment adherence activities within communities, so that health outcomes for HIV positive Ethiopians and their dependents are improved.

By partnering with local groups, the project will reach large numbers of people throughout the country. It will provide training, technical assistance, and managerial support to national implementing partners (NIPs) in addition to grants so that they can carry out activities. NIPs will extend their reach even further by issuing sub-grants to smaller community-based CSOs.

NIPs and CSOs will use part of their grant money to train and/or employ palliative care service providers including community care and support providers, nurses based in the CSOs (whom the project call "generalists"), and others who are staff seconded to CSOs who serve as regional coordinators. SCRHA will also collaborate closely with the government's health extension program by training urban health extension workers (UHEW) in clinical areas related to the SCRHA contract and coordinating the work of other palliative care providers with that of the HEWs.

2.2.2. *Target Areas and Populations*

The SCRHA project will support the delivery of services by CSOs in urban and peri-urban areas, targeting towns in seven regions (Amhara; Afar; Bensihangul-Gumuz; Gambela; Oromiya; Southern Nation, Nationalities, and Peoples Region (SNNPR); and Tigray) and one city administration (Dire Dawa) in a total of 300 towns in Ethiopia. Geographic areas (towns) are selected based on HIV prevalence and the numbers of ART recipients. In order to select the targets, reference is made to

national ART monthly reports (available on the Ethiopian AIDS Resources Center website) as well as FMoH single point, antenatal care (ANC), and Demographic and Health Survey (DHS) HIV prevalence estimates. The primary target populations in the SCRHA project are people who are HIV positive and/or TB patients and their families.

2.2.3. *Project Goal and Objectives*

The overall goal of the SCRHA project is to improve the quality of life of people affected by and infected with HIV/AIDS through support to CSOs.

The project's objectives include:

- Improving access to comprehensive HIV/AIDS community and home-based care services offered by local CSOs in high HIV prevalence areas, and strengthening coordination with and linkages to public health facilities with special emphasis on integrating home-based care services with child health, infectious disease, family planning and HIV clinical care services at public facilities;
- Strengthening and monitoring the performance and quality of HIV-related community and home-based care services offered by local civil society, strengthening and monitoring the performance and quality of referral patterns of individuals, and improving adherence care to anti-TB and antiretroviral therapy at household level; and
- Raising awareness of and demand for quality and comprehensive services, among households and communities impacted by HIV/AIDS, to be offered by local civil society and health facilities.

2.2.4. *Major Project Components*

The SCRHA project has five main components, which involve supporting:

- CSO delivery of community-based care and support services
- CSO delivery of HIV counseling and testing services

- CSO delivery of economic strengthening services
- CSO capacity-building for community-based HIV/AIDS services
- Human capacity development for HIV/AIDS services in the community

Among these five components, palliative care is a major fundamental facet of a comprehensive community/home based care and support program that also includes clinical, psychological, and spiritual support, as well as HIV prevention. It is deeply rooted in the understanding that the community, with appropriate support, has the potential to provide care and support as well as economic empowerment to its members who are affected by the HIV/AIDS. As such, both the target group and the larger community benefit from palliative care services.

2.3. *Palliative Care Concepts*

2.3.1. *General Overview*

Palliative care is defined by different bodies in different ways. However, the basic concepts of palliative care can be captured from definitions given by WHO, PEPFAR and MoH. As defined by the WHO (2002), palliative care is:

> an active and total approach to care, embracing physical, emotional, social, and spiritual elements. It focuses on quality of life for people with incurable diseases, support for the family, and includes the management of distressing symptoms, provision of respite and care through death and bereavement. It is provided for children for whom curative treatment is no longer the main focus of care and may extend over many years.

The World Health Organization states that effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of locally available community resources effectively. It can be successfully implemented even if resources are limited and can be provided in tertiary care facilities, community health centers, and even one's own home. Therefore, it is important to assess these needs and be able to respond with a holistic approach.

According to the Ministry of Health which has adopted the PEPFAR definition:

> palliative care optimizes quality of life by active anticipation, prevention and treatment of suffering. It emphasizes the use of an interdisciplinary team approach throughout the continuum of illness, placing critical importance on the building of respectful and trusting relationships. Palliative care in this context addresses physical, intellectual, emotional, social and spiritual needs. It facilitates patient autonomy, access to information and choice.

Palliative care in general:

- Affirms life and regards dying as a normal process;
- Provides a series of interventions that intend neither to shorten nor to prolong life;
- Neither hastens nor postpones death;
- Provides relief from pain and other distressing symptoms;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care is also recognized as a right. According to the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR), all people with severe illness have the right to palliative care[2,3]. Palliative care exists worldwide and flourishes out of a core respect for the dignity of the dying and for the struggle of the family.

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[2] Stjernsward, J. 2007. Palliative Care: The Public Health Strategy. *Journal of Public Health Policy* 28:42–55.

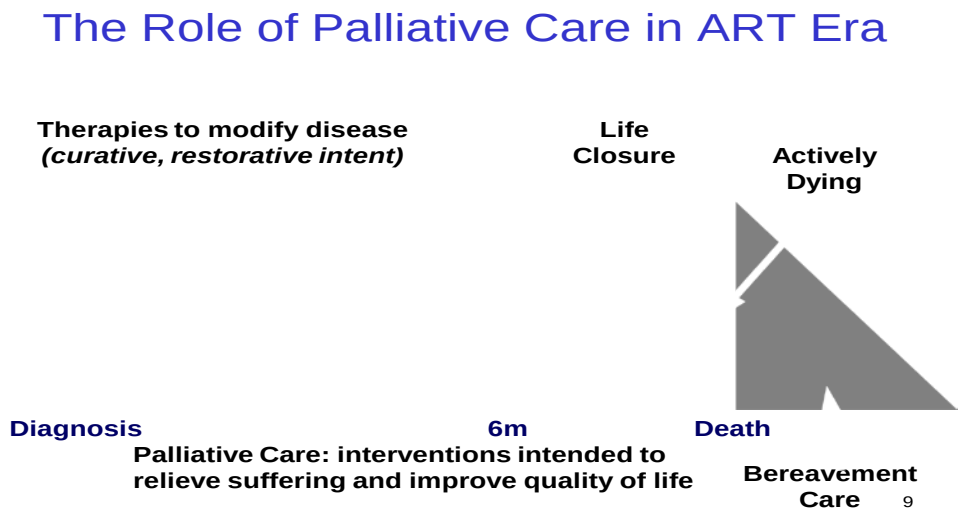
[3] Brennan, F. 2007. Palliative Care as an International Human Right. *Journal of Pain and Symptom Management*, 33(5):494–99.

The role of families in palliative care is very important. Patients and families may have little knowledge of the disease, its prognosis and its management, including palliative care. They may have low expectations of pain relief or unrealistically high expectations of treatment benefit. Every effort should be made to empower the patient, family, and community by:

- involving them in decision-making with regard to treatment;
- explaining treatments in such a way that they can give informed consent (or informed refusal);
- facilitating a continuing sense of being in control by providing appropriate advice and practical support; and
- educating and training community members and family caregivers.

Figure 1 below shows the integration of palliative care early in the disease process and represents the integrated model of palliative care in HIV management. Early in the disease process curative treatment is emphasized, but palliative care is still important to alleviate the side effects and to treat other conditions that affect quality of life such as neuropathy and depression. As the disease progresses, the balance shifts towards ensuring the patient's comfort and quality of life, as well as supporting the patient's family and friends in caring for the patient.

Figure I: The Role of Palliative Care in ART Era



As essential component of services delivered to PLHIV and their families, palliative care is the combination of measures that relieve suffering and improve the quality of life for those facing problems associated with progressive, chronic, life-threatening illnesses such as HIV, cancer, or chronic obstructive pulmonary disease. SCRHA has adopted the following definition for palliative care:

> comprehensive care and support that includes medical, psychosocial, spiritual counseling, nutrition, treatment and prophylaxis for opportunistic infections (OIs) and prevention of other infections provided at community/households levels to alleviate pain and suffering starting from the time of HIV diagnosis up to the end of life (adopted from Technical Working Group on PC, MOH, Ethiopia).

Palliative care is globally recognized as pivotal to HIV care. While WHO, PEPFAR, and other global organizations work at the policy level in palliative care, SCRHA, with its initial experience in HIV programs at the community level, has the comparative advantage in effectively identifying evidence-based palliative care best practices in the community. This strategy sets the organization on course for developing, enhancing, and extending palliative care services throughout HIV programs.

In Ethiopia, as in many other sub-Saharan countries, major gaps still prevail and the majority of HIV/AIDS and cancer patients' needs regarding palliative care and pain control are not considered a public health priority that can be effectively tackled

with relatively low cost measures. Developing a new service requires the collection of supporting data to establish the need for and feasibility of the proposed program. Such information can be used to illustrate the scale of unmet need and to identify patient populations who can benefit most from palliative care services. Furthermore, the process of assessing institutional and community need for a palliative care program will lead to enhanced dialogue, broadened institutional recognition of the importance of palliative care, and engagement of a critical mass.

Palliative care exists worldwide and flourishes out of a core respect for the dignity of the dying and for the struggle of the family. Palliative care is the combination of active and compassionate therapy based on spiritual, physical and psychosocial needs intended to comfort and support individuals and families who are living with life threatening illnesses. In many ways, it transcends medicine and is a reflection of the values of the community.

Important palliative care initiatives require both governmental as well as non-governmental backing, supported in many cases by international organizations. These initiatives have produced a solid knowledge base of how low-cost, good quality palliative care can be provided in low resource settings. They rely mainly on networks of community members, educated and supervised by a palliative care team.

2.4. The Need for Palliative Care in Resource Limited Areas

International health organizations, including WHO, recognize the importance of adequate pain control, symptom management, and psychosocial support as part of the equitable distribution of health resources. Resource-poor communities, such as those in Ethiopia, face a multitude of barriers including overwhelming numbers of patients, underdeveloped health care systems, and limited access to opioids. To minimize these challenges, various models and programs are being adapted to such settings. Overall, if the community based palliative care services are strengthened, then these challenges can be minimized and services can be easily managed in a home setting.

Chapter Three: Palliative Care Components in the SCRHA Context

The SCRHA project operates in seven regional states and one city administration, all of which are characterized as resource limited settings. In these settings, palliative care services face stronger challenges. Hence, as with ART and other treatments, the issue of access remains a serious issue for palliative care. Palliative care, as part of the continuum of care for HIV/AIDS affected people, can be integrated into the existing network, health promotion and prevention activities, and the provision of adequate quality treatment. These are key strategies to reduce the burden of HIV/AIDS.

Most notably, SCRHA palliative care services are based on the "integrated community-based palliative care" model, as indicated in the SCRHA project document, utilizing UHEWs and community care and support volunteer providers in home settings. There are unique psychosocial challenges to end-of-life care in much of the Ethiopian urban and peri-urban settings. For example, huge numbers of orphaned children place stress on the support systems in place. Women in general carry a greater economic burden and also bear most of the responsibility for care giving. Stigma against HIV-infected clients is still rampant.

However, integrating community/home-based palliative care services into the existing network will take many years if it is to have the expected impact on the population. This includes the provision of adequate quality treatment for HIV positive people and their families, which requires the development of appropriate and accessible health infrastructure and technology. In the meantime, patients can be relieved from their pain and suffering by using low cost approaches, mainly community-based strategies.

Palliative care areas in the SCRHA context include pain and symptom management, communication about illness and prognosis, exploration of the patient's goals and values, psychosocial and spiritual support, and care coordination, including hospice referral when applicable. Clinical palliative care service providers and UHEWs

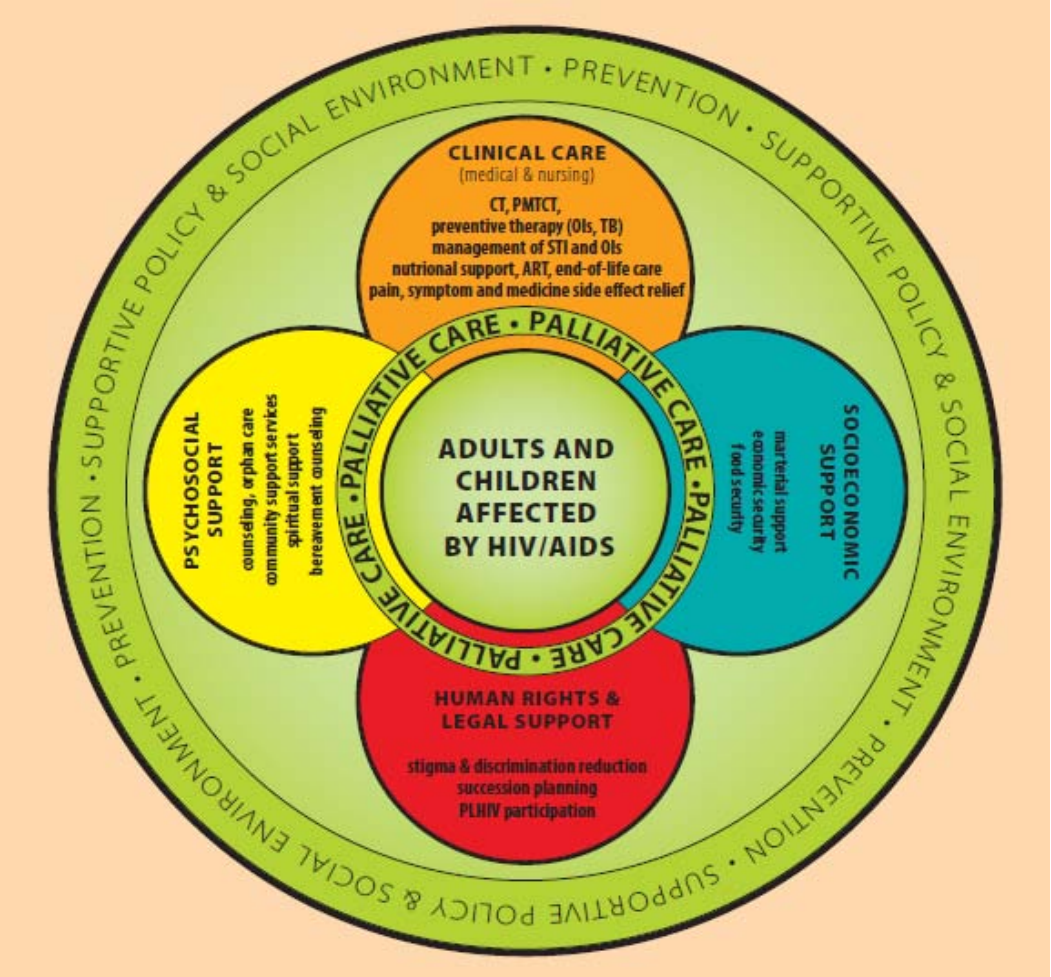
assist clients with complex symptom management and complicated medical decision making. Community care and support volunteer providers can supplement the clinical services by providing psychosocial and spiritual support, and supporting the local HIV/AIDS community coordination committee, and Idirs when a patient dies. Attention to these palliative care domains may improve adherence to complex treatment regimes and improve quality of life.

Both clinical and non-clinical aspects of palliative care services should be treated equally. Community care and support volunteer providers can provide non-clinical care and support activities while urban health extension workers manage the clinical care with close linkages at the nearest health facility. The interaction between these two components is shown in the supportive supervision tool that is attached to this manual (Annex VII). The essential elements of palliative care in the context of the SCRHA project specifically include: basic nursing care, symptom management, support for OVCs, as well as spiritual and psychological support. Details are shown in Table 2 below.

Table 2: Illustrative Components of Palliative Care Services

PC Service Category	Interventions
A. Clinical (Treatment and prophylaxis for OI)	✓ Pain and symptom management ✓ Hygiene and sanitation promotion ✓ Nursing care ✓ Nutrition counseling, ✓ End of life care and ✓ Preventive interventions including individual-level health education on abstinence and being faithful, condom promotion and distribution, promotion of gender-equitable norms, and hygiene and sanitation.
B. Non-Clinical or Support services	
Psychological	✓ Grief counseling support, linkage to family health and support groups, support for disclosure of HIV status, support OVC participation in scouts, theater and sport at schools, and referral to institutions providing psychiatric care ✓ Referral for Treatment of HIV related Psychiatric illnesses, such as depression and related anxieties ✓ Bereavement care
Spiritual	✓ Life review assessment and counseling, and ✓ Religious support
Social	✓ Assistance to individuals and family members in maintaining use of care and support services through PLHIV support groups, community mobilization through coffee ceremonies and community festivals, organization of anti-stigma events, referral for legal services, and linkages to food and economic strengthening services ✓ Assist clients in maintaining linkages to and use of care ✓ Preventing HIV infection ✓ Establish community support groups ✓ Community mobilization for PC ✓ Efforts to reduce stigma ✓ Financial and Material support to PLWHA and OVCs ✓ Legal services to assist with succession planning inheritance, rights and legal documentation such as living will or power of attorney ✓ Linkage to food support and income generating program ✓ Educational support and follow-up to OVCs

Figure II: Palliative Care Service Components Diagrammatic Representation



Source: Adopted from "Standards for Improving the Performance and Quality of Services in Palliative Care Programs", FHI, 2009.

Chapter Four: Major Activities and Management of Palliative Care Services Implementation

4.1. Introduction

It is very important to standardize the package of palliative care services provided at the community/household level by the FMoH. This standardization process is always undertaken after identifying the needs and gaps at each level as well as building the project execution capacity. It is imperative to establish standards for palliative care services and quality assurance monitoring for palliative care services. Establishing a system to refer patients who access clinical and non-clinical palliative care services is also critically important, so that higher level coordinators will recognize the need versus availability of services. In order to meet identified needs, it is essential to assess, train, assign and supervise responsible contact persons at each level i.e., Federal MoH, NIPs, CSOs, community care and support volunteer providers, UHEWs, and FBO. The next few sections of this manual will outline ways to standardize clinical and non-clinical palliative care services at the community/household level.

4.2. Human Resource Capacity Building

The limitations of human resource capacity at all levels (program, facility, and community) in Ethiopia create a serious bottle-neck for the scale-up of palliative care services as well as other HIV/AIDS interventions. In order to remedy this situation, a large number of health facility and community level personnel have to be trained and re-trained in the short and mid-term training programs. Human resource capacity can also be strengthened through refresher and on-the-job training of UHEWs, community care and support volunteer providers, and all other personnel who provide and support palliative care services and programs.

The SCRHA project leverages minimal existing resources without placing an undue burden on the health care system. For example, when a client visits a doctor for HIV services, it is an opportunity to address his or her care and support needs. Conversely, people who are getting PC services should also learn about HIV and

how to protect themselves and their partners. NIPs and CSOs will train health care workers (some of whom are volunteer community care and support providers), "generalists" (nurses and/or social workers based in the CSOs), staff seconded to CSOs (who serve as regional coordinators), and UHEWs in "support" and clinical areas so they are able to provide effective palliative care services to people affected by HIV/AIDS.

Training for providers in palliative care services should focus on the core competency areas prepared for UHEWs, community care and support volunteer providers, and supervisors (generalists). These competencies are addressed through the following activities:

- Review, update, and introduce clinical and non-clinical PC training curricula and develop a training plan;
- Assess needs, establish a database of technical and human resources, in all the implementation sites and identify the organizations' capacity to address gaps;
- Organize training of trainers (ToT) at various levels through institutions/key stakeholders that can help to sustain palliative care and HIV/AIDS trainings, if need be; and
- Plan for in-service/on-the-job or offsite training for service supervisors (generalists), community care and support volunteer providers, HEWs and jointly with all concerned stakeholders.

In addition to these, awareness raising, program/project management skill enhancement, systems strengthening (e.g. community referrals and linkages), health education, community involvement enhancement, and other community capacity building programs will be delivered to target households and SCRHA project palliative care beneficiary communities. Community level capacity enhancement activities will help to ensure the sustainability of and beneficiaries' feelings of ownership about palliative care services.

4.2.1. Core Competencies Required for Community Care and Support Volunteer Providers

In order to effectively provide PC services, community care and support volunteers need to have the following knowledge and skills:

- Explain basic facts about HIV/AIDS including modes of transmission, the importance of ART treatment, and their own roles and responsibilities in responding to the HIV epidemic;
- Explain how to assess the needs of individuals infected by HIV, their families and primary caregivers;
- Collect information pertinent to the services;
- Identify major PC needs of the selected households;
- Provide quality psychosocial and spiritual support for people living with HIV/AIDS;
- Explain how to provide care and support for OVC;
- Identify or map the existing referrals such as social and financial services that contribute to the palliative care service in the area;
- Refer people living with HIV, children affected by HIV, or others in need of advanced level services (e.g., orphans and other vulnerable children) to services that can assist them (e.g. economic strengthening);
- Provide end-of-life care and bereavement issues;
- Provide regular follow up and monitoring for all community palliative care services provided to PLHIV and their families;
- Network with local GOs, NGOs, CBOs, FBOs, and private partner offices; and
- Write and submit quality activity reports with strict deadlines.

4.2.2. Core Competences Required for UHEWs for Clinical PC Services

In order to provide effective clinical PC services, urban health extension workers need to have the following knowledge and skills:

- Describe what palliative care is;

- Describe the UHEW role in providing palliative care for PLHIV and their loved ones;
- Help patients to manage their symptoms and pain;
- Support the enhancement of PLHIV health through education about good nutrition and healthy eating habits;
- Manage client bereavement issues and discuss ways to provide end of life care;
- Provide regular follow up and monitoring on every clinical community palliative care service provided to PLHIV and their families;
- Network with local GOs, NGOs, CBOs, FBOs, and private partner offices; and
- Write and submit quality activity reports adhering to set deadlines.

Palliative care service providers, especially community care and support volunteers, will receive basic and refresher training on community palliative care through CSOs, NIPs and the SCRHA project team to develop these core competencies.

4.2.3. Standardizing Palliative Care Service Provider Training

The SCRHA project team in, partnership with the Federal MoH, IIPS, NIPs and CSOs, will standardize the UHEWs' and community volunteer providers' basic and refresher training programs on clinical and non-clinical PC components. The overall objective of the training is to strengthen the human capacity of SCRHA project partners for PC implementation. After taking the five-day training, the trainees are expected to be able to effectively provide care for HIV-positive clients and integrate these services at the household level in collaboration with the local administration, nearby health facilities and CBOs working on HIV/AIDS prevention, treatment and care.

For the non-clinical PC components, the following topics include, but are not limited to:

- Overview of non-health components in palliative care (PC);
- Basic facts about HIV and AIDS;

- Assessing needs of PLHIV and their families;
- Communication skills;
- Psychological, social and spiritual support;
- Psychosocial care and support to OVC and other vulnerable populations;
- End of life care; and
- Roles of community PC service providers.

For the clinical PC components the following topics include, but are not limited to:

- Overview of palliative care;
- Management of HIV and AIDS related conditions;
- Pain and symptom management;
- Nutrition and HIV;
- Sexual and reproductive health for HIV clients; and
- End of life care and bereavement support.

4.2.4. Establishing Coordination, Collaboration and Referral Systems among Partners

Coordination, collaboration, and networking and referral systems are highly interrelated and interlinked concepts described in this operations manual; this section of the manual will provide further explanation of these concepts.

Implementation of this operations manual calls for the active participation, involvement and collaboration of a wide range of actors including government bodies, NGOs (local and/or international) represented as NIPS and IIPs in the SCRHA project, donor agencies (e.g. USAID), CSOs, FBOs, and the community at large, including include PLHIV. Creation of effective partnership, coordination, and networking mechanisms for all sub-program areas for HIV care in general and community/home-based palliative care more specifically helps to prevent duplication of efforts and wastage of resources, enhance and promote exchange of best practices, and promote synergy among the main actors.

A strong referral system is essential to the success of a palliative care program. Referral forms and focal persons as well as a feedback system, resource directory, and referral network are necessary to ensure that palliative care is provided through a continuum of care with formal links to essential supportive services. In order to develop a strong referral system, partners should:

- Ensure that NIPs and CSOs develop a referral network committee to promote stronger referral relationships;
- Implement the-three-ones principle. The three ones include: one agreed upon AIDS action framework, one national coordinating committee, and one agreed upon country-level monitoring and evaluation system. HAPCO/MoH will coordinate the palliative care and HIV and AIDS related activities of multi-sectoral actors at all levels. The Multi-Sectoral Plan of Action for Universal Access to HIV Prevention, Treatment, Care and Support in Ethiopia 2007–2010 assigns the leading institutional role of coordination and networking to HAPCO and the partnership forums. The MoH will play a leading role in coordinating partners to implement the palliative care services. Working together closely to strengthen partnership and coordination mechanisms with HAPCO/MoH structures and other key stakeholders at each level is the best way for the SCRHA project to succeed in palliative care service delivery;
- Create a forum to facilitate coordination and networking among partner organizations involved in palliative care services and programs;
- Support the strengthening of HAPCO's and MoH's capacity (program, facility/health care workers and community/HEWs levels) to be able to coordinate and guide partner implementation and reporting of palliative care activities according to their core mandates;
- Disseminate the implementation guidelines at all levels;
- Prepare a database of organizations working on palliative care and HIV and AIDS (e.g. activities, locations, duration of programs); and

- Strengthen the technical working group on palliative care and HIV/AIDS at all levels, by including the MoH/HAPCO, facilities, CSO, FBO and other key partner organizations and communities working on palliative care. This will also help HAPCO/MoH to coordinate the activities of implementers and donors and encourage joint planning.

The term "linkages" refers to relationships between organizations; within the context of palliative care, these linkages are essential among health facilities as well as between health facilities and their communities. The SCRHA project will strengthen and expand all of these linkages while integrating PC service delivery. The family-centered approach of the SCRHA project provides an opportunity to integrate services easily within the household by using health extension workers for clinical services and other community providers for support service. The project will ensure effective referral to health facilities as well as advanced follow-up and treatment.

Palliative care providers should promote the development of linkages to essential services within health facilities, between health facilities and other health system levels, and among psychosocial, nutritional, welfare, legal, and spiritual support services. If needed, the provider may accompany the patient to the service or identify a volunteer to assist the patient in obtaining the needed service. Core palliative care services (out/inpatient care, primary care, and CHBC) need to be linked into one system of care to ensure that clients can easily access needed care.

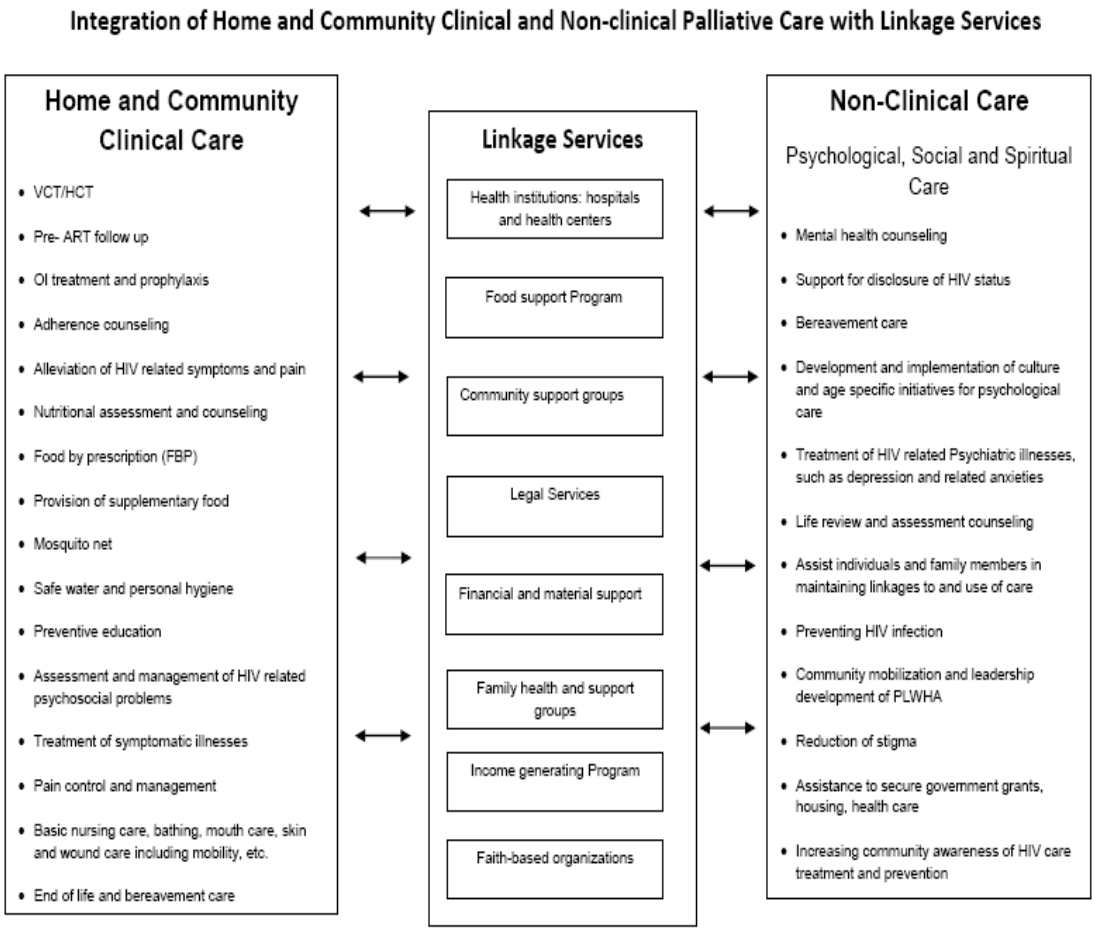
Table 3: Illustrative Palliative Care Services Referral Linkages

What Services or Needs to be Addressed?	Category of Services	Refer to Whom?
Mental health, spiritual counseling,	Counseling and Treatment	• Tertiary general and specialty hospitals • Faith-based institutions and organizations • Support groups
Legal support services, e.g.: • **child rights protection** • **abuse and child labor** • **land and property grabbing (esp. OVC)** • **stigma and discrimination** • **mainstreaming, etc.**	Legal protection and rights issues	• Government sector • Child care and protection agencies • Community elders
Economic assistance, e.g.: • **income generation activities, including seed money** • **schooling support, shelter, gardening support, etc**	Economic Strengthening	Financial institutions, e.g.: • Micro-finance institutions (MFIs) • Tax offices • Community contribution, grant giving organizations
Nutritional services, e.g.: • **gardening support** • **available food support**	Food security	• Grants • World Food Program (WFP) • Network of Ethiopian HIV Positives (NEP+) • EIFDDA • Governmental organizations

Through all referrals, special consideration must be given to maintain client confidentiality and autonomy. Palliative care services must be provided only with the explicit approval of the patient and his or her family. At a minimum, referral relationships should also be made with health institutions such as health posts; health centers; tertiary, general and specialty hospitals; micro-finance institutions (MFIs); the World Food Program (WFP), the Network of Ethiopian HIV Positives (NEP+), Ethiopian Interfaith Forum for Development Dialogue and Action

(EIFDDA), Justice and Police Offices, community structures, and others. Sample linkages are shown in Table 3 above.

Figure III: Community Palliative Care Services Integration at the Household Level



Source: SCRHA PMP, December 2009

Chapter Five: Major Roles and Responsibilities of SCRHA Palliative Care Services Implementing Partners

5.1. General View

Major PC services implementing partners include NIPs, CSOs, and PC service providers such as UHEWs and volunteer care and support providers. Since the role and responsibilities of partners in SCRHA project implementation keeps the same pattern to PC and ES, this manual follows similar pattern as that of the SCRHA ES Operations Guide, January 2010. As indicated in the ES Operations Guide, the technical assistance will be provided by SCRHA project team directly to NIPs and through NIPs to CSOs. In some cases, assistance can be provided directly to CSOs. The NIPS and CSOs will also work closely with government structures from the federal to the kebele levels.

5.2. Roles and Responsibilities of Government Bodies at Different Levels

Applying the community/home based palliative care operations manual will require a concerted effort by all stakeholders at the federal, regional and local levels. Specific roles and responsibilities for each level will include:

a. Federal Level

- Provide guidance and leadership;
- Create conducive environment for actors to work effectively (including the areas of policy and strategy development);
- Ensure necessary resource mobilization and allocation;
- Develop an overall program strategy for planning, resource mobilization and allocation, implementation, and monitoring and evaluation;
- Strengthen the legal framework and enforcement mechanisms for PC client support;
- Create partnership networks and coordinate key partners and stakeholders;
- Develop and standardize guidelines and curricula for PC services;
- Protect the rights of beneficiaries through existing protection mechanisms;

- Ensure the provision of quality services to PLHIV and their families through effective application of the PC operations manual; and
- Monitor and evaluate overall service delivery.

b. Regional Level

- Provide guidance and leadership;
- Adapt relevant policies and strategies in relation to the regional context;
- Ensure resource mobilization and allocation;
- Create enabling work atmosphere for all stakeholders;
- Utilize the PC operations manual as a planning and monitoring tool;
- Coordinate mobilization of local resources to support PC activities;
- Ensure that the operations manual suggested structures and activities are in place to promote quality PC services;
- Coordinate capacity building programs for implementing partners;
- Build partnerships with all actors and coordinate PC services at the regional level;
- Ensure that the SCRHA project provides quality PC services and produces the expected outcomes;
- Actively monitor and evaluate program implementation and service delivery; and
- Document and disseminate promising practices and lessons learned.

c. Woreda Level

- Build partnerships, coordinate and follow-up implementation of PC services;
- Create enabling environment for implementing partners specially NIPs and CSOs;
- Coordinate mobilization of local community and resources to support PC activities;

- Ensure that PC operations manual is practical and user friendly for all implementing partners to ensure quality service delivery;
- Coordinate provision of capacity building programs to implementing partners;
- Build partnerships with all actors and coordinate care and support programs;
- Actively monitor and evaluate PC service implementation and delivery; and
- Document and disseminate promising practices and lessons learned.

d. Kebele Level

- Identify partners and support the application of the PC operations manual;
- Lead the identification of care and support including PC beneficiaries and organize a database which includes geographic coverage;
- Identify households in need of PC services in collaboration with key actors, mobilize community resources and coordinate the responses of various players;
- Promote and protect the human and legal rights of PLHIV which includes efforts to reduce stigma and discrimination;
- Facilitate access to palliative care services;
- Facilitate the integration of PC services with all other Kebele level services; and
- Participate in program planning, implementation, monitoring and evaluation and reporting on PC activities.

5.3. Roles and Responsibilities of SCRHA Internal Stakeholders

CSOs coordinate and collaborate with NIP organizations engaged in similar interventions and can be leveraged to the mutual benefit of SCRHA project objectives. Table 4, below, presents the roles of the various actors involved in the SCRHA project, specifically for palliative care services.

Table 4: Roles of SCRHA Palliative Care Internal Stakeholders

SCRHA Project Team	• Provide operations guidance • Provide technical assistance and training to NIPs and CSOs • Provide grants to NIPs and selected CSOs • Conduct regular monitoring of NIPs and CSOs • Facilitate coordination among NIPs and federal and regional agencies • Consolidate quarterly, bi-annual, and annual reporting
NIPs	• Provide training for CVPs and UHEWs on care and support services • Provide supportive supervision services • Provide technical and financial support through CSOs • Engage in and develop partnership, coordination and networking mechanisms • Identify PC service linkages to clinical and non-clinical services, facilities, community structures, and other non-PC services
CSOs	• Coordinate with kebele palliative care committees • Assist with beneficiary selection • Identify and mobilize community volunteer providers and UHEWs • Identify and pursue cost sharing opportunities • Ensure the provision of training /consultation to beneficiaries • Create linkages with local level health facilities and other relevant agencies • Organize consultative workshops and various discussion forums • Participate in experience sharing among CSOs, partners and individuals • Participate and conduct site visits to PC delivery sites • Compile regular monthly, quarterly, bi-annual and annual activity reports
Community Care and Support Volunteers	• Deliver non-clinical care and support services • Collect raw data on PC service delivery • Identify non-clinical PC needs • Prepare and submit weekly accomplishment reports to supervisors • Support special populations (OVC, pregnant women, who may need special assistance, etc) • Refer clients for further care and support services to UHEWs, the nearby health facilities, FBOs or other similar charity organizations • Mobilize and sensitize the community for care and support services
UHEWs	• Offer clinical PC services for PLHIV • Refer clients for further care and treatment to nearby health facilities, FBOs or other similar charity organizations • Identify clinical PC needs • Prepare and submit weekly accomplishment reports to supervisors • Collect and keep records of non-clinical service delivery raw data

Households/ Beneficiaries	• Commit to proposed activities • Participate in training and cascade the results • Manage the resources wisely • Report results

5.4. Community and Household Level PC Service Providers

UHEWs and community care and support volunteers have counterparts in government and CSOs that are responsible for clinical and non-clinical palliative care service delivery respectively. Those community care and support volunteers who are selected, trained and supervised by CSOs report to CSOs, while UHEWs are selected, trained and supervised by respective regional health bureaus in view of integrating their service provision with other governmental and non-governmental organizations.

5.4.1. Community Care and Support Volunteer Providers

Community care and support volunteer providers are those who voluntarily serve the community after being trained in key palliative care services and selected by community representatives in collaboration with civil society organizations (CSO). The training provided to them is easily applicable, emphasizes practical issues, and focuses on effecting behavioral change. Community volunteers are expected to:

- Demonstrate knowledge and skills, starting with their own families;
- Disseminate health messages in their day to day activities such as during a coffee ceremony, a visit to a mother in labor or a sick child, or an *idir* meeting. They can also share these messages when fetching water, at marketplaces, or at other similar events and home visits;
- Deliver non-clinical (support) PC services which includes the follow tasks:
    - Sensitize and mobilize the community towards extensive palliative care services;
    - Conduct referral for advanced clinical services, counseling, economic strengthening, and other types of support;
    - Provide social, psychological, hygiene and sanitation, bereavement care and other palliative care services;

- Conduct regular home visits for palliative care services as frequently as the service standards require;
- Identify clients' needs and help them to develop community-based palliative care plans;
- Identify and map existing resources and link clients in need to caregivers and community support groups for effective use of the resources;
- Participate actively in combating stigma and discrimination;
- Provide social, educational and psychological support to OVCs;
- Record and report on PC service activities regularly.

5.4.1.1. Selection Process for Community Care and Support Volunteer Providers

In the selection process for community care and support volunteer providers, the involvement of government line offices is mandatory. To this end, the selection of community care and support volunteers shall be done by a committee comprised of members of the HIV/AIDS committee of the kebeles, CSO staff and NIPs representatives. The overall community care and support volunteers' selection process shall be coordinated by NIPs and CSOs.

In order to ensure fair participation by all interested community members, the announcement should be posted on visible areas of the town and shall be written in the local language. The notice shall include the tasks expected from the volunteer providers with the requirements listed below that. The selection process shall adhere to the selection criteria and the selection committee shall post the results of all selected community providers in visible areas of the town. The selection committee will reconsider its selection process if concrete or tangible evidence is available for changing the result. The committee may cancel or replace the selected community/home-based palliative care service provider if the committee believes it would no longer fulfill the selection criteria (for selection criteria, see Annex II).

5.4.1.2. Community Care and Support Volunteer Providers' Working Modalities

The program anticipates that the SCRHA project community care and support volunteers can actively be engaged for two years to reduce worker stress levels and burnout rates and prevent dependency on the project. The recruitment and capacity building of extra care and support volunteers care providers will also create additional trained and experienced human resource capacity for the community overall. After two years of service, new community care and support volunteer care providers will be recruited and trained by the respective CSO and/or NIP. When volunteers terminate their service, a farewell ceremony will be organized and they will receive a recognition certificate for their successful completion (see Annexes I and II for details).

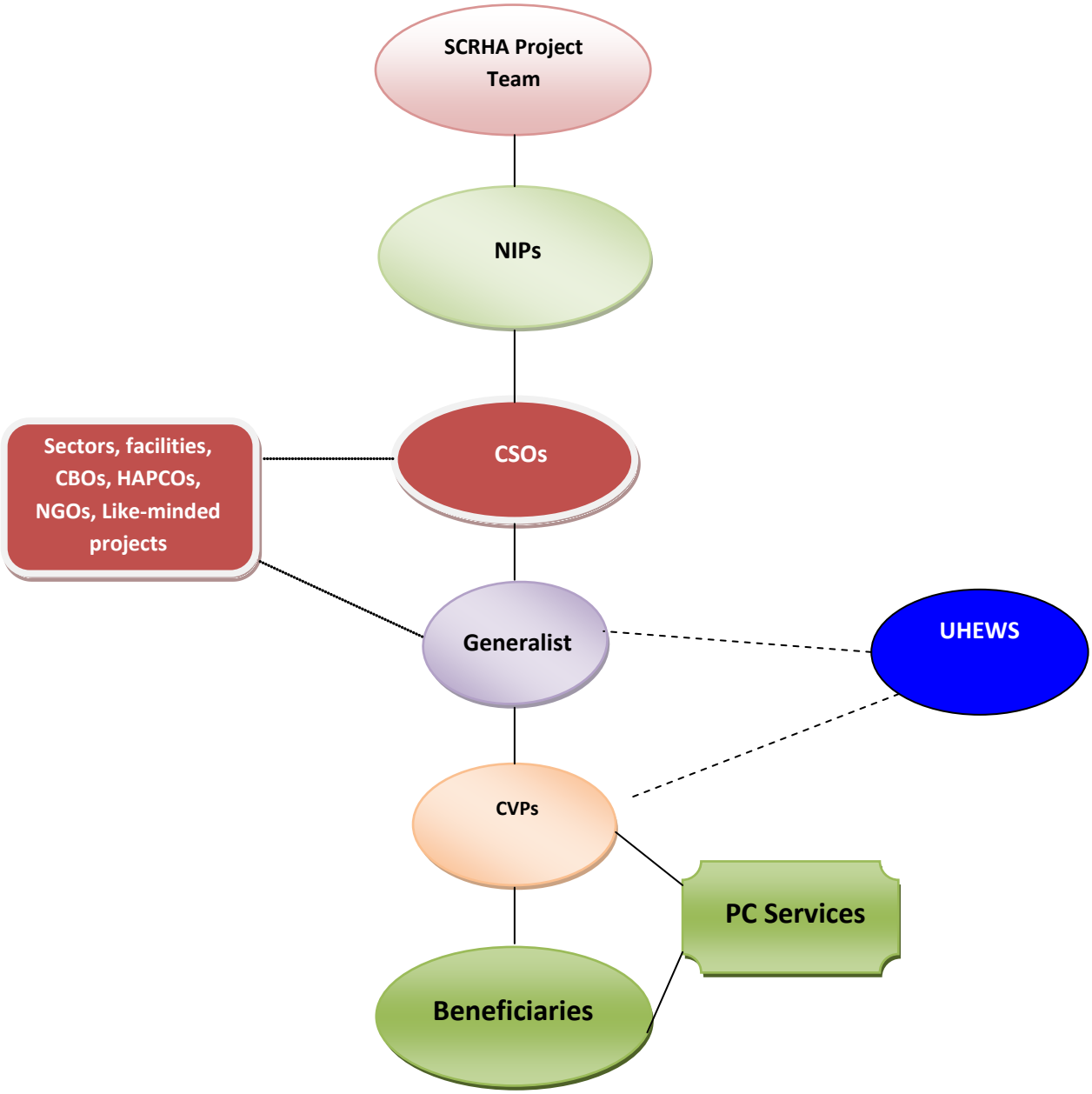
5.4.2. Urban Health Extension Workers

The government of Ethiopia has designed the health extension program as part of the basic health service; it is prepared as a package whereby families and communities are central to the program. The program focuses on developing knowledge and skills as well as building the stakeholder capacity for the improvement of community health. Thus, it serves as a health service bridge that will enable the community to make informed decisions about and take actions on issues related to its health. The program is implemented by trained extension workers as defined by the Ministry of Health.

One strategy that UHEWS use is referred to as the family package; in this case female and male heads of households are selected from each kebele to work as community health promoters. They are trained by health extension workers, receive support from them, and are supervised around how to make home visits to ensure the proper implementation of the health package. These selected heads of household become models for other community members in regard to preventing diseases and implementing healthy actions. Thus, the family package strategy serves to enhance health outcomes.

Another strategy used by UHEWs is referred to as the community package. This package is meant to be used by CBOs such as *Idir*, *Ekub*, FBOs, and government institutions such as schools and civic organization focusing on women, youth, and farmers' associations existing in a *kebele*. The aim of this package is to improve a community's awareness in terms of protecting their health and enabling them to lead health services as owners. This same strategy uses outreach health services for the same purpose.

Figure IV: Structure of Palliative Care Services by Implementation and Reporting Roles



Source: Adapted from SCRHA ES Operational Guide, January 2010

Chapter Six: Monitoring and Evaluation for SCRHA Palliative Care Services

6.1. Introduction

This section covers basic concepts of monitoring and evaluation (M&E), supportive supervision, implementation strategy, coordination of service, categorization or classification of supportive supervision indicators, allocation of resources and management support needed for strengthening supervision capacity at all levels, description and definition of indicators, guidance around frequency of data collection, responsible body for data collection and reporting mechanism, documentation, methods of measurement, and PC service quality assurance.

6.2. Community Palliative Care Monitoring and Evaluation Framework

Strengthening palliative care services' management, coordination, networking and monitoring and evaluation programs is essential to the successful implementation of the SCRHA project. Moreover, quality assurance and quality control are integral parts of effective community-based palliative care service delivery.

The SCRHA project is committed to measuring its progress through monitoring and evaluation as well as transferring M&E skills to NIPs and CSOs. The SCRHA team will support and collaborate with other United States Government (USG) and Government of Ethiopia (GoE) partners to strengthen the community-level monitoring and evaluation system. Strengthening approaches include training as well as the development of simple and effective tools and protocols, including routine planning and monitoring forms, registers, templates, data quality assurance, quality of service and 'most significant change' methodology. This will strengthen the quality of service and data at different levels and align both the community-based HIV/AIDS programs in general, as well as palliative care services in particular, which are run by different partners at different levels.

Effective implementation of the project in general and PC services in particular will be monitored weekly, monthly and quarterly through standardized reporting

mechanisms; quarterly through joint review meetings with all key stakeholders at the woreda level; and annually through joint review and an effectiveness assessment at the federal level. Depending on the prevailing conditions, bi-annual review meetings under the supervision of SCRHA team will be held at the regional level. The main activities of the project and good practices will also be documented both in print and through electronic media for project monitoring and future reference. The annual performance review and financial audit will be conducted by independent audit firms.

In order to strengthen PC services' data recording and processing mechanisms, a woreda-based data management system will be established in collaboration with relevant partners. The necessary training in data recording and management will be provided to care providers at all levels. Important data collection, compilation, and analysis tools will be designed for effective implementation of data recording and processing. The data management system will be computerized at all levels to facilitate consolidation and use for all other related programs run by different actors at different levels. This, in turn, will encourage national level actors to incorporate the outputs for national level reporting.

As can be seen in the framework Figure VI above (at the end of Chapter 5), the broken arrows are meant to indicate that there will be feedback mechanisms at all levels to strengthen the reporting system and to improve the data/report quality. As a strategy, supportive supervision and mentorship and review meetings will be utilized to gage the level of PC service implementation. The regular supportive supervision and mentorship will be conducted by the SCRHA team, the NIPs and the CSOs. The review meetings will be organized bi-annually or quarterly at the regional level in close consultation with the respective concerned government offices and NIPs/CSOs. As part of the data quality assurance mechanism, CSOs/NIPs will use the data quality assurance tool and onsite training/mentorship.

6.3. *Objectives of Palliative Care Service Monitoring and Evaluation*

In general, PC monitoring and evaluation is intended to improve the design and performance of an ongoing PC services. A formative evaluation provides an overall assessment about the effectiveness of completed PC services, often to ensure accountability, while a summative evaluation is conducted in order to generate knowledge about good practices registered during the course of PC service delivery. SCRHA community palliative care services' monitoring and evaluation program specifically helps to:

- Improve the performance of community care and support volunteers and UHEWs as well as community level CSOs operating in seven target regions and one city administration and enhance services effectiveness;
- Improve day-to-day decision-making processes in planning, implementation and monitoring and evaluation of PCs at the household level;
- Assess and enhance positive impacts of PC services on the target HIV affected households;
- Give early warning of the problematic activities and processes that require corrective actions through the use of effective supportive supervision tools;
- Empower PC providers, CSOs and NIPs at all levels by creating opportunities to critically reflect on performance and subsequently make decisions on efficient strategies and future directions;
- Demonstrate and strengthen accountability among all concerned SCRHA project key stakeholders; and
- Ensure quality service delivery to beneficiary households.

6.4. *Elements of Monitoring and Evaluation in Community Palliative Care Service Implementation*

A community palliative care service monitoring and evaluation framework can include the following major elements (each of which will be further discussed below):

- Data management (data collection, recording, aggregation)
- Analysis, verification, reporting, and feedback
- Site visit
- Review meetings
- Routine data quality assessment
- Service quality assessment
- Periodic evaluations

6.4.1. Data Management Strategies

The development or existence of an effective data management strategy enhances both evidence-based decision making and service implementation in a palliative care program. In PC service provision, data management includes both primary and secondary data collection, data recording and labeled aggregation by service providers, CSO experts, nearby health facilities, community HIV/AIDS committee members, generalists, CSOs, NIPs, and SCRHA project team members. However, PC services data management mainly focuses on primary data captured from service delivery spots which include households, referral sites such as health posts, economic strengthening service delivery systems, registry books, etc. where the HIV affected families receive the services directly.

Recording of these data can be done either:

1) at the household level by assigning data sheets to individual households;

2) at the service provider level, by using registry books and beneficiary visit cards;

3) at the generalist office level, using the data aggregation format collected from service providers, nearby health facilities, community PCs committee minutes, field supportive supervision checklists and personal observation records;

4) at the community PC service committee level using monthly progress assessment meeting minutes;

5) at the CSO and NIP level using supervision checklists, M&E checklists, monthly/quarterly/bi-annual/annual review meetings' minutes, appropriate computerized data capturing system and data book; or

6) at the SCRHA project coordination office (team) level, using checklists depicted above and specifically designed appropriate computerized data capturing systems.

Data aggregation can also be done at different levels using different mechanisms (computerized database for example SPSS, Epi Info, etc), systems and tools but closely related to data capturing levels which mainly follow the reporting structure depicted in Figure IV above. That is:

- The lowest data aggregation for PC services can be done weekly by household service providers obtained from individual beneficiary data cards and registry books mainly separate for PC and ES.
- The second level can be done monthly at a target town or generalist level using the data aggregation format applicable for both PC and ES services collected from service providers, nearby health facilities, community PC service committee minutes, supportive supervision checklists and personal observation records.
- The third level of data aggregation will occur through generalists in different ways such as supportive supervision checklists filled out at different times; monthly review meeting minutes especially for qualitative data collection like challenges, best practices, lessons learned, future threats in pursuing similar activities; reports from specified key stakeholders; and observation checklists.
- The fourth level quarterly, bi-annual and annual data aggregation comes from respective NIPs captured from CSOs, supportive supervision checklists filled out at different times, updates of computerized data capture (e.g. MS-Access conjugated to Crystal Reporting), and filled in field level observation checklists and best practice documentations.
- The annual, mid-term and project completion data aggregation can also be done at the SCRHA project coordination office or team level. This data is

based on updates of computerized data, NIPs periodic reports, periodically aggregated supportive supervision checklists, field observation checklists, different assessment and evaluation reports done for different purposes (annual PC services effectiveness assessment, mid-term evaluation, PC service impact assessment, etc), and collectively done minutes of review meetings at different times under the reporting period.

6.4.2. Analysis, Verification, Reporting, and Feedback Strategies

Monitoring and evaluation data analysis is a practice through which raw data are ordered and organized so that useful information can be extracted. The process of organizing and thinking about data is key to understanding what is contained in the data. There are a variety of ways in which people can approach data analysis, and it is notoriously easy to manipulate data during the analysis phase to push certain conclusions or agendas. For this reason, it is important to pay attention when data analysis is presented, and to think critically about the data and the conclusions drawn about the palliative care service delivery process.

Raw data can take a variety of forms, including measurements, survey responses, and observations. In its raw form, this information can be incredibly useful, but also overwhelming. Over the course of the data analysis process, the raw data is ordered in a way which will increase its usefulness. For example, survey results may be tallied, so that people can see at a glance how many people benefited from the palliative care services, and how people accessed palliative care services.

Charts, graphs, and textual write-ups of data are all forms of data analysis. These methods are designed to refine and distill the data so that readers can glean interesting information without needing to sort through all of the data on their own. Summarizing data and presenting data in a clear and understandable way are often critical to supporting arguments made with that data. The raw data may also be included in the form of an appendix so that people can look up specifics for themselves. Thus, data verification, analysis, and feedback collection mechanisms can also be done by different actors such as PC service providers, generalists, CSOs,

NIPs and SCRHA project staff members by using standard indicators, reporting formats and computerized systems.

6.4.3. Site Visit Strategies

The term "site visit" refers to an event in which an external evaluation team goes to an institution to evaluate verbal, written, and visual evidence. Site visits often last several days and are a key element of the quality evaluation process. Usually they involve a peer team of reviewers who go to the households where PC services are delivered. They observe and review the process as part of the assessment, audit, accreditation, or other external quality monitoring process. Thus, the purposes of site visits include: observing CSOs, households, and/or health facilities; interacting with staff members, generalists/\, and/or clients and their families; accessing documentation; scrutinizing tangible evidence of service achievements; and checking the veracity of self-assessment statements.

Site visits are done by generalists PC service committee members, CSO representatives, NIP representatives, and SCRHA project team members using standard field visit and field level observation checklists. Monthly, weekly and quarterly visits are done separately (as indicated in the roles and responsibilities section of this document), in part by generalists and in part by CSOs, in order to give technical support and receive confirmation on periodic reports. The majority of quarterly, biannual and annual site visits can be done jointly, in specified and selected sites by a group of key stakeholders. The focus of these visits are based on findings from CSO reports ; their purpose is mainly to check on a facility's best practices as well as below average services with the aim of informing future planning and alternative arrangements.

6.4.4. Review Meetings Strategies

In the SCRHA project context, PC service review meetings are usually done jointly. One type of review meeting can be done at targeted kebeles, towns, woredas, and/or regional and national levels on a weekly, monthly, bi-annual or annual basis. Mid-term and project completion final review meetings are also schedule as appropriate.

Weekly joint review meetings organized by generalists are conducted among community PC committee members, generalists, kebele representatives, care providers, beneficiary representatives, and CSO representatives from the targeted town. Monthly joint review meetings organized by CSOs must be held among NIP representatives, CSOs representatives, generalists, target town representatives, health facility representatives, ES coordinators, service referral recipient representatives (e.g. orphans' support NGOs), and the SCRHA project team representative. Quarterly and bi-annual review meetings constitute a similar mix of participants with a few additional participants at bi-annual meetings.

These review meetings are to be carried out at the regional level, organized by selected NIP representatives among the SCRHA project team, as well as representatives from other NIPs, , CSOs, regional and woreda level CPC service committee, Bureau of Health (BoH), Regional HAPCO, and other like-minded GOs, NGOs, CBOs and FBOs. In similar arrangements, annual review meetings organized by the SCRHA project team are to be held among wider stakeholder representatives, including policy makers and national coordinators and actors.

6.4.5. Assessment and Periodic Evaluation Strategies

These are similar but hierarchically differentiated actions, which require various levels of evaluation processes. Generalists and or PC specialists will routinely conduct the weekly data quality assessment at the service recipient's, household's or service provider's level. The service quality assessment can be done at different times using field visit checklists as well as the structured survey questionnaire , incorporating PC service delivery standards for people affected by HIV/AIDS. This may require a longer time and wider coverage in order to make a comparative analysis for checking accomplishments against the standards.

Reviewers will also conduct periodic evaluations to check the same information. In the context of PC service, periodic evaluations will involve checking the: competence of service providers, adequacy and quality of the services, applicability of data capturing and reporting mechanisms, effectiveness of the devised system, and more.

The recommendations and feedback obtained from all three of these levels of assessment will support and enhance the improvement of community palliative care service implementation.

6.5. Palliative Care Service Monitoring and Evaluation Indicators

The SCRHA PC service monitoring and evaluation indicators are based on the monitoring and evaluation framework, guidelines, and system tools developed or adopted for the national HIV and AIDS program. The SCRHA project Performance Monitoring Plan (PMP) addresses overall community-level monitoring and evaluation needs relative to HIV/AIDS as implemented by CSOs and PC service providers. The project's participatory monitoring and evaluation plan will be prepared in collaboration with all key stakeholders and the necessary training will be provided to these key stakeholder representatives in the operational areas. The main types of indicators include:

- **Input indicators:** measure all investments and recurrent costs of resources (e.g. human, financial, facility, equipment, supplies) needed to enable the community palliative care services or actions to be delivered/taken among targeted areas of operations. These include measures for trained service providers, supervisors, registry books, manuals, checklists, reporting formats, first aid kits, health facilities, vehicles, office equipment and furniture, etc. which are applicable for PC service implementation.
- **Process indicators**: attempt to set standards for the quality of PC activities to be carried out, such as measures of appropriate training delivery, adequate supervision, reporting, data management, preparation, printing, dissemination and use of print materials (manuals, guidelines, registers, M&E and supportive supervision checklists, etc), and many others applicable to PC service delivery.
- **Output/process indicators**: measure results of inputs incorporated in the process that are expected in the short-term at a level in which the SCRHA project supported palliative care service is functioning. It measures the adequacy of operations (services delivered) in terms of quality, equity,

utilization, access, cost-effectiveness, efficiency, and continuity (e.g. number of services delivered, medicines provided, IEC messages delivered). It also measures how well PC services are functioning in terms of given objectives (performance). Examples of output/process indicators include: number of volunteers trained, number of people/households affected by HIV and AIDS who received palliative care services, number of PC registers distributed and utilized in a targeted kebele, and number of referrals administered by specific recipient stakeholder in a specified kebele or town. Additional indicators are shown in Table 5 below.

- **Outcome indicators:** measure the main changes brought about in individual households or targeted communities due to the delivery of PC services that are expected in the long-term. Examples of these indicators include improved knowledge, attitudinal or behavioral changes, changes in way of living, change in a beneficiary's income level, effect of prolongation of target PLHIV's family life, percentage increase in referral recipient's institutions, and organization service delivery system improvements.
- **Impact indicators:** measure the long-term effects of the SCRHA project individually as well as jointly with other similar organizations and the national program that have brought about observable changes to the target community. Examples of impact indicators include reduction of HIV prevalence rate, rate of income change per capita due to effective implementation of SCRHA project, ES intervention, etc. These kinds of changes can only be measured after the mid-term evaluation or, even more likely, after the entire project has been completed. In the case of the SCRHA project, this could take as long as three to five years with cross-reference to baseline data.

Table 5: Output Indicators

- **Number of HIV positive individuals reached with basic palliative care services during the reporting period**
- **Number of HIV positive individuals reached with palliative care services during the reporting period**
- **Number of palliative care mentors deployed to CSOs during the reporting period**
- **Number of CSOs provided support to offer palliative care services during the reporting period**
- **Number of laypersons/community care and support volunteer providers trained in community/home based palliative care during the reporting period**
- **Number of laypersons active in providing palliative care (basic or advanced) at the end of the reporting period**
- **Number and percentage of people known to have HIV and AIDS in target intervention areas referred economic strengthening**
- **Number and percentage of people known to have HIV/AIDS in target intervention areas referred for advanced professional counseling and/or spiritual counseling**
- **Number and percentage of known HIV positive pregnant women who receive community-based care and support through to the post-partum period, including accompanying them for drug prophylaxis for themselves and their newborn infants**
- **Number of HIV and AIDS-related orphans and vulnerable children (OVC) who benefit from one or two of the services in the basic OVC package of services**
- **Number of HIV and AIDS-related orphans and vulnerable children (OVC) who benefit from three or more of the services in the basic OVC package of services**

6.6. PC Quality Assurance and Quality Control: Conceptual Framework and Application

6.6.1. Quality Assurance

Quality Assurance (*QA*) refers to a process for the systematic monitoring and evaluation of a specific project, service, or facility to ensure that standards of quality are being met (see Annex I). Note that quality standards are defined by the SCRHA project sponsor, USAID. Having quality assurance processes in place cannot absolutely guarantee the delivery of near perfect PC services, but it can increase the likelihood of success of these efforts. Although quality standards may be defined by the project sponsor, the real test of quality is determined by the intended users, clients or PLHIV and their families. The term 'quality' is not synonymous with the terms 'expensive' or 'high quality'; even cultural medicine practices with low prices can be considered 'quality' if they meet the needs of the client.

QA is more than just testing the quality of aspects of a project, service or facility; rather, the process involves analyzing the quality of services to make sure that they conform to specific requirements and comply with established plans. There are two key principles that characterize effective QA. First, it must be "fit for purpose, meaning that the PC services delivered to households should be suitable for the intended purpose. Second, services should be "right the first time," meaning that to the extent possible, mistakes should be minimized. QA tasks include regulation of the quality of resources used for PC service delivery, coordination of partners, delivery of clinical and/or non-clinical services, as well as other components.

6.6.2. Steps Involved in the Quality Assurance Process

There are various steps involved in the quality assurance process, which include:

- Test previous reports
- Plan to improve
- Design to include improvements and requirements
- Deliver the service with improvements
- Review new item and improvements
- Test new service item

The quality assurance process is very rigorous and requires a lot of testing and planning. The SCRHA team or else the NIPs and CSOs with which they collaborate have to comply with set requirements, implement new requirements, and improve upon outdated service protocols. In addition to following requirements, they have to comply with the needs of PLHIV and their families.

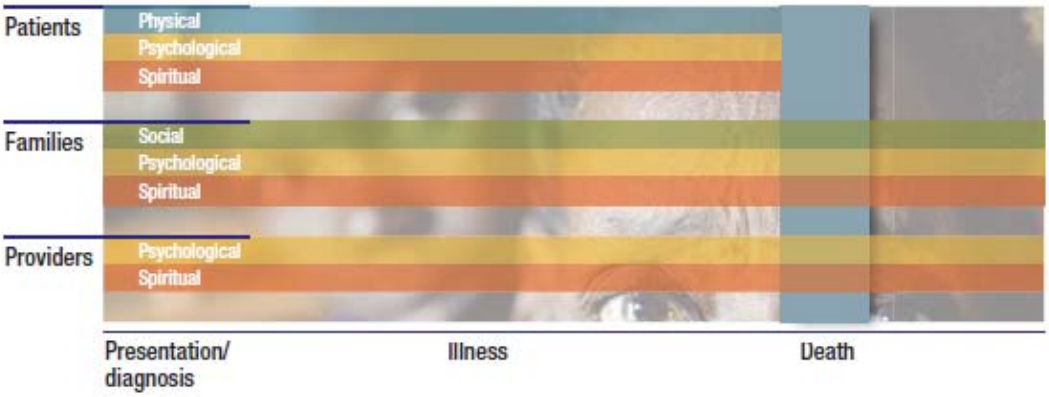
6.6.3. Quality Assurance versus Quality Control

Within the context of palliative care, quality control emphasizes testing the PC service package to uncover defects, and reporting to managers or generalists who make the decisions about whether to allow or deny the delivery of all or some of the PC service elements. Quality assurance attempts to improve and stabilize PC service delivery and associated processes, to avoid, or at least minimize, issues that led to the defects in the first place. In order to minimize potential mistakes, several quality assurance methodologies are used. However, this does not eliminate the need for quality control; some service parameters are so critical that pre-testing is still essential. Quality control activities are treated as one element of the overall quality assurance process.

6.6.4. *Quality Assurance and Quality Control: Application to SCRHA PC Services*

Ensuring effectiveness in community and home based PC service delivery is critical to SCRHA project success. The degree of effectiveness may be ascertained through well a designed M and E framework. Effective implementation of the project in general and PC services in particular will be monitored weekly, monthly and quarterly through the use of standardized reporting mechanisms, monthly and quarterly joint review meetings with all key stakeholders at the woreda level, and annual joint review and effectiveness assessments at the federal level. Depending on the prevailing conditions, bi-annual review meetings under the supervision of the SCRHA team will be held at the regional level. The main activities of the project and best practices will also be documented both in print and electronic media for project monitoring and future reference.

Figure V: Quality-of-Life Dimensions of Palliative Care



Source: WHO (2002a) National cancer control programme: policies and managerial guidelines, 2nd ed. Geneva

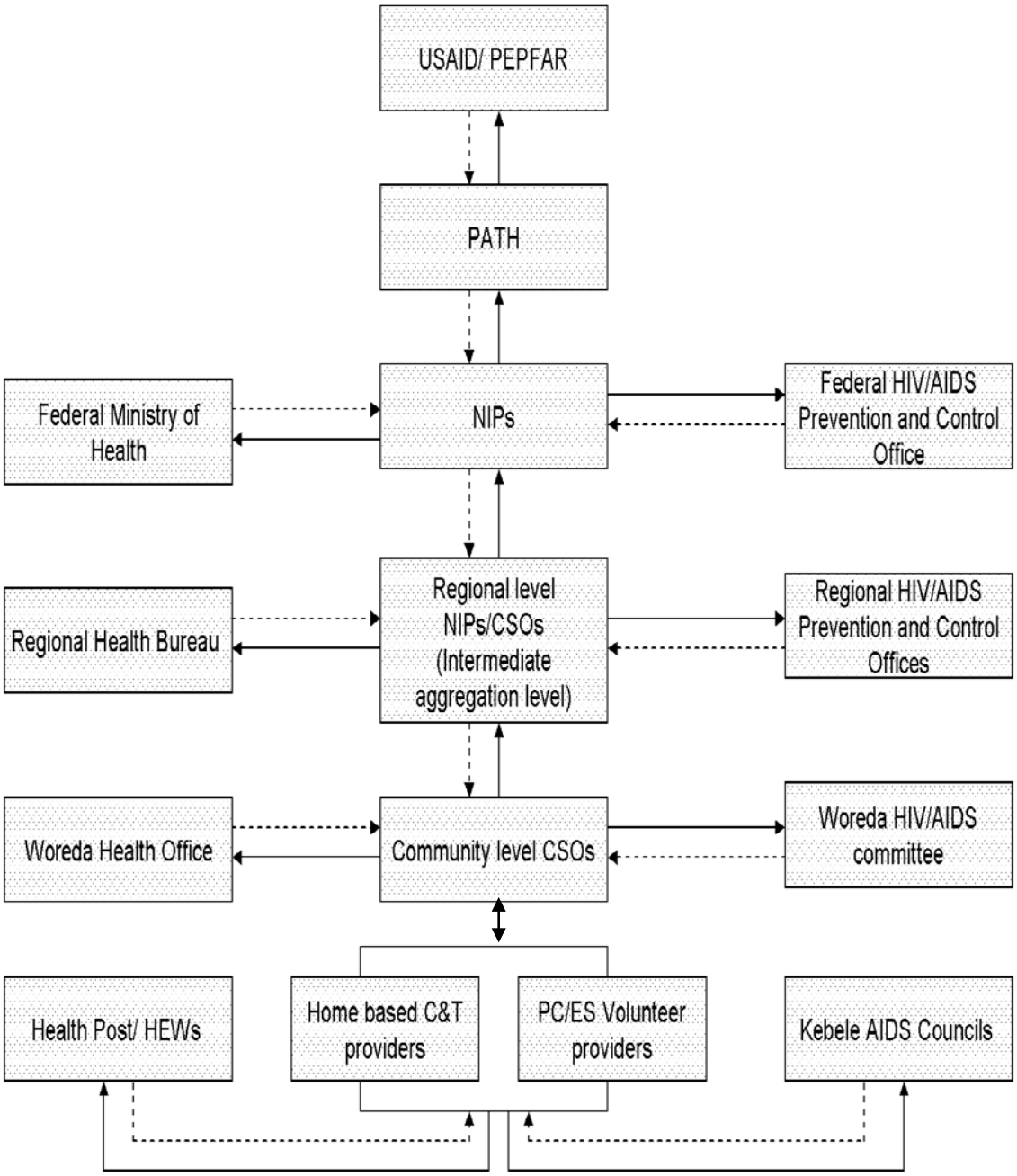
Strengthening the management, coordination, networking and monitoring and evaluation programs of PC services is essential to the successful implementation of the project. Therefore, PC focal persons will be recruited, deployed and trained on comprehensive palliative care program management, coordination, networking and M and E systems.

In addition, in order to strengthen PC services' data recording and processing mechanisms, a woreda-based data management system will be established in collaboration with relevant partners. The necessary training in data recording and management will be provided to expert data managers. Important data collection, compilation, and analysis tools will be designed for effective implementation of data recording and processing. Also, the data management system will be computerized at all levels to facilitate consolidation and use at a national level by programs run by actors across various levels. This will, in turn, encourage national level actors to incorporate the outputs for national level reporting as well as all other managerial decisions.

The data collection tools are expected to be specific to each clinical and non-clinical PC service indicator. NIP and CSO staff members should be familiarized with the tools and oriented to the purpose of the monitoring and evaluation process. All stakeholders should be introduced to the monitoring and evaluation tools which are needed for integration with the national M and E system in order to ensure the sustainability of services. In order to support the integration gap, a strong referral mechanism must be built as part of a well designed service package at the household level.

There will be feedback mechanisms at all levels to strengthen the reporting system and improve the data quality (see Figure VI, below). In order to enhance supportive supervision processes, mentorship and review meetings will be conducted to gage the level of PC service implementation. Regular supportive supervision and mentorship will be conducted by the NIPs and CSOs at different levels. The review meetings will be organized biannually or quarterly at the regional level, in close consultation with the respective concerned government offices and NIPs/CSOs. As part of the data quality assurance mechanism, NIPs/CSOs will use the data quality assurance tool as well as on site training or mentorship.

Figure VI: Community and Home Based PC Service Data and Information Flow



Source: SCRHA, PMP, 2009

The conceptual framework for monitoring the quality of palliative care services by community care and support volunteers involves various tasks as described below.

A. Competency (knowledge/ability to provide palliative care services)

- Systematically assess locally available resources for palliative care referral services
- Map resources for palliative care referrals
- Conduct palliative care needs assessment and utilize the results to effectively address needs at the household level
- Apply skills gained through basic and refresher training programs for the effective provision of community/home based palliative care services

B. Interaction

- Effectively use interpersonal communication skills in order to sensitively work with PLHIV and OVC
- Achieve effective results in counseling
- Address gender equity and equality in all PC client services in all circumstances
- Address age appropriateness of all PC communications

C. Availability and/or access to ES and VCT services

- Frequently follow-up with clients after initiation visit/assessment (done by CSO and PC generalist)
- Ensure accessibility of PC services
- Ensure that CSO members are available to clients during office hours
- Make services accessible to women (day care/child care) and OVC

D. Linkages and/or referrals

- Map referral services and availability of resources
- Use updated list of referrals for community care and support volunteer providers
- Keep an updated referral system (including referral slips)
- Link to health facilities and spiritual services
- Link to administrative support from the government (if community care and support volunteer providers are not available)
- Support and encourage linkages with public health facilities

- Provide protection to OVC (legal advice and support on land and property grabbing)
- Ensure local resource usage
- Link to support services for women and OVC

E. Stigma:

- Address stigmatizing behavior directed towards PLHIV and OVC
- Coordinate among various sectors in order to provide comprehensive services

F. Confidentiality: "Consent for Shared Confidentiality"

- Ensure confidentiality in the home. Service providers and SCRHA partners do not share any information with family members without the consent of the client
- Ensure confidentiality in the community. Providers must keep client information in a safe place and document it in a confidential way. They should not share clients' information with other community members without the consent of the client
- Ensure confidentiality in all data management steps and in reporting at all levels

G. Data Quality/Security (from the perspective of community care and support volunteer providers)

- Ensure completeness of record-keeping/registers
- Ensure accuracy of data compilation
- Record/store data effectively (ensure accuracy of household records on palliative care components)
- Make use of stored data for PC management, reporting and decision-making
- Ensure data bank control (cross-cutting with economic strengthening and HCT)
- Update reference materials, checklists, latest progress, etc.

H. Safety issues

- Be familiar with safety issues as outlined in the PC Operations Manual and ES Operations Guide (safe handling, storage and preparation)
- Identify safety components, written documentation, as well as distribution and dissemination to clients (e.g. hand-washing before and after use of first aid services)

6.7. Palliative Care Service Standards

SCRHA recognizes that standards support the improvement of quality services. The purpose of these community and home-based palliative care services standards is to guide the SCRHA PC project to meet the overall goal of improved quality of life for clients and their families. The standards represent the essential elements that must be in place in order for quality services to be offered. These standards are thus intended to help the SCRHA team as well as NIP and CSO staff members and partners involved in palliative care to design, manage, assess, and improve the performance of their palliative care programs. An important operational focus for SCRHA involves the integration of community and home-based palliative care services into all other existing HIV/AIDS care and support activities, rather than thinking of them as standalone services. The SCRHA community/home based palliative care standards apply to community care and support volunteer providers and UHEWs providing services to PLHIV and their families in the home and to the family caregivers.

6.8. Documenting and Reporting on SCRHA Palliative Care Services

6.8.1. Supportive Supervision

To achieve the intended results through CPC service implementation, frequent supportive supervision, technical assistance, and follow up visits will be conducted by various actors in collaboration with all relevant key stakeholders operating in the selected regions, woredas, towns, and households. Project workers will collaborate with stakeholders based on the type of activities planned in the project. Refer to the proposed supportive supervision checklist attached in Annex VII for further details.

As stated earlier, indicators are essential elements of the supportive supervision checklist. Indicators should be quantifiable measures of things that one can count; indicators that are difficult to measure, poorly defined, or not able to be independently validated when audited should be avoided. Technical assistance in the form of supportive supervision can be obtained to conduct a baseline study as well.

6.8.2. Reporting Mechanisms

Community palliative care services are major components of SCRHA project interventions. In the SCRHA palliative care services delivery process, raw data will be captured by the community care and support volunteer providers and those UHEWs who act at the household and community level. The data capturing forms, attached in Annex IX, address the important data requirements of the SCRHA project palliative care services. There are four separate data capturing and reporting forms developed for PC; data captured by these forms will then be compiled and reported to the next level. Feedback and data will run both up and down the reporting channels so that all levels have access to the same information. As described in the SCRHA PMP document, the following four levels can be utilized for PC services reporting:

Reporting level one: The palliative care service providers (both community care and support volunteer providers as well as urban health extension workers (UHEWs) will compile and submit their weekly and monthly reports to their immediate supervisors/generalists or CSOs, and horizontally to all partners to whom they are accountable to at the town/household level using attached reporting forms in Annex IX.

Reporting level two: The CSOs will compile the quarterly reports using data or information obtained through various means as well as reports from lower levels and/or generalists. They will then submit those reports to the NIPs and other requesting high level partners as well as HAPCO and the MoH.

Reporting level three: At this level, the NIPs and IIPs will aggregate reports which summarize palliative care services outputs and achievements across all intervention areas. NIPs and IIPs will compile third level quarterly, bi-annual and annual reporting by using CSO reports, joint review meeting minutes, their own technical and supportive supervision reports, and other secondary data as input. They will then report their findings to the SCRHA project team, relevant sector offices and CSOs as required by the overall SCRHA project. This third level of reporting will

provide highlights of national level outputs in the areas of CPC services in particular.

Reporting level four: "The SCRHA Project Team (PATH/Westat) will compile aggregated quarterly, bi-annual and annual reports of palliative care services' with other intervention areas' accomplishment reports received from the NIPs and IIPs and reports to USAID/PEPFAR. The same report or extract from the report that is required by the USAID/PEPFAR will also be shared with the Federal HAPCO/Federal Ministry of Health" (SCRHA, PMP, 2009). This aggregate level report may or may not follow formats and procedures designed specifically for palliative care services reporting.

Chapter Seven: SCRHA Project Palliative Care Service Sustainability

7.1. General Overview

In order for palliative care services to be sustainable and comprehensive, they should be integrated with existing health systems and tailored to the specific socio-cultural context of the target community. To this effect, households must take ownership of the palliative care services they and their surrounding community members need in order to ensure continuous access.

Palliative care coordinating committees operate at the kebele and government levels. CBOs and CSOs need to incorporate their continued service packages and development agendas during planning, implementation and evaluation of all other community-based interventions. These services, in turn, need to be linked with nearby health facilities as well as public and private institutions that provide health and related services. At the coordinating parties' level (which includes the MoH/HAPCO), the SCRHA project team, NIPs and CSOs need to ensure proper cascading of required policies, regulations, standards, guidelines, knowledge and working modalities for effective and sustained implementation of community-based palliative care services among targeted 300 urban and peri-urban towns in Ethiopia.

By building upon the existing experiences and capacity of national implementing partners and CSOs that are directly involved in the implementation of palliative care services, the SCRHA project is able to both strengthen the program and ensure sustainability. This creates an environment in which the CSOs are better able to adapt, improve, and expand upon the quality and number of services. This approach also helps to sharpen the systems they use for management, monitoring, and linking with health facilities.

Strengthening the capacity of national actors like the Federal Ministry of Health and Federal HAPCO, is crucial to the effort to build upon existing efforts and to ensure sustainability of community and/or home based palliative care services at all levels.

This effort will serve to fully integrate many of the SCRHA project components directly into the existing system where they will remain effective for years after the project phases out.

Community level awareness raising and ownership and capacity building activities will enhance the sustainability of palliative care services at the grassroots level. The beneficiary community must take ownership of the services and learn how to manage them without higher level support. This can be achieved through targeted training and awareness raising activities conducted side-by-side with palliative care services implementation. Community ownership and participation can be achieved in many different ways, but in this specific context effective social mobilization can contribute significantly to the sustainable implementation of palliative care services at the community and household level.

7.2. Social Mobilization as a Strategy for Sustaining PC Services

Social mobilization in this context consists of an anti-HIV/AIDS public movement process in which the community capitalizes on its assets and capacities to prevent and control HIV/AIDS. By taking ownership and action at the forefront, with a shared sense of urgency, communities will be able to reduce and reverse the spread of the pandemic and provide care and support to infected, affected and vulnerable people (FHAPCO/MoH 2007). This effort will contribute to increased utilization of HIV/AIDS services, with a primary focus on community-based palliative care.

The objectives of social mobilization efforts in the context of SCRHA palliative care service implementation are to enhance the knowledge of target communities and bring about behavioral change as well as to encourage communities to see that HIV is everyone's problem and equip them to fight the pandemic as a community. As a result of social mobilization efforts, the SCRHA project expects the following outcomes in the target project operational areas:

- Community members will receive the correct information about HIV/AIDS;
- Community members will understand HIV control and prevention methods;

- Community members will be aware of harmful traditional practices that fuel the spread of the virus;
- Community members will be well aware of the negative impact of stigma and discrimination;
- Community members will have increased awareness about ART, and as a result the demand for ART services will increase;
- Community care and support volunteers will serve as models in the community and will assist community members to obtain needed support from other volunteers who can provide free services;
- Community members' ownership, participation and direct involvement in the palliative care services fight against HIV and AIDS will be enhanced; and
- Community or home-based palliative care services will expand to meet the needs of PLHIV, OVC and their custodians, and dependent people who have lost their caretakers.

In order to intensify community and home-based palliative care social mobilization efforts within the context of enhancing and expanding the services for the SCRHA project, the following strategies have to be in place. These include:

- Utilizing existing community institutions and structure;
- Ensuring continuity of community conversation in collaboration with HAPCO at all levels;
- Ensuring the transmission of anti-HIV and AIDS messages through appropriate media;
- Sharing and expanding good practices among target communities;
- Strengthening the skills and knowledge of community palliative care providers based on periodic needs assessment results;
- Facilitating and holding annual kebele level anti-AIDS festival;
- Strengthening institutional support at various levels including strengthening coordinated efforts and partnership;

- Establishing an AIDS information system and encouraging the use of that system; and
- Strengthening supportive supervision and evaluation systems at the community level.

The effort to raise community awareness is an essential component of the palliative care services program implementation. Community members need to know about the importance of PC services, as well as when and where they are available, and how the services work. One way to do this is to facilitate a community conversation (CC) on palliative care issues. This would involve distributing IEC materials on palliative care services which need to be prepared and adapted to local languages. At the same time, all stakeholders need to jointly plan and implement the CC sessions on palliative care services (i.e., dissemination of IEC/BCC materials and managing CC).

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Annexes

ANNEX I: Community and Home Based Palliative Care Standards

Functional Areas	Dimensions of Quality	Quality Characteristics
Management (To increase ownership and leadership in palliative care service delivery)	Management systems support the effective delivery of palliative care services within the home and community	• Supervision of community healthcare workers is conducted by a trained health professional at least monthly. • Written policies and procedures that support community palliative care have been approved by the relevant authority. • Policies and procedures are communicated to service providers and implemented. • Policies and procedures conform to professional standards of care, as defined by the national palliative care technical working group or relevant government body. • Related safety standards and are in place and infection control measures taken.
Human Resources (To increase local capacity to deliver palliative care)	Human resources are sufficient and sufficiently supported to deliver palliative care in the home and community	• Capacity building of community palliative care workers (CPCW) includes sufficient training to master all assigned tasks in accordance with the country's palliative care program or the SCRHA project palliative care strategy. • Regular supervision, feedback on data and recordkeeping, organizational updates, information exchanges, and on-the-job training are provided. • All CPCW receive a written contract or description of expected tasks (including roles, responsibilities, and rights) in accordance with local labor laws. • Written human resource policies comply with country labor laws and address CPCW working conditions, including patient/worker ratios. • A support and motivation system is fairly and equitably implemented and appropriate to the country context.
Commodities, Medicines, and Educational Materials (To increase access to essential palliative care medicines and commodities)	Appropriate and sufficient educational materials, medicines, and commodities for palliative care clients and service providers are consistently available and accessible in the community	• CPCWs have the essential materials to adequately perform their work. • An effective resource management system, including for medicines, ensures the constant availability of drugs and other necessary resources for quality care • There is collaboration with government in procurement of essential materials and commodities. • Infection control measures, including proper medical waste management, are understood by community workers, clients, and their families, and are supported with the necessary policies, practices, and supplies.
Service Delivery (To increase access to palliative care services though a continuum of care)	Services are delivered with respect and dignity for the patient, family members and caregiver. They are holistic, comprehensive, and effective within the	• Clear criteria identify who should benefit from community-based palliative care, based on country context and individuals' needs. • Both children and adults are equally eligible for services. • Services are provided to all who require palliative care: no discrimination is made based on the nature of disease. • The minimum service package includes (but is not limited to) the holistic assessment and care planning, a closed-loop or two-way referrals, pain management, symptom care, end-of life care, and emotional, social, and spiritual support. • The minimum service package is communicated with beneficiaries and partners, in accordance with national palliative care standards (if

	continuum of care	they exist) or the SCRHA palliative care strategy. • An interdisciplinary and holistic care plan is developed and followed-up on for each patient at all stages of palliative care. • A confidential case record is maintained with regular follow-up notes and periodic reassessments and case reviews. • An interdisciplinary approach is applied at the community level, i.e., a combination of healthcare workers, PLHIV, social workers, and other sector representatives work as a palliative care team. • A community-based feedback mechanism gathers and takes action on relevant suggestions. • Government quality control systems and guidelines are adhered to.
Quality Assurance and Quality Improvement (To increase the quality of palliative care services)	All elements of the palliative care system are monitored and analyzed with the aim of reaching coverage targets and improving quality of services	• A monitoring and evaluation plan is developed for each community program, in accordance with national guidelines. • Indicators are based on palliative care national guidance, or guidance from SCRHA or other relevant bodies. • Monitoring tools reflect the components of the essential palliative care package and a functional interdisciplinary care team approach.
Safety		• Services are provided in a confidential manner (in accordance with the do-no harm strategy) by trained and experienced service providers and professionals • Referrals are made to skilled service providers and on the basis of need • PC services are provided safely (according to recognized standards) and in appropriate settings with appropriate commodities and supplies as stated above
Access/Reach		• Existence of a referral network of local services • Community-based services are strengthened • Services are provided locally (either in the community by community based workers or at local health facilities or service providers) • Barriers to PC services are assessed and addressed (i.e. transportation, fee waivers, etc) • On-going access to treatment (including ART) is ensured • Services are client-friendly
Sustainability		• Community ownership and health education is promoted. Caregivers are encouraged and supported to seek health services. • Civil society and private health facilities are involved in an effort to improve the quality of health care. • The community has knowledge of health issues and the ability to relay this information. • Prevention activities and referral linkages are in place, strengthened and well functioning. • Increased Government resources for system strengthening and coverage to improve access and quality of services.

Source: adapted from: Standards for Improving the Performance and Quality of Services in Palliative Care Programs (FHI, December 2009) and Standard Service Delivery Guidelines for OVC Care and Support Programs (MoWA & FHAPCO, November 2009)

ANNEX II: SCRHA Selection Process and Criteria for Palliative Care and Economic Strengthening Service Providers

I. Major Roles of Community Care and Support Volunteers

1. Sensitize and mobilize the community regarding extensive palliative care and economic strengthening services
2. Provide referrals for TB, STI, PMTCT, and other support
3. Provide medical, social, psychological, hygiene and sanitation, bereavement care and other palliative care services
4. Conduct regular home visits for palliative care and economic strengthening services
5. Identify feasible business ideas and provide assistance to clients on how to develop business plans
6. Create linkages with microfinance institutions and work to get grants and revolving funds for households
7. Identify existing economic strengthening (ES) opportunities and link with households
8. Provide business development services on marketing, record keeping , etc
9. Participate actively in combating stigma and discrimination
10. Provide social, educational and psychological support to OVCs
11. Carry out adherence counseling on ART and TB-DOTS
12. Link clients to care givers and community support
13. Regularly record and report on PC and ES activities

II. Selection Process

1. The selection process shall be coordinated by NIPs and CSOs
2. In the selection process, the involvement of government line offices is mandatory. To this end, the selection process shall be done by a committee comprised of members of HIV and AIDS committees of the kebeles of the town, CSO staff members, and NIP representatives
3. In order to ensure the fair participation of all interested community members, meeting announcements should be posted in visible areas of the town and shall be written in the local language
4. The notice shall include the job description for the volunteer providers which lists expected tasks and requirements
5. The selection process shall adhere to the selection criteria

6. The selection committee shall post the results of the selection process with a list of all selected community providers in visible areas of the town
7. The selection committee will reconsider its selection process if concrete or tangible evidence is available to change the result
8. The committee may cancel or replace the selected community care provider if the committee believes it would no longer be able to fulfill the selection criteria

III. Selection Criteria

1. Strong interest in care provision, volunteer activities and other related services
2. Completion of 10th grade education (for some per-urban towns, completion of 8th grade can considered depending on availability)
3. Familiarity with local language and culture
4. Residence in the community where s/he work as a counselor, care provider
5. Being respected and known for his/her good social conduct by the community
6. Being self motivated, hard working and proactive
7. Involvement in community based interventions such as Anti-AIDS club, community based care, volunteer activities, etc…
8. Sound interpersonal relations and good communication skills
9. Members of families affected/infected by HIV and AIDS will be prioritized
10. A volunteer not involved in other organizations who are providing similar services
11. Age minimum of 25 years old
12. Female providers will be given priority

The selection criteria and as well as the selection process may be amended depending on emerging developments

IV. Service Year of Volunteer Care Providers

The program anticipates that volunteers can be actively engaged for two years. After two years of service new volunteers will be recruited by the respective NIP-CSO. When volunteers terminate their service following this process, a farewell ceremony will be organized and they will receive a recognition certificate for their successful completion.

Annex III: SCRHA Palliative Care Service Mapping Directory Tool for CSOs

Ser No	Name of organization working on Palliative Care	Type of org: GO, NGO, CSO, etc	Organization Contact Information (tel, Fax, e-mail)			Name and address of contact person	Type of available services	Kebele	Specific Area	Source of Funds	Possible areas of cooperation
			Tel	Fax	E-mail						
1											
2											
3											
4											
5											
6											
7											
8											
9											
	N.B - Organizations working on palliative care could be providing clinical or non clinical services. Therefore, it is essential to check the detailed SCRHA palliative care activities critically.										

ANNEX IV: Palliative Care Services Referral Form

Name of person making referral: _____

Position: _____

Name of client/patient: _____**Client IDN:** _____

Client gender: ___ **Client Age:** ___

Address: _____ **Town:** _____ **Kebele:** _____

Reason for referral: _____

Please put a "√" mark in the boxes below for type of services to which client is referred.

Type of service	**"√"**
Food support	☐
Financial support	☐
Social support	☐
Spiritual support	☐
Educational support	☐
BDS services	☐
HCT	☐
TB diagnosis	☐
STI and OI diagnosis and Rx	☐

Referred to: _____

Feedback Slip

Name of client: _____

Type of services provided: _____

Name of service Provider: _____**Position**_____

Date: _____ **Signature:** _____

ANNEX V: Guidelines for the Identification and Documentation of Good Practices in HIV/AIDS Palliative Care Interventions

1. Purpose

This note has been put together to assist UHEWs and community volunteers and their program directors to identify and document brief case studies of good practices resulting from SCRHA interventions. The purpose is for workers to learn from these experiences and identify what approaches work best and why. These case studies are meant to contribute to the national and international knowledge base about what is effective in HIV and AIDS palliative care interventions. The goal is to draw lessons learned from such cases to inform the process of improving practice elsewhere. In identifying and documenting such cases, it is important that they are evidence-based and linked to the project's Performance Monitoring Plan.

What is a good practice?

Developing good practices involves systematically building upon effective approaches to any given issue by examining existing experiences and processes that work; understanding them in the light of agreed upon values, expert opinion and best available evidence; and extracting from them lessons that can be applied in the context of different social, economic and cultural settings.

Further, a good practice can be defined as anything that works in some way in dealing with HIV/AIDS in the community that may have implications for practice at any level elsewhere. The following are implicit in this definition:

- A good practice can represent *any* type of practice, small or large;
- It can represent a practice at any level ranging from broad policy-level activities, community level action, to practices in the health sector;
- It need not represent an overall project or program. Even if a project has not been 'successful', there may still be good practices that it developed or applied;
- A key principle is that a good practice must be some activity that *has actually been tried and shown to work*, i.e. as distinct from what may be a potentially good idea but has not actually been tested. It could, however, represent work in progress, providing preliminary or intermediate findings.

- The overriding criteria should be the potential *usefulness* of a good practice to others in stimulating new ideas or providing guidance on how one can be more effective in some aspect related to HIV/AIDS prevention.

2. Some criteria for determining what makes a practice "good"

The following are key criteria of good practices:

- **Innovative or creative:** What is special about the practice that makes it of potential interest to others?
- **Effective/impactful:** What evidence is there that the practice actually has made a difference? Can the impact of the practice be documented in some way, through a formal program evaluation or through other means?
- **Replicable:** Is this a practice that might have applicability in some way to other situations or settings? Note that a practice does not have to be copied or "cloned" to be useful to others.
- **Sustainable:** Is the practice and/or its benefits likely to continue in some way, and to continue being effective, over the medium to long term? This, for example, could involve continuation of a project or activity after its initial funding is expected to expire.
- **Responsive and rights-based:** Is the practice consistent with the needs? Has it involved a consensus-building and participatory approach? Is it respectful of the interests and desires of the beneficiaries and key stakeholders? Is it in accordance with SCRHA's values and principles?
- **Efficient and implementable: Were** resources (human, financial and others) used in a way to maximize impact?

3. A checklist for identifying a good practice

- Reflects generally accepted human rights and values;
- Includes a commitment to the wellbeing of individuals, communities and the nation;
- Is ethical and meets universal standards of compassion, tolerance, respect, confidentiality, empowerment and participation;

- Reflects best available evidence;
- Is relevant and tackles the program;
- Is appropriate to the community situation, country and culture;
- Can be documented and shown to be effective in more than one setting or situation;
- Is affordable and adds value;
- Is sustainable in terms of structures, capacity and funding to continue working over the long term without outside support;
- Incorporates systematic monitoring and evaluation of its impact.

ANNEX VI: Palliative Care Services Needs Assessment Tool

1. Questionnaire for Urban Patients

Date of interview _____ Interviewer_____

Residence (village/division) _____

1. Patient's age _____ (years)
2. Patient's gender. Male ____Female____ (Put a tick mark)
3. Region: _____
4. Marital Status: Single ____Married ____ Widowed ____ Separated/divorced____ (please tick one).
5. Present occupation (please tick one).

   Professional*_____ Business man/woman_____

   Housewife _____ Peasant_____

   Farmer _____ Student _____

   Unemployed _____ Other (specify)_____

   **Professional: Teacher/Doctor/Nurse/Engineer/Accountant/Administrator, etc.*

6. Past occupation (please tick one).

   Professional*_____ Business man/woman_____

   Housewife _____ Peasant_____

   Farmer _____ Student _____

   Unemployed _____ Other (specify)_____

7. Religion (please tick one).

   Roman Catholic____ Muslim_____

   Orthodox _____ Evangelical _____

   Other (specify) _____

8. Level of Education (please tick one).

   None ____ Primary_____

   Secondary _____ Tertiary ____

9. (a) Do you know what disease you are suffering from? (knowledge of the diagnosis)

   Yes __No ___ (tick one)

   (b) If yes, what disease(s) are you suffering from? (please tick one)

   Cancer _____ Typhoid _____

   HIV _____ Tuberculosis _____

   Both HIV and cancer _____ Witchcraft _____

Other (specify) _____

10. When did you first know that you have this illness? (please tick one)

Less than a year ago ____ Over one year ago ____

About two years ago ___ A long time back ____

I really cannot remember ____

11. How did you find out about your illness? (please tick one)

Through a test at a health facility ____

I suspected when I lost my spouse/lover _____

I made my own conclusions when I saw the symptoms/signs ____

My doctor told me _____

Other (specify) _____

12. Who did you first tell about your illness? (please tick one)

My Parent(s)_____ My spouse _____

My brother/sister _____ My children _____

My best friend _____ I haven't told anyone _____

Other (specify) _____

13. How did they find out about your illness? (please tick one)

I told them myself when I received the news _____

My doctor broke the news to them _____

They made their own conclusions when they saw the symptoms _____

Other (specify) _____

14. How did your spouse/family react when they learned of your illness? (please tick one)

They were shocked but stood by me _____

They were shocked and angry with me _____

My spouse rejected me and sent me/went away _____

They rejected me _____

They were indifferent _____

They are resigned to the situation _____

I really do not know _____

Other (specify) _____

15. Have you felt any stigma because of your illness?

Yes _____ No _____ (please tick one)

16. How have you handled the stigma that accompanies this disease? (please tick one)

The fact that my family stood by me helped _____

By accepting the diagnosis and being open about it _____

I just keep to myself _____

Talking to a counselor helped me to cope

By meeting and interacting with others who have the same disease _____

I have a strong faith in God and this helped _____

I have refused to accept the diagnosis _____

Other (specify) _____

17. What is your greatest fear right now? _____

_____

18. Who takes care of you? (Specify your main caregiver) (please tick one)

My spouse _____ My mother _____

My sister/brother _____ My children _____

My grandchildren _____ My grandparent(s) _____

My aunt from the village _____ Someone the family hired to do so _____

A friend _____ Other (specify) _____

19. What are the main problems you are facing as a result of your illness? (Tick all that apply):

Physical _____ Social _____

Economic _____ Spiritual _____

Emotional _____ Other (specify)_____

20. How is your medical treatment paid for? (please tick one)

I meet my own expenses _____ My employer _____

Family _____ Friends _____

A nongovernmental organization _____Other (specify) _____

21. How are your other needs and those of your family paid for? (please tick one)

By myself _____ Family _____

Friends _____ A nongovernmental organization _____

Other (specify) _____

22. Roughly what is your monthly expenditure on treatment? (please tick one)

Less than 5,000 _____ 5,000–15,000 _____ 16,000–25,000 _____

26,000–35,000 _____ 36,000–50,000 _____ Over 50,000 _____

I really do not know _____

23. (a) How far is the nearest health facility from your home? (please tick one)

Right across the road _____ Less than a half a kilometer _____;

Over a kilometer ____ About 1–5 kilometers _____

Over 5 kilometers ____ I really do not know ____

(b) What type of health facility is it? (please tick one)

Government _____ Private ____

Nongovernmental _____

24. Do you have people who visit you regularly?

Yes ____ No _____ (please tick one)

25. Where do they come from? (please tick one)

From the home care team ____

They are my friends from the neighborhood _____

They are my relatives _____

I do not know _____

26. Where do you get your medical treatment? (please tick one)

From the home care team that visits me regularly _____

I buy what I need from the nearby drug shops/pharmacy _____

My doctor supplies what I need _____

My family buys what I need _____

Donations from friends _____

Other (specify) _____

27. How has the home care team helped you? (please tick one)

By providing drugs and counseling _____

They provide me with foodstuffs _____

Financially _____

By providing drugs/foodstuffs/counseling _____

By providing drugs/foodstuffs/money _____

Not applicable _____

Other (specify) _____

28. What more help would you like the home care team to give you? (please tick one)

Services (drugs/medication/legal/spiritual/etc.) _____

Foodstuffs _____

Family support (counseling/IGA/ finance, etc.) _____

Financial support _____

All the above _____

Other (specify) _____

Not applicable _____

29. What type of medication are you using in your treatment? (please tick one)

    Western medicines only _____

    Herbal medicines only _____

    Both Western medicines and herbs _____

30. Where do you prefer to be looked after during your illness? (please tick one)

    Here at home _____

    In hospital _____

    I really do not mind where _____

31. Give reasons for your answer _____

_____.

2. Questionnaire for Family Caregivers

Date of interview _____ Interviewer_____

Residence (Region/Woreda/Kebele/House no.) _____

1. Patient's age. _____ (years)
2. Patient's gender. Male ____ Female ____ (please tick one)
3. Tribe _____
4. Marital Status (please tick one).

   Single _____ Married _____

   Widowed _____ Separated/divorced _____
5. Present occupation. (please tick one)

   Professional*_____ Businessman/woman_____

   Housewife _____ Politician/Civic Leader _____

   Peasant Farmer _____ Student _____

   Unemployed _____ Other (specify)_____

   **Professional: Teacher/Doctor/Nurse/Engineer/Accountant/Administrator, etc.*
6. Past occupation. (please tick one)

   Professional*_____ Businessman/woman_____

   Housewife _____ Politician/Civic Leader _____

   Peasant Farmer _____ Student _____

   Unemployed _____ Other (specify)_____

   **Professional: Teacher/Doctor/Nurse/Engineer/Accountant/Administrator, etc.*
7. Religion. (please tick one)

   Roman Catholic _____ Muslim _____

   Orthodox _____ Evangelical_____

   Traditionalist _____ Other (specify) _____
8. Level of Education. (please tick one)

   None _____ Primary _____

   Secondary _____ Tertiary _____
9. Relationship to patient. (please tick one)

   Parent _____ Child _____

   Brother/sister _____ Grandparent _____

   Spouse _____ Aunt _____

   In-law _____ Friend _____

None –hired by the family _____ Other (specify) _____

10. What is the patient's diagnosis? (please tick one)

Cancer _____ HIV _____

Both HIV and cancer _____ Typhoid _____

Tuberculosis _____ Witchcraft _____

I do not know_____ Other (specify) _____

11. Have you ever looked after a terminally ill person before? (please tick one)

Yes _____ No _____

12. How did you come to be looking after this patient? (please tick one)

He/she is my spouse _____ I was the only one available _____

He/she is my brother/sister _____ He/she is my friend _____

I was asked by the patient _____ I have been hired by the family _____

The spouse abandoned him/her _____ He/she is my child _____

He/she is my parent _____ I volunteered to look after patient ____

Other (specify) _____

13. (a) Were you given any kind of training to do what you are doing? (please tick one)

Yes _____ No _____

(b) If so, by whom? (please tick one)

By the home care team _____ By Hospice _____

Other (specify) _____ Not applicable _____

(c) If so, for how long? (please tick one)

For one day ____ For a week _____

For a fortnight _____ For 1–3 months _____

For 4–6 months _____ For 7–12 months _____

Not indicated _____ Not applicable _____

Continuous – whenever the home care team visits_____

14. (a) Do you receive any kind of support to look after this patient? (please tick one)

Yes ____ No ____

(b) If so, what kind of support was it? (please tick all that apply)

Financial_____ Protective wear _____(e.g. gloves, apron/coat etc.)

Foodstuffs _____ Drugs/medication _____

There is somebody to take over when I am tired or need to go somewhere _____

Transport_____ Other (specify) _____

Not applicable _____

(c) If so, who gave you this support? (please tick all that apply)

The home care team _____ Friends _____

Children _____ My parents _____

My in-laws _____ I support myself from my salary _____

Other (specify) _____

Not applicable _____

15. Are you remunerated in any way for looking after this patient?

Yes ____ No _____ (please tick one)

16. (a) Does the patient tell you about his/her problems? (please tick one)

Yes ____ No ____ Sometimes _____

(b) If so, what are the patient's needs?

_____

_____

17. Does the sick person appreciate what you do for him/her? (please tick one)

Yes ____ No ____ I can't tell ____

18. What major problems are you encountering as you look after this patient?

_____

_____

19. What exactly do you do in caring for this patient?

_____

_____

20. If the patient's condition changes or the patient develops a problem where do you go for help? (please tick one)

To the nearest clinic where a doctor/nurse usually helps _____

To the herbalist _____

To the nearest hospital _____

I do my own first aid using glucose and drugs from the hospice _____

I go to the home care team that normally looks after him/her _____

I just wait for the next visit from the home care team _____

I go to the nearest relative _____

Other (specify) _____

21. What are your most pressing needs right now?

_____

_____

22. If you were given the chance to be trained to look after this patient, what would you like to learn?

_____

_____

23. What assistance, if given to you, would make it easier for you to look after this patient? (please tick one)

Financial _____	Foodstuffs _____
Extra bedding _____	An income generating project _____
Free drugs _____	An assistant _____
Protective wear such as gloves _____	Training in general patient care _____

24. Given a choice, where would you prefer to look after this patient? (please tick one)

Here at the patient's home _____	In hospital _____
I really do not mind either way _____	In my own home in the village _____

Please give reasons for your answer _____

3. Guide for Focus Group Discussions

1. What are the main health problems in your village/community?
   (Allow free listing and then prioritize the three most important ones)

2. Which diseases do you think are incurable?
   (Allow free listing and then prioritize to four most common ones in the area)

3. Who is the most affected by the four most common incurable diseases?
   (Young, old, male, female, children, etc.)

4. What symptoms are associated with these diseases?

5. How does the community here cope with these diseases?
   (Treatment/coping strategies – medical, traditional healers, spiritual, etc.)

6. What is the cost for each of these treatment options?

7. What are the most common needs among these people with incurable diseases?
   (Identify the disease first and get the needs for each disease)

8. How best do you think these various needs can be met?

9. How can the community help these people who are terminally ill and their families?

10. What sort of health services would you like to see provided for such people in your village?

11. If such services are provided how can they be maintained/sustained?
    (If cost sharing is mentioned what would be the minimum charge per person?)

12. How best do you think the government can help the terminally ill and their families?

13. Any other comment you would like to share with us?

Thank you very much.

4. Guide for Interviewing Key Informants

Key informants could include: counselors, traditional healers, church leaders, hospital superintendents, and health workers in charge of HIV or cancer wards.

1. What do you think are the (a) needs and (b) problems of the terminally ill?
2. How can these needs be met in the best possible way?
3. What local resources can you see available to help the terminally ill and their families?
4. How can these resources be maximized or enhanced?
5. How, in your opinion, does the community view these people?
6. How can communities support these people and their families?
7. What do you think the minimum health care package for the terminally ill should be?

Thank you.

ANNEX VII: SCRHA Community Level PC Service Delivery Supportive Supervision Checklists

A) Program Level Use

This supportive supervision checklist is meant to help SCRHA staff conduct supportive supervision at CSOs during implementation of specific palliative care activities.

I. Identification

Date of visit (MM/DD/YYYY) ___/___/___ Region _____,

Town visited _____

NIP and CSO under which the visited town functions:_____

Name(s) and organization of supervisor/supervision team members

1. _____

2. _____

3. _____

II. Service Availability

Question/Item	Yes /No	Comments/ Problems observed	On-site corrective actions	Planned corrective actions
1. Are all clinical PC services being provided in this town? (use scoring based on codes in the register. e.g. 16/117 if only one service is missing)				
2. Are all non-clinical services being provided in the town? (Use scoring based on codes in the register)				
3. Is there any service interruption?				
4. If yes to Q3, for how long and why?				

III. Availability of Resources (Human and Material)

Question/Item	Yes/No	Comments/ Problems observed	On-site corrective actions	Planned corrective actions
1. Is there an adequate number of: a) PC registers b) TB registers c) PC kits d) referral forms e) reference materials?	a. Y/N b. Y/N c. Y/N d. Y/N e. Y/N			
2. Are all VPs engaged in providing PC services? (write in proportion of VPs working/trained)				
3. Is the generalist engaged in coordinating PC services?				
4. Does the CSO management provide adequate support to the program?				

IV. Networking and Linkage

Question/Item	Yes/No	Comments/ Problems observed	On-site corrective actions	Planned corrective actions
1. Is there a functional referral system between the community and health facilities?				
2. Is there a functional referral system between the community and other care and support organizations?				
3. If yes, are there any referral forms used to refer clients?				
4. Is there a system of back referral of beneficiaries to the community/CSOs?				

5. Is there a mechanism whereby different service providing organizations (in the referral loop) regularly meet and discuss?				
6. Is there a good relationship between CSO and town health offices or HEWs?				

V. Data Quality and Reporting

Question/Item	Yes/No	Comments/Problems observed	On-site corrective actions	Planned corrective actions
1. Are the beneficiary registration forms in place?				
2. Are the registers complete? If no, determine how this might affect the reporting				
3. Are all items in the PC registers and reporting forms well understood by data collectors and generalist?				
4. Is there a good mechanism of collecting data on clinical PC?				
5. Is the CSO providing timely reports to the NIP?				

VI. Coaching/Mentoring and Management Support

Question/Item	Yes/No	Comments/ Problems observed	On-site corrective actions	Planned corrective actions
1. Is there any technical gap in providing PC services (compared to the expected competence)observed among: a) VPs b)Generalists c)other CSO staff	 a. Y/N b. Y/N c. Y/N			
2. Is there an advisory committee for PC in the town that oversees the program regularly?				
3. Is there a regular mentoring support (coaching) provided by the generalist or other CSO staff to VPs?				
4. Does the generalist provide support to the HEWs on the clinical aspects of PC services, and data quality?				

VII. General comments and suggestions _____

_____

_____

VIII. **Summary of good practices**

_____

_____

_____

IX. Name and signature of the supervisor/supervision team members

Names	Date	Signature
_____	_____	_____
_____	_____	_____
_____	_____	_____

B) Monitoring and Evaluation and Supportive Supervision

Region _____ Zone _____ Woreda _____ Kebele _____

CSO _____ Health Facility _____Date of visit _____

Monitoring and Evaluation	**Yes**	**No**	**N/A**	**Remark**
Does the CSO adapt and implement the SCRHA standard M and E tools, guidelines, registers, reporting forms, and SOPs?				
Does the CSO have a monitoring and evaluation unit?				
Does the M and E unit have appropriate staff and materials?				
Does the CSO assign appropriate, responsible personnel for M and E implementation?				
Does the CSO conduct regular on-the-job training on M and E for community volunteers, focal personnel, supervisors /program managers, and health workers /HEWs?				
Does the CSO equip all levels with appropriate materials for M and E implementation?				
Is there an electronic network that links each level of the health system in the region?				
Is there specific budget allocation for M and E?				
Have you completely utilized the budget allocated on M and E for the last six months?				Proportion:
Does the CSO organize M and E review meetings?				
Were recommendations forwarded based on identified implementation problems? List. 1. _____ _____ 2. _____ _____				

3. _____ _____
Were actions taken based on constructive recommendations? List and verify if possible. 1. _____ _____ 2. _____ _____ 3. _____ _____

Have you supervised volunteers and HEWs during the last six months?				Proportion:
Have you provided written feedback after supervision?[verify with copies]				Proportion:

M and E review

- Was there a shortage of reporting forms since the date of last supervision? Yes___ No___
- Look at the copy of last report sent to the next level
    - Was it sent on time? Yes___ No___
    - Was it complete? Yes___ No___

What was your finding on the core palliative care indicators?

Core indicator	**Achievement**

Were action points identified for performance improvement? List.

1. _____ _____ 2. _____ _____ 3. _____ _____				
Were actions taken based on identified action points? List and verify if possible. 1. _____ _____ 2. _____ _____ 3. _____ _____				
Are the planned activities carried out as scheduled?				

Summary of the findings

Major problems identified during this SS session

1. _____

_____

_____

2. _____

_____

_____

3. _____

_____

_____

4. _____

_____

_____

5. _____

_____

_____

Summary of agreed upon action points

Action points	*Responsible*	*Date due*
1.		
2.		
3.		
4.		
5.		
6.		

ANNEX VIII: Community Palliative Care Services Planning Template

Tasks *What will be done?*	**Time** *When will be tasks be completed? (due date)?*	**Resources** *What resources are required? Which ones should be provided by the SCHRA grant, and which can be from other sources?*	**Person/People** *Who is responsible for making sure that the task is accomplished on time?*	**Milestones** *What are the markers that indicate that the task is accomplished?*

ANNEX IX: Monthly Report Compiling Form (for Generalists)

		1. New **Non** clinical	Repeat **Non-** clinical	2. New **Clinincal**	Repeat **Clinincal**	3. New TB **Screen**	Repeat **TB screen**	4. New **TB DOTS**	Repeat **TB DOTS**	5. New **STI screen**	Repeat **STI screen**	6. New **Referral**	Repeat **Referral**	7. New Prev. Education	Repeat Prev Education	space available	Individuals Received at least One PC
VP1	Month Total All																
VP1	total Males																
VP1	page total Females																
VP1	Page total 0-14																
VP1	page total 15-17																
VP1	page total 18+																
VP1	OVC reached																
VP1	pregnant or lactate																
VP2	Month Total All																
VP2	total Males																
VP2	page total Females																
VP2	Page total 0-14																
VP2	page total 15-17																
VP2	page total 18+																
VP2	OVC reached																
VP2	pregnant or lactate																
VP3	Month Total All																
VP3	total Males																
VP3	page total Females																
VP3	Page total 0-14																
VP3	page total 15-17																
VP3	page total 18+																
VP3	OVC reached																

NIP Name:

Code

CSO Name:

Code

Generalis Name:

Month

gear

Page 1

ANNEX X: Palliative Care Register for Community Volunteer Providers

DO NOT MERGE CELLS UNLESS ABSOLUTELY NECESSARY

PM#	ስም ከነ አያት	እድሜ	ፆታ	ነፃነ ጠር/ የምታጠባ	ወላጅ ያላ ተጋላጭ
1			M F	Y N	Y N
2			M F	Y N	Y N
3			M F	Y N	Y N
4			M F	Y N	Y N
5			M F	Y N	Y N
6			M F	Y N	Y N

NIP Name: Code:

CSO Name: Code:

VP Name: Code:

HH Address Code:

የከተማዉ ሥም _____

	ስም ከነ አያት	እድሜ	ፆታ	ነፃነ ጠር የምታጠባ
7			M F	Y N
8			M F	Y N

PM No.	የመጀመሪያ ስም	ቀን	የጉብኝት ቅይጥ (ኮድ)	ፆታ	ከ 0-14 ዓመት	ከ15-17 ዓመት	18 እና በላይ	ነፃነ ጠር/ የምታጠባ	ወላጅ ያላ ተጋላጭ	1. ኦዲስ ከአእክል ያልሆነ	ድጋሚ ከአእክል ያልሆነ	2. ኦዲስ ከአእክል የሆነ	ድጋሚ ከአእክ	3. ኦዲስ ቲቢ ፍተሻ	ድጋሚ ቲቢ ፍተሻ	4. ኦዲስ ቲቢ መድሃኒት ከትትል	ድጋሚ ቲቢ መድሃኒት ከትትል	5. ኦዲስ አባላዘር በሽታ ፍተሻ	ድጋሚ አባላዘር በሽታ ፍተሻ	6. ኦዲስ ፈፈራል	ድጋሚ ፈፈራል	7. ኦዲስ የመከላከል ትትት	ድጋሚ የመከላከል ትትት
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N
				M F				Y N	Y N					+ -	+ -	Y N	Y N	+ -	+ -			Y N	Y N

አጠቃላይ (ሁለቱም ፆታ: ሁሉም እድሜ)	ድምር
ወንድ	ድምር
ሴት	ድምር
ከ0-14 ዓመት	ድምር
ከ15-17 ዓመት	ድምር
18 ዓመት እና በላይ	ድምር
ወላጅ ያላተጋላጭ	ድምር
ነፃነ ጠርየሚያጠቡ	ድምር

1. ከአእክል ያልሆነ	ኮድ
በነ ልቦናዊ ድጋፍ	1
ማህበራዊ ድጋፍ	2
መንፈሳዊ ድጋፍ	3

2. ከአእክል የሆነ	ኮድ
ቅድመ ፀረ ቫይረስ ህክምና ከትትል	1
ፀረ ቫይረስ ህክምና ከትትል	2
ስነ ምግብምግባባት ምክር	3
የነርሲንግ ክፍል	4
የህይወት ማብቂያ ክፍል	5
የአእምሮ ጤና ችግር ድጋፍ	6
ወባ መከላከል ንፅህናና ውሃ	7
የህመም ማስታገሻ	8
ሌላ ከአእክል (አባላዘር በሽታ/ቲቢ	9

ቲቢ/አባላዘር በሽታ ፍተሻ	ኮድ
ምልክት የታየባቸው	1(+)
ምልክት የያልታየባቸው	2(-)

6. የጤና ፈፈራል	ኮድ		ኮድ
አባላዘር በሽታ ምርመራና ህክምና	1	የኤች አይ ቪ ምርመ	4
የቲቢ በሽታ ምርመራና ህክምና	2	ተንሳፋ በሽታዎች	5
ከእናት ወደልጅ ቫይረሱን መከላከል	3	ሌላ የጤና እክልግሁ፡	6

ANNEX XI: Guide on Monthly Report VP Data Aggregation and Compilation (for generalists)

Objective: This guide is meant to assist users in correctly aggregating VPs data and compiling monthly quantitative reports.

Palliative Care VP data Aggregation and Reporting Templates

Attached to this document is a Microsoft excel file named "SCR_Generalist VP PC data aggregation Template_24August2010_AS" that is used to aggregate VPs' data and compile monthly reports. The file contains two sheets named "Generalist VP PC Aggregation" and "CSO PC Monthly Reporting Format." These two sheets are detailed below.

The first sheet (Generalist VP PC Aggregation) contains data aggregation tables for a maximum of 50 VPs that could be available per CSO. There are a total of 8 variables for new (the light columns) and 8 variables for repeat (the shaded columns) PC services that could be provided to an individual (see the template below). These variables are further disaggregated by gender, age, OVC status, and pregnancy/lactation status. Except for variable number 8, all of the variables listed provide a direct summary of the number of individuals provided PC services by VPs. The generalist needs to sit down with someone from the CSO to aggregate the number of people reached by VPs. For instance, if a volunteer provider reaches twenty households in a particular month, then the generalist should add up the total number of individuals reached by different PC services in all households that the VP reached in that month. Because there are summary tables on each VP PC register it will not be difficult to add up the total number of people reached by the VP and enter into the aggregation template displayed below.

Variable number eight (new first time ever reached with any type of PC service) can be obtained by counting the total number of individuals reached by any type of PC service for the first time. The assumption is that these individuals have never received any type of PC service from the CSO since SCRHA started supporting the CSO and/or never been reported before to NIP/SCRHA as having been reached by any type of PC services. To correctly count the number of people reached under this indicator it is absolutely essential to review all VP PC registers to see who received any of the PC services for the first time during the reporting month. The "repeat person contacts reached with any PC" indicator, on the other hand, counts those individuals who have already received at least one type of PC service

before and reported to NIP/SCHRA and received the same and/or another type of PC service during the reporting month.

Template 1: Generalist VP PC Aggregation

VP Name _____	1. New **Non clinical**	Repeat **Non-clinical**	2. New **Clinical**	Repeat **Clinical**	3. New **TB Screen**	Repeat **TB screen**	4. New **TB DOTS**	Repeat **TB DOTS**	5. New **STI screen**	Repeat **STI screen**	6. New **Referral**	Repeat **Referral**	7. New **Prev. Education**	Repeat **Prev. Education**	8.New **first time ever reached with any PC**	Repeat **person contacts reached with any PC**
Month Total All																
total Males																
total Females																
total 0-14																
total 15-17																
total 18+																
OVC reached																
pregnant or lactating																

The second sheet (CSO PC Monthly Reporting Format) contains a table for aggregation and reporting of all individuals reached with at least one type of PC service during the reporting month.

After the generalist has aggregated the number of individuals provided with different types of PC services by each VP in the above aggregation template, then he/she should add up the number of people reached with different types of PC services and enter those data into the monthly reporting table shown below. All people reached by all VPs in the CSO during the reporting month should be aggregated and entered into the reporting template. Because the table/reporting template is exactly the same as the aggregation template, generalists can fill in the reporting form by adding up all aggregation tables entered into the VP data aggregation templates. It is recommended that generalists use a computer to automatically generate the monthly quantitative report from the VP aggregated data when available. In that case, the simple formula will be used to automatically generate monthly reports from individual VP aggregated data.

Template 2: CSO PC Monthly Reporting Format

	1. New **Non clinical**	Repeat **Non-clinical**	2. New **Clinical**	Repeat **Clinical**	3. New **TB Screen**	Repeat **TB screen**	4. New **TB DOTS**	Repeat **TB DOTS**	5. New **STI screen**	Repeat **STI screen**	6. New **Referral**	Repeat **Referral**	7. New **Prev. Education**	Repeat **Prev. Education**	8.New **first time ever reached with any PC**	Repeat **person contacts reached with any PC**
Month Total All																
total Males																
total Females																
total 0-14																
total 15-17																
total 18+																
OVC reached																
pregnant or lactating																

ANNEX XII: Guide on how to Fill Out Palliative Care Registration Forms by Care and Support Volunteer Providers

Objective: This guide is intended to give detailed information to the volunteer provider on how to use the palliative care registration forms. Hopefully this will prevent confusion for day to day users and the generalist who supervises the service provision and prepares monthly and quarterly reports.

General instruction

1. This standardized registration forms must be printed on **A4 size** paper. The user should not change the paper size, paper orientation, or word fonts. The registers have already been developed, and they are in a standard format; by not changing the format, the user helps to maintain user-friendliness and uniformity of the registers across the CSOs. This will also make the generation of the database easier, so that reports can be generated more easily.

2. This register has three parts. The first part is for general information such as the NIP's name, the CSO's name, the VP's name, the household names, and the towns where this service was provided. Note that household addresses can be given by a code and this will be given by the generalist to all VPs.

   The second parts of the registers is for the house hold members' profiles in which all members are listed for the first time (after the VP has identified an entry point to the household through the index case). This will include information about the total number of beneficiaries from the SCRHA project (both infected and affected members of the family should get the services). The following variables will be collected at this point:

a. **Name of the household members**: at this point the client's name, the father's name and the grandfather's name should be registered correctly (to make the registers user friendly, one household is assumed to have up to 8 members)

b. **Age of household members:** the age should be recorded in completed years. For example, a person who is 17 years, 11 months and 29 days old will be

registered as a 17 year old; a newborn and an 11 month old child will each be registered as age "0"

c. **Sex:** please circle either M or F, not both

d. **Pregnancy /lactating mother:** this applies only to women who are older than age 14. Please mark "Y" if the woman says she is pregnant or has been breastfeeding her child in the last 42 days, otherwise mark "N" This column is not applicable and should be left blank for males or females under 14 years of age

e. **OVC:** If child is considered an OVC as per the OVC definition for Ethiopia, then consider the child as OVC and circle "Y." If the child is not OVC, then circle "N"

f. **NB:** this part of the register will be completed for the first time when the VP providers visit the household. This part may be updated if a new person comes to that house (e.g. newborn baby)

The third parts is the most important and critical part of the register. This should be completed only if the clients are receiving any type of services according to your training. Variables that are collected in this section include:

1. **FM Number:** this is taken from the household profile completed in the first parts of the register. For example, if a person is registered in the first part with the FM 4, this will be automatically taken if the service **is given.** Note that this does not need to be written in any particular order (1,2,3 etc) can be (7,1,6,4)
2. **Write the first name only:** this will reduce unnecessary burden for volunteer providers; further details can be found in the household profile
3. **Duration for the visit**: this is the total time it takes for VP providers to provide services at a given time (this can be for one service or for more than one service)
4. **Sex**: circle M for male or F for female

5. **Age category**: find out the age of the client from the household profile data and mark (X) according to the category labeled in the register. At this time do not ask the client his age again.
6. **Pregnant /lactating:** take the information from the household profile above, mark appropriately
7. **The services**
    a. **New non-clinical services:** if the client received non-clinical services, then write code 1, 2 or 3 according to your training. If the service is being provided for the second time, then write the name and mark according to the code given in the repeat non-clinical services section
    b. **Clinical services (new and repeat)**: if the client received for the first time any of the clinical services from the list (1-9), then please mark an"X" under new. However, the if the client is not new, then mark an "X" under the repeat column
    c. **Screening for TB**: the client will be screened for TB using the TB symptom screening checklist. Circle (+) if the client is symptom positive or (-) if the client is symptom negative (this will be applied accordingly for new and repeat clients).
    d. **Screening for STIs**: the client will be screened for STIs using the STI symptom screening checklist. Circle (+) if the client is symptom positive or (-) if the client is symptom negative (this will be applied accordingly for new and repeat clients).
    e. **Referral for health:** the client can be referred for various reasons to the health facilities (this could be health referrals mentioned by code from 1-6) .This will be applied to new or repeat clients accordingly.
    f. **Prevention activities:** this refers to evidence-based prevention activities, and can apply to new or repeat clients

Important Operational Definition

OVC is defined in this project as follows and taken from the standard PEPFAR definition and adopted by MOH Ethiopia:

A child 0-17 years old, who is either orphaned or made more vulnerable because of HIV/AIDS.

Orphan: Has lost one or both parents to HIV/AIDS

Vulnerable: Is more vulnerable because of any or all of the following factors that result from HIV/AIDS:

1. Is HIV-positive;
2. Lives without adequate adult support (e.g., in a household with chronically ill parents, a household that has experienced a recent death from chronic illness, a household headed by a grandparent, and/or a household headed by a child);
3. Lives outside of family care (e.g., in residential care or on the streets); or
4. Is marginalized, stigmatized, or discriminated against.

ANNEX XIII: CSO Scope of Work Form

Name of CSO _____

Introduction

_____ has been selected as one of CSOs to implement the Strengthening Communities' Response to HIV/AIDS (SCRHA) Project in_____ Region _____Towns for a period of _____. Accordingly, the CSO is expected to:

1) Plan and manage the implementation of the project at grassroots level
2) Provide information and support the implementation of trainings designed to be given to PC and ES providers.
   i. Play a lead role in the selection of Volunteer PC Providers and send them for the training.
   ii. Facilitate the participation of PC providers in the Economic Strengthening training components.
3) Directly implement Palliative Care and Economic Strengthening services by deploying PC providers
4) Build the capacity of PC providers in training experience sharing.

I. Scope of Work

The scope of work described below indicates the activities expected to be accomplished by respective CSOs.

Planning and Programming

a) With the support and information provided by the National Implementing Partner (NIP), develop annual and quarterly plan and budget for the project.
b) Based on the direction provided by the NIP, prepare grant application for the implementation of SCRHA project.
c) In close consultation with the NIP's responsible staff, participate in the preparation of the PC and ES training plans.
d) In accordance with targets given to respective towns under its jurisdiction, the CSO leads the selection of PC and ES service providers in collaboration with concerned sector government organizations and representatives of the community.