

Guide on

# How to design a Palliative Care Development Plan for cancer and other conditions

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## Purpose of the guide

This document summarises the steps and procedures for designing a development plan for palliative care. This is to be done by applying existing evidence to the diverse situations in low- and middle-income countries (LMICs) within the framework of the City Cancer Challenge Foundation (C/Can) project, in response to the urgent need to increase access to palliative care for cancer patients. The recommendations made in this document are the result of a technical revision made by an external expert in palliative care nominated by the African Palliative Care Association (APCA), Emmanuel Luyirika, in consultation with the C/Can Technical Cooperation team and Paola Ruiz, and based on the experiences and outputs developed by the palliative care groups in C/Can's cities: Rasheed Ofose-Poku and Christian Campi. This guide is expected to be interpreted, analysed and adapted on the basis of the local context and the need to build a multisectoral consultative process within the city.

# 1. Introduction

The steps outlined in this summary are meant to simplify the process of laying down an affordable and implementable palliative care development plan that can ensure an evidence-based and patient-centred response to the palliative care needs of a given population at local, district, municipal, city or national level. By following these steps, the individuals or entity developing the service can ensure that all the ingredients of the plan are captured and proper processes laid down to ensure a successful and sustainable programme. This will work for a palliative care plan for cancer patients as well as those with palliative care needs due to other conditions.

The process should be followed the following steps:

- 1 Situational analysis
- 2 Planning implementation
- 3 Monitoring, evaluation and reporting

## 2. Situational analysis

The first step is to undertake a situational analysis of the target area and population.

### 2.1 Collect the basic data of the geographical area through a situational analysis, so as to know your target area of coverage geographically and by total population

The target area may be a municipality within a city, a district, a province or a whole country. The extra information required related to the geographical area chosen can be taken from the bureau of statistics of the country which linking the geographical area with other aspects such as population size, demographics, health services and other variables. This step can also be done as part of a situational analysis or a survey, perhaps through a stakeholder focus group.

The situational analysis will also give an indication as to what percentage of the population in the targeted geographical area is affected by cancer and other chronic conditions and aging, for which palliative care is needed and where they are located; urban, peri-urban, rural, very rural or hard to reach areas.

The situational analysis should also pay special attention to key populations such as the disabled persons, displaced persons or refugees, the homeless and others who may have cancer and other conditions for which palliative care is needed, but who may be stigmatised, leading to exclusion from accessing services.

Information can be gathered through a survey, hosting focus groups and using data from the national ministry of health as part of the data collected in the national health management information system, as well as local or provincial governments complemented by data from the annual abstracts of the national bureau of statistics in a given country for that geographical area.

As part of this process, gather information about emerging conditions that may complicate the burden for palliative care services and, provide for the palliative care burden that may also be caused by emerging infectious diseases of an epidemic nature, especially in Africa, the Middle East and Asia, where diseases such as Ebola, Marburg, Bird flu and other emerging diseases have been known to occur and complicate access to palliative care.

### 2.2 Get to know the intended beneficiary population by location, total number, age, gender and common conditions for which palliative care is needed from what is already documented

Desk review of key documents in the country should complement the data collected in the surveys or focus groups.

## 3. Developing the plan for implementation

Anticipate the spectrum of patients' needs to range from simple to diverse and complex and planning for physical, psychological, social, spiritual, legal and other needs in a culturally-sensitive manner.

Anticipate and plan for needs of family members; spouses, parents, children, (dependants) and other relatives, as well as primary care-givers at home arising out of the illness of a family member.

### 3.1. Define the package of services that meet the needs of the targeted population and area you want to provide

The package should provide for:

- › The range of services to address physical, psychological, social, spiritual, legal and other needs that can be provided in the programme
- › Other services that can be provided for through the scoping of and linkage with potential partners with complimentary services in the defined geographical area for sharing resources and referral.

The package should include:

- › A list of essential palliative care medicines covering the aspects to be addressed, including access to essential controlled medicines for pain and symptom control.
- › Routine care to address the patient symptoms, wounds and other physical and psychosocial needs. Spiritual care and other psychosocial services, legal, nutrition and other services that the patients and their families might require should be included.
- › Equipment and patient assistive devices. Find out if radiotherapy will be available for cancer patients as a palliative modality and also for palliative care emergencies such as bleeding, spinal cord compression, superior vena cava syndrome etc.
- › The teams of professionals and non-professionals to deliver those services.
- › Develop or adopt a **home care kit** that staff who visit homes must carry.
- › The needs unique to children should be included in the package.

### 3.2. Design a management team and staff structure

This should reflect the team with diverse multidisciplinary skills required from doctors, nurses, pharmacists/pharmacy techs/dispensers, social workers, spiritual care givers and other allied health workers to offer comprehensive services which address those patients' needs identified by age, gender and site/geographical location.

### 3.3. Define the space requirements for your programme

This should be adequate to house the onsite outpatient services and/or inpatient services or as a base for the outreach or home-based care services.

### 3.4. Define the transport requirements for the programme

Depending on the geographical reach targeted, and especially if home-based care or community outreach is planned, determine the transport requirements which may be by foot or dedicated vehicle such as bicycle, motor bike or car. Some programmes can also use the public transport system.

### 3.5. Develop the necessary organisational policies, manuals, guidelines and tools

These are to provide a clear supportive framework within the organisation for the managers to manage the human resources, financial resources and other organisational assets in a manner that safeguard patients and their families and complies with the national patient care guidelines and policies. Clinical guidelines and tools should also be provided to the staff.

### 3.6. Develop a training plan

The training plan is to orient your team on the policies, guidelines and operational tools such as medical record forms, reporting tools and other documents outlined above. The training on management of palliative care conditions such as pain and others is referred to the next section of this document.

### 3.7. Determine financial and other resources needed and sources of funding

Determine the required budget to meet the needs such as the infrastructure, staff, consumables and operational funds. A well-designed budget will help make the programme development and initiation very seamless.

Resources may be allocated from the national or local government, donors, national or community health insurance or patient user fees. (User fees are a major stress and often totally impoverish patients and their families.

### 3.8. Recruit your staff team

This involves recruiting multidisciplinary teams with the required skills and experience that fit within the staff structure to meet patients' needs within the available resources. Train your staff team as per the training plan.

## 4. Monitoring, evaluation and reporting

Set up a robust monitoring, evaluation and reporting framework with clear indicators that meet your needs, those of the national ministry of health and donors reporting requirements. Ensure that you capture the indicators that will help you know what is going on and improve the services, and also to allow you report to the national ministry of health, the national medicines control authorities (medicines or drug control council) especially for controlled medicines, the atomic energy authorities where radiotherapy is used and your other donors.

Be sure to include a client and family satisfaction feedback mechanism in the monitoring and evaluation plan.

Plan to have operations research output as part of your programme to inform others and also document best practices.

Plan in a manner that the monitoring and evaluation cycle can be repeated periodically.



## 5. References

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