



# Romania

## Palliative Care Strategy and National Development Plan 2018 - 2022

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# Palliative Care Strategy and Development Plan 2018 - 2022

## 1. Introduction

The purpose of this paper is to outline a strategy and five-year plan for developing palliative care services in Romania. The author wishes to thank all those involved in the development of this strategy and plan, especially members of the Palliative Care Working Group (GTL-PAL) and the Palliative Care Commission. This paper should be read in conjunction with the population based **Palliative Care Needs Assessment, undertaken in 2016/17.**<sup>(1)</sup> The Palliative Care Needs Assessment gives a base-line for developing this strategy to improve palliative care services in Romania. This paper is set out in the following sections:

1. Introduction
2. Overview of Palliative Care
3. Development of Palliative Care in Romania
4. Health Service Context and New Palliative Care Legislation
5. Palliative Care Need in Romania
6. Strategy for Palliative Care and Sources of Funding
7. Proposed Development Plan for Palliative Care

## 2. Overview of Palliative Care

Palliative care seeks to relieve suffering and improve the quality of life for those with life-limiting conditions. It is a holistic approach that improves the quality of life for patients and their families by addressing the physical, psychosocial and spiritual needs associated with life-threatening illness. The World Health Organisation (WHO), defines palliative care as *'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'*<sup>(2)</sup>

Modern palliative care has developed rapidly in western countries in the last part of the twentieth century. Starting with the work of Dr. Dame Cicely Saunders in the UK in the early 1960, the modern philosophy of 'terminal care' was developed. Dr. Saunders philosophy promoted caring for the physical, psychological, social and spiritual needs of the dying patient and their families through true interdisciplinary teamwork. In 1967, Dr. Saunders founded St Christopher's Hospice in South London, in the UK. As the first 'modern' hospice it was unique in combining three key principles: excellent clinical care, education and research and it soon became an inspiration around the world. Others in the world, were also working to improve the experience of the dying and their families. In 1965, Glaser and Strauss published their research into dying patients in hospitals in the USA in 1969, Dr. Elisabeth Kubler Ross outlined her ideas on the stages of dying and in 1975 the Canadian physician Balfour Mount established a palliative care ward at the Royal Victoria Hospital, Canada.

Over time, the focus of 'terminal care' widened from caring for those who were dying to those who experienced problems with symptom control earlier in their disease. This led the new term '*palliative care*' which was adopted to describe the approach of caring for dying patients and their families, this term is now used world-wide. For many years palliative care was only provided for patients suffering from cancer. Patients with end-stage conditions, other than cancer, were denied palliative care services. However, with more people living longer with progressive illnesses and as the benefits of palliative care became more recognised, palliative care has become more widely available for adults and children who are suffering from any life limiting conditions. Palliative care is provided in a range of different settings, including in the home, out-patients clinics, day centers, hospital wards and specialist hospice settings.

Over the last two decades palliative care development has been spurred on by many different international policies and agreements. In 2014 when the World Health Assembly (WHA) passed its first palliative care resolution, recognizing palliative care as a '*human right and a state obligation*'. The resolution states that access to palliative care and pain relief is an element of the right to health and encourages member states to integrate palliative care into their healthcare systems, improve funding, training in palliative care and the availability of pain relief. Despite such broad recognition of palliative care, worldwide only about 14% of people who need palliative care currently receive it. <sup>(3)</sup>

### 3. Development of Palliative Care in Romania

Palliative care started in Romania in 1992, when the Hospice Casa Sperantei (HCS) Foundation was set up as a non-governmental charity through a UK-Romanian partnership with the charity Hospices of Hope UK. The organisation's mission was to introduce and develop palliative care in Romania. A decade later, HCS established the first Romanian centre for palliative care services and education in Brasov. Since that time HCS has been actively involved in developing palliative care services and national and international education programmes. It has also played a major part in the advancement and integration of palliative care into the Romanian healthcare system.

The National Association of Palliative Care (ANIP) was founded in 1997 by Dr Daniela Mosoiu. Several important regulations specific to palliative care were advanced by ANIP, including a new law for the use of analgesia, new financing mechanisms for palliative care services and the establishment of palliative care standards and minimum staffing ratios for palliative care in-patient units in 2010. ANIP members have also been actively involved in several pilot projects aimed at improving palliative care services and education. The key milestones in developing palliative care in Romania are set out in **Appendix 2**. These advancements have helped to progress the development of palliative care in Romania. However, many of the initiatives have taken years to achieve and have not included in a wider national health service strategy. Most of the initiatives have relied on funding from grants or charitable sources and have been driven by the commitment of a few passionate individuals who have had the tenacity to bring about the changes needed to improve the lives of those who are suffering from life-limiting conditions.

### 4. Health Service Context and New Palliative Care Legislation

The Romanian National Health Strategy 2014 - 2020 is the key policy document that sets out the vision and direction for health services in Romania. A fundamental principle, contained in the strategy, is for the health system to provide *“equal access to essential services through a cost-efficiency and evidence-based approach.”* In 2014, the Romanian ANIP estimated that only 7.9% of the need for palliative care were covered by existing palliative care services. The National Health Strategy 2014 – 2020 sets an ambitious strategic target of reaching 60% coverage for patients requiring palliative care by 2020. <sup>(4)</sup>

The Frame Contract, signed between the Health Minister and the National House of Insurance, regulates the relationship between the providers of palliative care services and the other health care sectors. This document stipulates the conditions of admission into and out of inpatient units and into palliative home care services. The National Agency for Standardization in Health Care, reviewed the palliative care quality standards, developed by the National Association for Palliative Care, and have included specific standards for palliative care in inpatient units. <sup>(5)</sup>

Palliative care is offered by a range of diverse providers paid under contracts with the District Houses of Insurance (DHIHs), (for health services) or by the Ministry of Labour, Family and Social Protection and Elderly (for social services). Each palliative care service provider must sign an annual reimbursement contract. Home-based palliative care services are still isolated initiatives and their funding, through the health insurances system is low, even though 70% of people in Romania die at home. <sup>(6)</sup>

In March 2018 a new law (No. 253/2018) <sup>(7)</sup> was passed that allows for the development of palliative care medicine in Romania. The new regulation includes the list of beneficiaries entitled to palliative care (**see Appendix 2**), sets out the different levels of palliative care service provision and states how, where and by whom, those services will be delivered. The aim of this legislations is to ensure that everyone in Romania has access to appropriate palliative care services to meet their needs.

In 2014, the World Bank approved a EUR 250 million loan to Romania to improve the health system. The *'Health Sector Reform – Improving Health System Quality and Efficiency Project'*. <sup>(8)</sup> The project includes the following components:

- i) Rationalisation and changes to acute hospitals and developing key hospitals that will become the backbone of the hospital network.
- ii) Strengthening ambulatory care, establishing specialised secondary ambulatory day care, diagnostic and treatment centres, enhancing primary health care services at the community level and developing capacity for long-term care and palliative care.
- iii) Improving health sector governance and stewardship and improving the quality of medical care services.
- iv) Providing support with project management, monitoring and evaluation

The World Bank Health Sector Reform Project includes improving palliative care in Romania. It has set a target of establishing **90 ambulatory specialised, palliative care out-patient centres, 90 palliative care home care teams and 29 palliative care in-patient units** by 2020 within the public health system, to ensure uniform coverage of palliative care services across the country.

There are several healthcare projects underway in Romania to support the changes required to transform health services in Romania. Some projects are supported through the World Bank funding, others are funded by external agencies or grants. They include:

- **Development of Regional Health Services Master Plans** – health service development plans are being compiled for each Region. These plans set out the changes in healthcare services for each Region, for example in NW, NE and SW regions there are plans to develop mono specialty hospitals, decommission some hospitals and develop Outpatient Units. The development of palliative care services should be included in each of the Regional master plans - *(World Bank Project)*
- **Integrated community centres** – new centres which combine healthcare, education and social care services - *(Swiss and Norway Funds)*
- **Out-patient Units for ambulatory care patients** – including outpatient clinics, diagnostic and treatment facilities - *(World Bank Project)*

The Ministry of Health is working towards trying to integrate these different projects to ensure there is synergy between each of the projects

## **5. Palliative Care Need in Romania**

As part of the World Bank project an assessment of palliative care need in Romania was undertaken in 2017, in collaboration with the Palliative Care Technical Working Group and Palliative Care Commission. The purpose of the population-based needs assessment was to gain an understanding of the current need for palliative care in Romania and to identify the type and distribution of palliative care services required to meet that need.

The full palliative care needs assessment report sets out the demographic and epidemiological profiles of Romania, quantifies the palliative care need, identifies the current palliative care coverage in the country, identifies the gaps in services provision and sets out the challenges and opportunities in developing palliative care services Romania

The Palliative Care Needs Assessment Report, (*December 2017*), <sup>(1)</sup> should be read in conjunction with this paper to appreciate the rationale for the proposals set out in this strategy and development plan. **A summary of the palliative care need in Romania is set out below. The current palliative care capacity (beds, clinics, home-care teams, staff), and the required palliative care capacity to meet the palliative care need is addressed in the strategy chapter of this report.**

- **Palliative Care Need**

The population of Romania is declining and is currently just under 20 million. A combination of people living longer and life style factors (smoking, obesity and alcohol consumption) is leading to a greater demand for health services, especially for people with chronic, progressive diseases and cancer. This disease burden is increasing the need for both general health services and palliative care services.

Over half the population in Romania live in urban areas, with the greatest density of people living in cities with more than 100,000 inhabitants. However, over 43% of the population still live in rural areas of communes between 500 – 1,000 people. Although the population volume is lower in rural areas, mortality rates are higher in some rural areas and health outcomes poorer. Health care services are less available in rural areas, even when they are available people have to travel further, with inadequate transports systems, to access the services. Healthcare professionals are also less available in the rural areas, leading to some areas not having access to a family doctor or specialist health services.

The poverty rate in Romania is still the second highest in the EU and the country has the fifth highest score for income inequality in the EU. Approximately 40% of the population are at risk of poverty and social exclusion and this is especially prevalent in the Roma community. Poverty has a direct impact on health, creating the need for the provision of health services which are available and accessible to everyone regardless of their social or economic position.

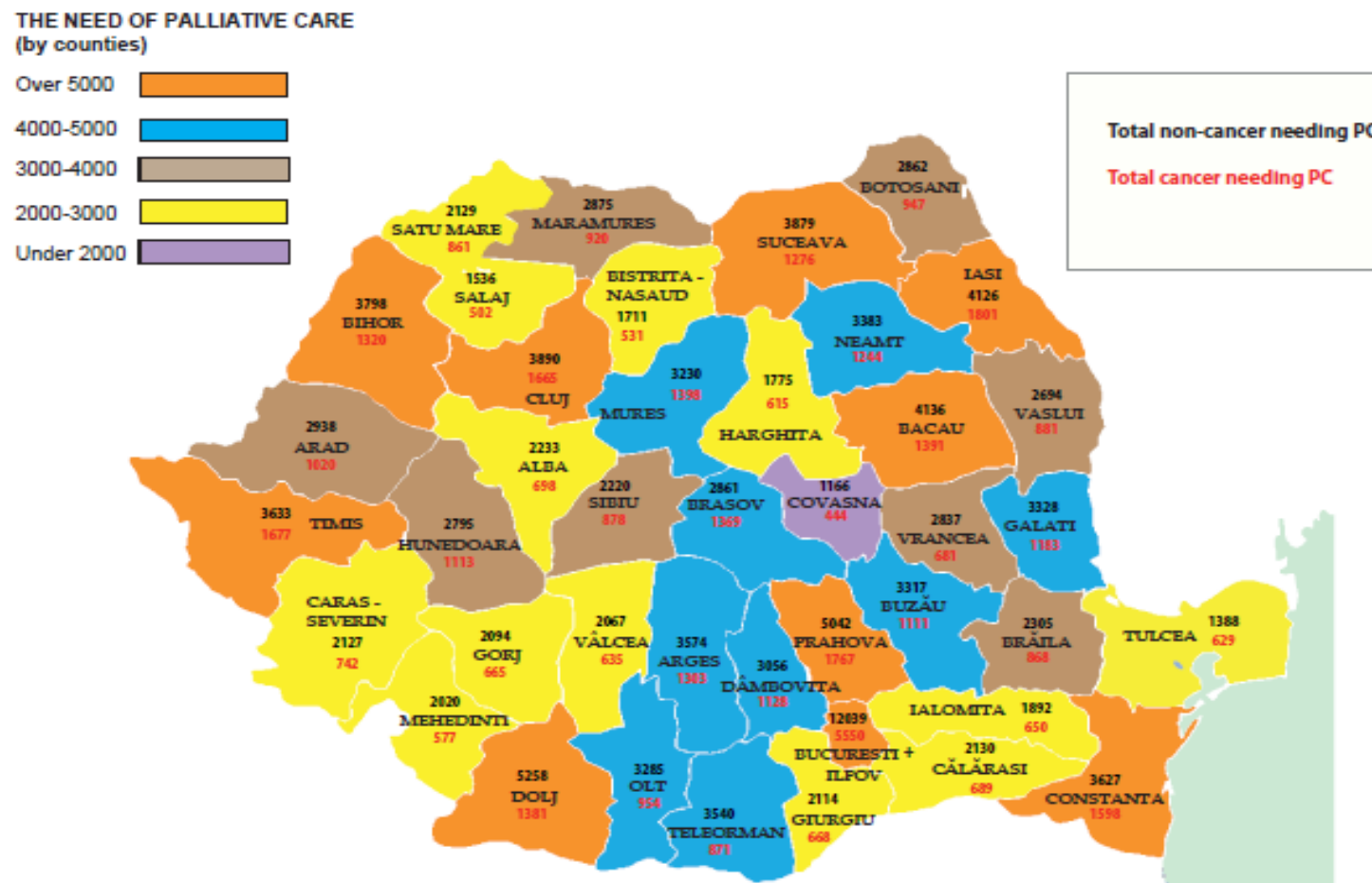
The main causes of death in Romania are circulatory disease, followed by malignant tumours, ischaemic heart disease and cerebrovascular disease. More people are now living longer with the effects of serious chronic illnesses towards the end of their life.

The assessment of palliative care need has identified there is approximately **172,663** people in need of palliative care every year in Romania. The majority, 73%, suffer from chronic, non-oncological conditions and 20% suffer from terminal oncological conditions. There is a general



spread of patients with palliative care needs across the country, but the counties of Prahova, Dolj, Constanta, Iasi and Suceava have the highest need for palliative care services. The palliative care need is also high in the some of the rural areas, presenting a challenge when designing services to meet the need in these isolated areas.

In undertaking the review of palliative care need we were able to highlight those counties where the palliative care need is the greatest and also identify if that need was due to oncological or non-oncological conditions. **The map below summarises the palliative care need for cancer and non-cancer patients per county and shows the areas with the greatest need.**



# PALLIATIVE CARE STRATEGY

## 6. Palliative Care Strategy

Information obtained from the Palliative Care Need Assessment, The Regional Health Master Plans, (developed as part of the World Bank Healthcare Reform Project) and the development of the new Palliative Care Legislation passed this year, has led us to review and revise the strategy for palliative care, which was developed in 2012. **The following chapter sets out a proposed national strategy for developing palliative care services in Romania over the next five years.**

### 6.1. Palliative Care Vision, Mission and Objectives

#### ➤ Our Vision:

Our vision for palliative care is that everyone who needs basic and specialist palliative care in Romania will have access to high-quality palliative care services which are integrated into all levels of healthcare systems, regardless of where they live or their ability to pay.

#### ➤ Our Mission:

In developing this strategy our purpose is to alleviate suffering and improve the quality of life of all beneficiaries with life-limiting conditions in Romania who require palliative care and to provide support to their families and carers when needed

#### ➤ Our Objectives: To achieve our mission we will work towards:

- developing and implementing basic and specialist level palliative care services across the whole of the country
- ensuring the appropriate level of services are available to meet the needs of all patients in Romania who require palliative care, and their families, regardless of where they live or their ability to pay
- ensuring palliative care is provided in the most appropriate setting to meet the palliative care needs of patients' and their families
- providing the appropriate support to the families and carers of patients requiring palliative care

- growing the number of specialist palliative care professionals and providing on-going professional development training/education
- developing the competence of other health/social care professionals in understanding and applying the principles of basic palliative care
- encouraging a greater understanding of the principles and benefits of palliative care in the public through education and public awareness

## 6.2 Principles for Health Service Planning

All health service planning requires a systematic approach if it is to be effective and meet the needs of the population. The following principles should be considered when planning the development of any new health service, including palliative care services:

- **Needs and Service User Preference Driven** – The overriding requirement for palliative care services is that they should be designed and delivered to meet the specific and distinctive needs of the people that they are intended for. The needs should determine what services are required and where possible how, where, when and who should provide the services.
- **Availability** – palliative care services should be available throughout the country even in the remotest areas. There is a commitment to achieve a 60% national coverage by 2020, though this is as a proportion of those who are eligible for palliative care rather than geographic coverage. It is also desirable that palliative care services should be available at the times (time of day, day of week) convenient to the people who need the services.
- **Accessibility** – once the services have been made available every effort should be made to eliminate any barriers to people accessing those services. The barriers typically include:
  - **Economic** – whatever system is used for financing palliative care services in Romania the goal should be to remove the ability to pay for services as a potential restriction to access

- **Geographic** – given that Romania has one of the highest proportions in Europe of people living in rural areas, ensuring that there are no geographic barriers is a real challenge especially where the rural infrastructure is poorly developed and public transportation non-existent. To the extent possible palliative care services should be taken to the people who require them
  - **Language** – although Romanian is the nation’s official language there may be communities where the spoken language is Hungarian, Romani, Ukrainian, German, Serbian or Russian requiring services to be provided in these languages.
  - **Intellectual** – health services are often offered in an intellectual incomprehensible way to those who are not part of the system nor experienced in its use. Simple, effective structures and communication are required.
  - **Cultural** – given the heavy component of social and spiritual care in palliative care, it is important that services are designed nationally to allow the flexibility to meet local cultural differences without restriction
- **Quality** – A realistic approach for Romania in defining quality in palliative care is to define ‘best practices’ in terms of what is achievable in the country over the coming years. Already many countries are defining minimum ‘acceptable’ standards, whilst also being aware of higher ‘desirable’ standards to aspire to. Also, it is true that the many of the elements that define ‘good quality palliative care’ are not resource dependent. High quality is more to do with the nature of the interaction of the healthcare professional with the person needing palliative care (and their family/carers), the appropriate interventions that are used and the responsiveness of the system as a whole.
  - **Continuity of care** – Specialisation has delivered many benefits for patients requiring palliative care. However, the challenge in palliative care is to overcome the boundaries which sometimes impact on the continuity of care, such as secondary/primary care, curable/incurable, in-patient/outpatient/home settings etc.
  - **Cost of care (cost/benefit)** – the value of palliative care is more qualitative (adding quality to life), than quantitative (adding years to life). Although there are quantitative benefits, particularly in cost avoidance, these are poorly documented. Palliative care makes its case based on the value its services add to a person’s life. The case which is self-evident to those who receive palliative care and their

care givers. However, the value of palliative care needs to be understood more broadly by all stakeholders including tax payers, politicians, government officials, health insurers and other health care professionals.

### 6.3 Beneficiaries of Palliative Care

New legislation, (Ministry of Health Order 253/2018), <sup>(7)</sup> lists the beneficiaries who are now entitled to palliative care in Romania. These include both adults and children with cancer and non-cancer life-limiting conditions (*see appendix 2*).

### 6.4 The Needs of People with Life-limiting Conditions

The physical and emotional effects of living with a life-limiting condition differ from person to person. Differences in age, cultural background, personality, faith, and family support systems may all influence how an individual responds and copes with a life-limiting condition. People with life-limiting conditions present with a wide range of different needs which can be met by the holistic approach provided through palliative care. Comprehensive palliative care seeks to meet the following needs of each patient:

- i) **Physical Needs** – the physical needs of people suffering with life-ending conditions can be grouped into two categories:
  - Need for symptom control - common physical symptoms associated with life threatening conditions include pain, fatigue, loss of appetite, nausea, vomiting, shortness of breath, and insomnia. Many of these can be relieved with medication or by using other methods, such as palliative radiation therapy, physiotherapy and alternative therapies e.g. acupuncture and aromatherapy.
  - Need for essential nursing care - as an individual reaches the end stage of their life they will frequently need help with many of the normal activities of daily living that they have previously been able to do for themselves e.g. washing, moving, using the toilet, feeding and drinking. These physical needs might be able to be met within the family support system or there may be a need for a greater input from the palliative care team
  
- ii) **Emotional needs and support with coping** – The emotional needs of people and their families suffering life-ending conditions can be

considerable:

- People facing the end of life often experience several different emotions. Depression, anxiety and fear are only a few of the concerns that can be addressed through palliative care. Palliative care professionals can demonstrate an understanding of these needs and provide support, comfort and counselling if needed. They can also recommend resources, support groups, hold family meetings, or make referrals to mental health professionals, if appropriate.
- It is not only the individual that suffers when a person is dying, the family of that loved one also has to cope with a number of different emotions, both during the individual's illness and following their death. These emotions may include anger, anxiety, sadness, fear, confusion, emptiness and guilt. Not everyone experiences all or any of these emotions and, although bereavement is a natural reaction to death, the palliative care team can offer both help and expertise in supporting the family both before, and after the death, of a loved one.

iii) **Practical and social needs** - People with life-limiting conditions may have financial and legal worries, insurance questions, employment concerns and concerns about writing wills and practical day-to-day issues. For some individuals the technical language and details of laws and forms are hard to understand. To ease the burden, the palliative care team may assist in helping the individual and their family or co-ordinate the appropriate services to assist them.

iv) **Spiritual** – People's life-limiting conditions and families often look more deeply for meaning in their lives. Some find the disease brings them more faith, whereas others question their faith as they struggle to understand why this condition has happened to them. Palliative care practitioners can help people explore their beliefs and values so that they can find a sense of peace or reach a point of acceptance that is appropriate for their situation.

## **6.5 Palliative Care Services Required to Meet the Needs of People with Life-limiting Conditions**

- **Care Planning** – planning and agreeing with the beneficiary and their family (if so desired) and other healthcare professionals what care interventions and goals should be undertaken. Care planning includes:
  - Assessment – assessment is not a one-off event, rather it is an interactive and on-going process of assessment and re-assessment as the individual and family’s condition/situation changes over the course of an illness. It includes the assessment of physical, psychological, social, and spiritual needs and is undertaken by members of the multi-disciplinary palliative care team.
  - Implementing care – this can be undertaken by the person themselves (self-care), family members or healthcare professionals
  - Monitoring and evaluating care – again, this should be a joint activity between the recipients of the care, their family and those providing the care
  
- **Symptom control** – includes control of physical and emotional symptoms experienced by the individual. These differ from person to person depending on the individuals medical condition, age, background, personal characteristics, coping mechanisms and social support network, as well as their specific medical condition
  
- **Medical services** – includes the input from the specialist palliative care physician in relation to assessing and managing symptoms through using the appropriate medical interventions/medication.
  
- **Nursing care** – includes help and support with activities of daily living, effective communication with the individual and their family and specific nursing interventions e.g. dressings, venipuncture and support with the management and administration of medication
  
- **Therapy services** – includes physiotherapy, occupational therapy, creative (music/art/drama) therapy
  
- **Pharmacy services** – includes advising on prescriptions and preparing and dispensing medication
  
- **Psychological service** – includes counselling, support with the management of pain and bereavement services
  
- **Social services** – includes help with financial issues, obtaining specialised equipment, arranging respite care and holiday breaks



- **Chaplaincy services** – spiritual support can be provided by all carers. The services of a chaplain may be needed depending on an individual's beliefs and spiritual needs
- **Information service** – covers a range of information from clinical (e.g. conditions, symptom control) to social care (e.g. benefits and resources)
- **Education and training** service for patients and their family/carers and healthcare professionals

The overall goal of palliative care is to improve the quality of life of those being cared for. The person receiving palliative care needs to experience several things in the care process that will accomplish this. These include:

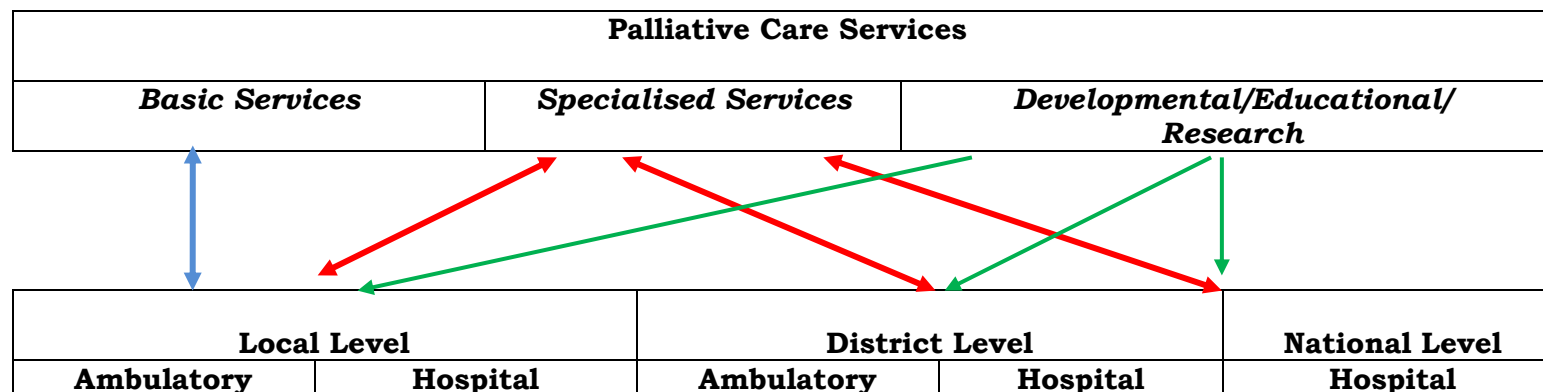
- Being treated as individuals, with dignity and with respect for their culture, lifestyles and beliefs
- Having their 'voice' heard and being valued for who they are
- Having a chance to celebrate and enjoy life while they are still strong enough to do so
- Having both the opportunity and support to talk within the family about their illness and prognosis if they choose to do so
- Participating in excellent, on-going face-to-face communication with palliative care health and social care professionals about their condition, care, treatment, aspirations, worries, fears and concerns
- Receiving appropriate information about their condition and possible treatment which is given in an honest, timely and sensitive manner at all stages of their illness
- Understanding what options are available to them, including the options available for care and treatment, where they can be cared for, who will care for them and what other services are available to support and help them and their families
- Participating, with their family and healthcare professionals, in the development of their care goals and plan
- Knowing that their physical symptoms will be managed to a degree and is consistent with their condition
- Relief from their physical and emotional symptoms in the most appropriate way that suits their individual needs
- Emotional support from professionals who have time to listen and who show empathy and understanding of their concerns
- Reassurance that they will only undergo those interventions for which they have given informed consent

- Services that are well co-ordinated and of a high quality, delivered by healthcare professionals and lay-people who have had the appropriate level of education and training
- Support and advice on financial and, if appropriate, employment issues
- Appropriate support to enable them to explore spiritual issues if they choose to
- Companionship, if they so choose and peace throughout the journey of their illness and the process of dying
- Dying in the place of their choice free from pain, anxiety and other distressing symptoms
- Being assured that their family and carers will be supported throughout the illness and in bereavement.

### 6.6 Approach to Delivering Palliative Care Services Within a National Structure

The Romania Healthcare Strategy 2014-2020 promotes the decentralisation of health care services and moves away from a hierarchical structure. It is this approach that has been adopted in proposing the way forward for developing palliative care services. The provision of palliative care services can be thought of on three geographically defined levels: local, district and national.

The types of services which can be provided at these levels – **basic, specialised and developmental** (including education and research) – are discussed in the following pages. As well as beginning to describe the context in which palliative care services are provided, the table below indicates the types of horizontal relationships that palliative care should have with ambulatory care and in-patient services



### Basic Palliative Care Services

- Assessment
  - Patient
  - Competency
- Care planning
- Symptom control
- Pain control
- Medication
- Counselling
- Monitoring
- Terminal care
- Education
- Spiritual support
- Psychological support

|   |   |   |                                  |                         |
|---|---|---|----------------------------------|-------------------------|
| Home Care<br>Dispensaries<br>Primary Care<br>Physicians | Rural (intern med,<br>peds. 120 beds)<br>Town/municipal<br>(gen 250-400 beds) | Diagnostic &<br>Treatment Centres<br>Outpatient depts.<br>Specialty<br>physicians | First level of<br>specialisation | Specialty<br>(Tertiary) |
|---|---|---|----------------------------------|-------------------------|

The following section explains in more detail the basic and specialized palliative care services and sets out what should be undertaken at national level.

#### 6.7 Basic Palliative Care Services Should be Provided at a Local Level to Those People Who Have Relatively Straight Forward Needs

- The first aim is to provide as much palliative care as possible in the person's home locality (when this is appropriate) whether this is in their home or a community location be it one of the dispensaries, general practitioners' offices, or hospital outpatient departments, considering the person's preferences and those of their family/carers
- To the greatest extent possible basic palliative care services should be provided through existing professional and lay resources which have been trained in the provision of palliative care. It is not expected that these services will be provided by full time dedicated palliative care staff for the most part.
- The range of basic services which should be provided locally is listed in the adjacent box. Most of these services are self-explanatory but some may not be:
  - Assessment at the local level is of two types:
    - assessment of the patient's condition and service needs
    - assessment of the availability and competence of local capabilities to meet these needs
  - Symptom and pain control – using recognised tools for assessing and measuring symptoms and pain
  - Medication – within agreed protocols
  - Terminal care – skilled nursing and medical care and support at the end of life

People who can receive palliative care at the local level are expected to be those who have relatively straight forward needs, few if any co-morbidities and are in a stable condition. Protocols that define when a referral should be made to the specialised palliative care services should be established and followed. They are likely to include such considerations as persistence, severity and complexity of problems.

## 6.8 Specialist Palliative Care Services Should be Provided at a Regional Level to Those People Who Have Complex Needs

- A significant proportion of patients in need of palliative care will require specialist palliative care services. These patients could be expected to have one or more of the following characteristics:
  - complex physical and/or emotional needs
  - symptoms which are difficult to alleviate or control or which fluctuate
  - multiple pathology (co-morbidities associated or not with their primary cancer)
  - a poor social support network or the need for respite care
- Specialist palliative care services include:
  - Care Planning done jointly with the care recipient, their family and healthcare professionals - includes assessment of physical, psychological, social and spiritual needs, developing/implementing the care plan and monitoring and evaluating care
  - Symptom control – control of physical and emotional symptoms. These will differ from person to person depending on the individual’s medical condition, age, background, personal characteristics, coping mechanisms and social support network, as well as their specific medical condition
  - Medical services – input from specialist palliative care physicians in relation to assessing and managing symptoms using appropriate medical interventions and medication.
  - Nursing care – help and support with activities of daily living, effective communication and nursing interventions
  - Therapy services – physiotherapy, occupational therapy, creative (music/art/drama) therapy
  - Pharmacy services – advising on prescriptions, preparing and dispensing medication
  - Psychological service – counselling, support with pain management and bereavement services
  - Social services - help with financial issues, obtaining specialised equipment, respite care/holiday breaks
  - Chaplaincy services – spiritual support can be provided by others
  - Information service – covers a range of information from clinical information (e.g. conditions, symptom control) to social care information (e.g. benefits and resources)

### Specialist Palliative Care Services

- Assessment (Patient)
- Care planning
- Symptom/pain control
- Medical
- Nursing care
- Counselling
- Diagnostic
- Therapeutic
- Pharmacy
- Psychological
- Social
- Chaplaincy/spiritual
- Education & training – patient and staff

## 6.9 Some Services Should be Provided at the National Level Through a Consortium of Palliative Care Providers

- There will be benefit in palliative care providers working together to address areas of mutual interest that are more efficiently dealt with at a national level. These include
  - i) Promulgating and disseminating standards of care and care protocols
  - ii) Peer review of performance and outcomes
  - iii) Gathering statistics on need, utilisation, cost etc.
  - iv) Surveying the opinions of patients, care givers, fund raisers, volunteers, the public etc. about palliative care
  - v) Patient advocacy initiatives
  - vi) National campaigns to raise the awareness of palliative care services
  
- Lobbying government representatives and health insurance funds could also be done on a national basis
  
- Providing input to education and research programmes should also be done on a national basis
  
- International links and participation is often done on an individual basis and whilst this should continue there are certain international programs that Romania will want to be represented at and participate in on a national basis
  
- The existing coalition/ National Association of Providers of Palliative Care is the sensible vehicle for developing this full range of activities

## 6.10 Education and Research Programmes Should be Developed as Part of Romania's Palliative Care Strategy

The following education programmes and research should be a key component of implementing this strategy:

- **Patient and Carer Education:** Patient and carer education programmes that teach patients to self-care, and as importantly, instructs them when to seek professional help, self-care education could include:
  - how to maintain independence throughout their illness
  - how to be an 'active' rather than 'passive' user of the service by participating in decision making and understanding the choices they have available to them
  - the physical and psychological self-help approaches to managing pain
  - the self-management of analgesia (within guidelines agreed with the medical practitioner)
  - family and lay carers provide much of the palliative care that patients receive, with the right education and training this care could be provided more expertly
  
- **Professional Education:** Romania has already made a good start in this area with the accredited National Post Graduate Center. There are two types of professional education:
  - i) Professional healthcare workers who have patient contact and wish to increase their knowledge and skills in palliative care
  - ii) Professional staff who wish to become dedicated palliative care workers and require more advanced knowledge and skills to enable them to provide specialist palliative care services
  
- **Research** – on-going research into palliative care is important to ensure the advancement of palliative care medicine and the use of evidence-based practice by healthcare professionals. The two types of research that are most needed are as follows:
  - Clinical research seeking to develop improved care practices and the effectiveness of different medication
  - Studies exploring the relationship between costs and outcomes, effectiveness, efficiency and value for money

Research programmes should be university based but underpinned by the practical experience of working with people requiring palliative care.

### 6.11 Palliative Care Services Should be Provided in a Range of Different Settings

- **Home care:**

Both basic and specialist services can be provided in the home. Specialist services would be co-ordinated support for people with complex needs and should be provided by specialist staff in the patient's home where this is desired and is practical. This may involve the specialist palliative care team providing advice alongside the patient's own family doctor and home nursing services to enable someone to stay in their own home. Specialist palliative care teams should also provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home, often known as 'hospice at home'.

- **Family Doctors Surgeries**

- **Ambulatory care/Out patients/day care facilities** offering a range of opportunities for assessment and review of patients' needs and to enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship. Many also offer creative and complementary therapies.

- **Palliative care centres in general and specialist hospitals:** in-patient facilities dedicated to palliative care for people who need and will benefit from continuous support and care of the specialist palliative care team

- **Hospices:** similarly, facilities dedicated to palliative care for people who need and will benefit from continuous support and care of the specialist palliative care team



## 6.12 Agreed Ratios for Palliative Care Services and Staffing

The ratios for determining the number of palliative care beds, palliative care out-patient departments and home based palliative care teams and staff has been set out in the Romanian Ministry of Health Regional Service Plans (2016). The staffing ratio for palliative care in-patient beds, out-patient clinics and palliative care home-based teams has also been agreed in the regulations. The table below sets out the agreed ratios:

### Palliative Care Service and Staffing Ratios

| <b>Number of Palliative Care In-patient Beds per population</b>   | <b>Number of Palliative Care Out-patient Clinics per population</b>  | <b>Number of Palliative Care Home-based Teams per Population</b>  |
|---|--|---|
| 25 PC beds per 125,000 population   | 1 PC out-patient clinic per 60,000 population  | 1 PC home-based team per 40,000 population  |
| <b>Staffing ratio for palliative care inpatient beds</b>  | <b>Staffing ratio for palliative care outpatient clinic</b>  | <b>Staffing ratio for home-based team</b>   |
| <ul style="list-style-type: none"> <li>• 1 doctor with PC subspecialty per 12 beds</li> <li>• 1 nurse with PC specialty per 8 beds per shift</li> <li>• 1 nurse-assistant per 8 beds per shift</li> <li>• 1 social worker per 25 beds</li> <li>• 0.5 psychologist per 12 beds ;</li> <li>• 4 - part-time other staff (physiotherapist, spiritual counsellor)</li> </ul> | 1 palliative care outpatient team consists of: <ul style="list-style-type: none"> <li>• 1 doctor</li> <li>• 1 nurse</li> <li>• 0.5 social worker</li> <li>• 2 part-time other staff (physiotherapist, spiritual counsellor)</li> </ul> | 1 palliative care home-based team consists of: <ul style="list-style-type: none"> <li>• 2 doctors</li> <li>• 4 nurses</li> <li>• 1 psychologist</li> <li>• 0.5 physiotherapist</li> </ul> |

**These ratios have been used have been used in the Palliative Care Needs Assessment to determine the number of additional palliative care services and healthcare professionals that are required to meet the palliative care needs of the population**



### 6.13 Current Palliative Care Service Capacity in Romania

Using information from the 2016 Palliative Care Services Register,<sup>(9)</sup> data from the Survey of Palliative Care Providers (2015)<sup>(10)</sup> and the Palliative Care Needs Assessment (2017),<sup>(1)</sup> we identified that the following palliative care services are available across the eight Regions:

- **In-Patient Palliative Care Beds:**

Palliative care in-patient beds are provided in a range of different settings including public and private hospitals and NGO hospices. There is a total of 83 providers of palliative care across the country, approximately 61% are public providers, 21% private (fee-paying) providers and 17% NGOs (not-for-profit) providers.

There is a total of **1,779** palliative care beds in the country. **1,037 (59%)** are not-for-profit beds provided by public funding or NGO's providers. The highest number of palliative care beds (45%) are in the North-East Region, (815 beds). However, it should be noted that almost half of these beds (370) are private, fee-paying beds and therefore not accessible to the whole population.

There are **17 counties** across the whole country that do not have any public or not-for-profit beds. The **Southern** part of the country is the worst served in terms of palliative care beds. The **South-West Region** has only 1% of the country's palliative care beds, (22 beds in Dolj), and four counties without any palliative care beds. The **South Region** has only 5% of the country's palliative care beds, (88 beds in Arges, Giurgiu and Prahova) and also four counties without any palliative care beds.

There is disparity in the distribution of palliative care beds between Regions and between counties within the same Region. For example, Iasi has the largest concentration of palliative care beds, 69% (570 beds) in the North-East Region, while two counties in the same region, Botosani and Vaslui do not have any palliative care beds. However, it is possible that beds in Iasi also serve the counties of Botosani and Vaslui. Brasov has 42% of the palliative care beds in the Centre Region and Covasna does not have any beds. This pattern of uneven distribution of palliative care beds is found across the country. The 2015 survey of palliative care providers shows that Iasi and Brasov have the highest number of palliative care admissions per district. This is not surprising as both these counties have the highest number of beds in the country.

- **Home-Based Palliative Care Teams:**

There is a very small number of home-based palliative care teams serving the population of Romania, in **total 13 teams** provide palliative care to patients at home. The Centre Region has the largest number of teams with 7 home-based palliative care teams, one in each of the districts, and 3

in Brasov. The North-East Region has 2 home-based teams in Bacu, the North-West Region has 2 home-based teams, 1 in Bihor and 1 in Cluj. The South has 1 home-based team in Giurgiu and Bucharest has 1 home-based palliative care team.

The West, South West and South-East Regions do not have any home-based palliative care teams. All home-based palliative care teams are provided through NGOs.

- **Palliative Care Outpatient Departments:**

Romania is very poorly served with palliative care outpatient departments, there is only a **total of 3** palliative care outpatient departments in the whole of in Romania, 2 in Brasov and 1 in Bucharest. These outpatient services are provided through an NGO.

- **Palliative Care Day Centres:**

There is a **total of 5** palliative care day centres, 1 in Arges, 1 in Dolj, 2 in Brasov and 1 in Bucharest. All the palliative care day centres are provided through NGOs.

- **Bereavement Support:**

Providing bereavement support to families following the death of a family member is recognised internationally as being an essential part of good quality palliative care. The data from the 2015 survey shows that only 56% of palliative care providers in Romania offer a bereavement service to families, this may be due to bereavement support not being included in funding for palliative care services.

- **Clinical Protocols:**

Over the last decade, internationally, clinical protocols have become an increasingly familiar part of clinical practice. Clinical protocols are evidence-based guidelines for specific conditions or symptoms. Clinical protocols aim to improve the quality of clinical decisions and the consistency of patient care between physicians and across healthcare settings. Protocols are also useful in helping to manage costs by ensuring interventions are based on research-based practice. The 2015 survey of palliative care providers showed that over 80% of providers were using protocols in their work, however only 1 provider was using 20 protocols, with approximately 68% of providers using only three or less protocols.

### 6.14 Current Palliative Care Healthcare Professionals

The following table shows current number of professional staff, the numbers that are required and the gap between the two. This is set out for each of the different professional groups, for each of the three palliative care services. Some specialist palliative care doctors are not currently working in palliative care. However, for this analysis, we have assumed that **all** the current specialist palliative care doctors (those with the competency in specialist palliative care) will, in the future, be working in palliative care.

| Region            | Specialist Doctors Current* | Specialist doctors REQUIRED<br>(For beds, OP, and home care teams) | Gap         | Nurses Current | Specialist Nurses REQUIRED<br>(For beds, OP's and home care teams) | Gap         | Social workers current | Social workers REQUIRED<br>(For beds and home care) | Gap        |
|-------------------|-----------------------------|--|-------------|----------------|--|-------------|------------------------|---|------------|
| North West        | 91                          | 214  | 123         | 73             | 600  | 527         | 1                      | 42.5  | 41.5       |
| North East        | 91                          | 272  | 181         | 105            | 762  | 657         | 1                      | 53  | 52         |
| Centre            | 95                          | 196  | 101         | 66             | 548  | 482         | 4                      | 38.5  | 34.5       |
| South East        | 36                          | 206  | 170         | 52             | 578  | 526         | 0                      | 40.5  | 40.5       |
| South             | 33                          | 253  | 220         | 16             | 709  | 693         | 2                      | 49  | 47         |
| South West        | 8                           | 166  | 158         | 0              | 467  | 467         | 0                      | 32.5  | 32.5       |
| West              | 41                          | 150  | 109         | 33             | 421  | 388         | 1                      | 29  | 28         |
| Bucharest - Ilfov | 85                          | 190  | 105         | 45             | 532  | 487         | 3                      | 37  | 34         |
| <b>Total</b>      | <b>480</b>                  | <b>1647</b>  | <b>1167</b> | <b>390</b>     | <b>4617</b>  | <b>4227</b> | <b>12</b>              | <b>322</b>  | <b>310</b> |

\*Note: Included all doctors with a speciality competence in palliative care

### 6.15 Additional Palliative Care Services and Healthcare Professionals Required

The Palliative Care Needs Assessment (2017) sets out in detail the current and required palliative care services and healthcare professionals by Region and identifies the gaps and additional services and staff required by Region. The following summary of that information.

Currently there is a total of **1,779** palliative care beds across the country, with **1,037 (59%)** being non-fee-paying beds provided by public funding or NGO providers. There are only **3 palliative care out-patient** and **13 palliative home care teams** in the country and these are provided by NGOs. Across the whole of Romania, there is a large deficit of palliative care services and specialist palliative care healthcare professionals compared with what is required to meet the palliative care needs of the population. There is a disparity of palliative care services between Regions and counties. This deficit is greater in the Southern part of the country and in some rural areas. Less than 2% of the family doctors have received training in providing a basic level of palliative care, meaning that palliative care is very underdeveloped at primary care level.

The following table summarises the number of **additional** palliative care services and healthcare professionals (excluding therapists and psychologists) that are required at a Regional level, to meet the palliative care needs of the population.

#### Additional Palliative Care Services and Healthcare Professionals Required

| Region     | Regional Population (2015) | Additional PC beds required | Additional PC outpatient clinics required | Additional PC home- teams required | Additional specialist PC doctors required | Additional specialist PC nurses required | Additional PC social workers required |
|------------|----------------------------|-----------------------------|---|------------------------------------|---|--|---------------------------------------|
| North-West | 2,581,768                  | 395                         | 43  | 64                                 | 123                                       | 527                                      | 41.5                                  |
| North-East | 3,263,564                  | 208                         | 54  | 80                                 | 181                                       | 657                                      | 52                                    |
| Centre     | 2,346,562                  | 357                         | 37  | 57                                 | 101                                       | 482                                      | 34.5                                  |
| South-East | 2,481,684                  | 441                         | 41  | 62                                 | 170                                       | 526                                      | 40.5                                  |
| South      | 3,047,055                  | 574                         | 50  | 76                                 | 220                                       | 693                                      | 47                                    |

|                   |                   |             |            |            |             |             |            |
|-------------------|-------------------|-------------|------------|------------|-------------|-------------|------------|
| South-West        | 2,005,253         | 379         | 33         | 50         | 158         | 467         | 32.5       |
| West              | 1,807,287         | 229         | 30         | 45         | 109         | 388         | 28         |
| Bucharest - Ilfov | 2,286,524         | 342         | 37         | 56         | 105         | 487         | 34         |
| <b>TOTAL</b>      | <b>19,819,697</b> | <b>2925</b> | <b>325</b> | <b>490</b> | <b>1167</b> | <b>4227</b> | <b>310</b> |

### 6.16 Source of Funding for Implementing the Palliative Care Strategy

- **International Context**

Internationally sources of funding for the provision of palliative care services vary according the different ways in which healthcare is funded. In many countries, funding for palliative care services is financed through the same system as mainstream health financing. However, mixed funding models exist in most countries, meaning that service providers depend on multiple resources . Table 1 provides an overview of the national arrangements for funding in fourteen countries and highlights whether palliative care is part of the main funding system, whether a dedicated palliative care budget exists, and if there is reliance on charitable funds and out-of-pocket payments (or co-payments).

**Table 1 - Sources of Funding for Palliative Care in 14 Countries**

| Country         | Integration in predominant system for funding collection | Dedicated palliative care budget | Main allocation mechanism                                     | Reliance on charitable funds (self-reported) | Out-of-pocket payments                |
|-----------------|--|----------------------------------|---|--|---------------------------------------|
| Australia       | -  | +                                | Public third party  | -  | -                                     |
| England         | +  | +                                | Public third party  | +  | -                                     |
| Germany         | +  | -                                | Public and private third party                                | +  | -                                     |
| Hungary         | +  | +                                | Public third party, some through hospital budget              | +  | -                                     |
| Ireland         | +  | +                                | Public third party, some through general health care budget   | +  | + (private insurance cover available) |
| New Zealand     | +  | +                                | Public third party, some through hospital budget              | +  | -                                     |
| The Netherlands | +  | +                                | Hospital: private third party, Hospice: private third parties | +  | + (private insurance cover available) |
| Norway          | +  | +                                | Public third party  | -  | -                                     |
| Poland          | +  | +                                | Public third party  | +  | -                                     |
| Spain           | +  | +                                | Public third party  | +  | -                                     |
| Sweden          | +  | +                                | Public third party  | -  | -                                     |
| Switzerland     | +  | +                                | Public and private third parties                              | -  | +                                     |
| USA             | +  | +                                | Public and private third parties                              | +  | +                                     |
| Wales           | +  | +                                | Public third party  | +  | -                                     |

Source: Groeneveld, E. et al; *Funding Models in Palliative Care: Lessons from international Experience, Palliative Medicine 2017, Vol. 31* <sup>(11)</sup>

- **Romania – Sources of Funding for Palliative Care**

The Health Care System in Romania is a decentralized and pluralistic social health insurance system, administrated and regulated by the National Health Insurance Fund, with contractual relationships between purchasers, the health insurance funds, and health care providers.

Public health funds are pooled from the compulsory health insurance payments paid by the insured as 10% of the gross income, according to the Law of Social Health Insurance, introduced in 1998. <sup>(12)</sup>



Most primary care services are available free of charge, but there is a list of services provided by family doctors and general practitioners (GPs) that are paid for by patients.

There are co-payments for medications prescribed by the family doctors and GPs. Regulations define the lists of medicines that are completely or partially subsidized by the government, with the established amount of the co-payment for the defined pharmaceuticals and medical interventions. These lists are agreed by the Ministry of Health and the National House of Health Insurances.

There are funding mechanisms in place for palliative care in inpatient units, in outpatient services and home-based palliative care, but no health funding for day care services or bereavement services.

There are a number of different funding sources and different providers of palliative care in Romania. These are set out in **Table 2** set out on the following page.

**Table 2 – Sources of Funding for Palliative Care in Romania**

| Funding Source      | Funding Agent  | Service Provider   |
|---------------------|--|--|
| Ministry of Finance | Ministry of Health – County Health Boards<br>Ministry of Labour – County Agencies for Social Services (based on law 34/1998)<br><br>Ministry of Public Administration – County Council (based on law 350/2005) | Public hospitals (Inpatient and outpatient units), for initial capital costs and maintenance<br>NGO (annual application, funding awarded on competitive basis) for the social component of licensed services in: <ul style="list-style-type: none"> <li>- Day care</li> <li>- Home based palliative care</li> <li>- Respite care in inpatient units</li> </ul> |

|                                   |  |   |
|-----------------------------------|--|---|
|                                   | National House of Health Insurance – Local Houses of Insurance   | Public or private providers (funding awarded based on priorities in local development strategies)<br>Public or private inpatient units<br>Public or private outpatient clinics (independent or integrated in hospitals)<br>Public and private home-based palliative care services |
| Community                         | Employees – through 2% provision of the fiscal code<br>Employers - through sponsorship law 32/2002. General population through donations | Public and private providers<br>Public or private providers   |
| Foreign Governments               | Germany<br>The Netherlands   | Hospice Carl Wolf, Sibiu, Romania<br>PACARO project for GP's (ended)  |
| Foreign NGOs                      | Charitable NGOs in UK, USA, The Netherlands, Switzerland and France  | Romanian NGO's  |
| International grant making bodies | Open Society Foundations through CPSS and FOSI<br>EU – PHARE, etc.   | NGO<br>NGO and public providers   |

Source: Mosoiu, D., Dumitrescu, MA., and Connor, R. (2014) 'Developing a Costing Framework for Palliative Care Services', *Journal of Pain and Symptom Management*, Vol. 48 No. 4, October 2014 <sup>(13)</sup>

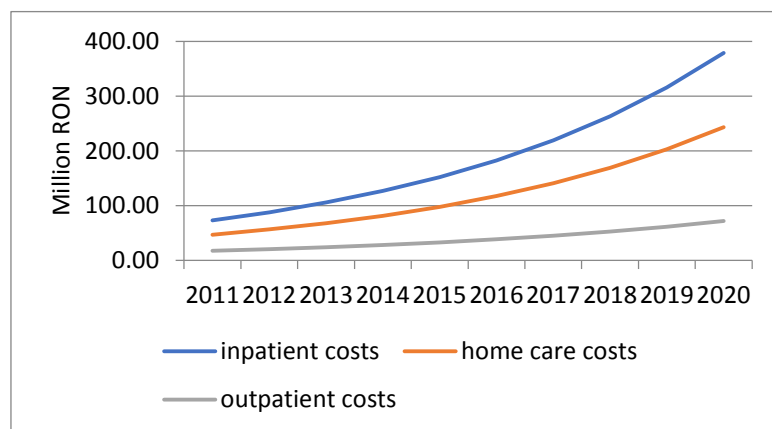
- **Palliative Care Costs**

It is difficult to get an accurate estimate of the amount of money that is spent on palliative care in Romania at the present time. The costs of whatever palliative care is provided as part of the acute care episode for a patient or as a follow up cannot be isolated from other costs. Even where specialist centers provide palliative care the costing systems are such, or non-existent, to make it difficult to estimate the true cost of palliative care. Only where there are freestanding centers can some idea of the cost of palliative care on a per-patient basis be obtained.

A project, 'Developing a Costing Framework for Palliative Care Services',<sup>(13)</sup> undertaken in 2010, identified the cost for palliative care in an inpatient unit was 325 Ron per day (approximately \$82 USD) and 101 Ron (approximately \$25 USD) for a specialist home-care visit. The insurance system is partially reimbursing these costs at 235 Ron per day for each admission day and 102 Ron per home-based palliative care visit.

The funding for home-based palliative care services has been simplified since 2018; patients need to request a palliative care recommendation from the specialist physician and get approval at the district level; therefore, few providers are offering such services, although these are the services most sought after by patients. There is some funding provided for the day care centres through the Ministry of Labour, at 125 Ron per month (approximately \$32 USD), for outpatient palliative care consultations between 30-80 Ron/consultation (depending on the age of the patient) but no funding for mobile hospital teams. For basic palliative care, provided by GPs for cancer patients, the costs are not reimbursed by the health insurance system. The projected cost of providing palliative care in three settings up to the year 2020 is shown on the chart below.

### Projected costs of palliative care in three settings



- Inpatient costs are projected to rise to an estimated 378 million RON in 2020
- Home care costs are projected to rise to an estimated 243 million RON in 2020
- The cost of palliative care provided on an outpatient basis has then to be added to these numbers and this is projected to rise from to an estimated 70 million RON in 2020.

The total cost of delivering palliative care in these three settings is projected to rise to an estimated 691 million RON in 2020

### • New Palliative Care Legislation

The 2017 Palliative Care Needs Assessment identified there is an insufficient and inequitable distribution of palliative care services across Romania. The new Palliative Care legislation No. 253/2018 passed in March 2018 attempts to address this problem by enshrining in law the right of every Romania citizen to access palliative care services if they need them. **However, the law will only become reality if there is an increase in government funding to support the on-going direct care costs of providing palliative care services.** This Palliative Care Strategy

identifies the types of palliative care services that should be provided at local, district and national level. The following table below sets out the services at each level and identifies the governance and financing sources for each level.

| Level    | Ambulatory  | Palliative Care                       | Hospitals (In patient)   | Governance/ Management  | Source of Financing                                   |
|----------|---|---------------------------------------|--|---|---|
| Local    | Dispensaries<br>Primary care physicians                                     | Basic Services                        | Rural (internal medicine, paediatrics)<br>– 120 beds<br>Town/municipal<br>(general 250-400 beds) | Local town halls<br>Local network<br>District Public Health<br>Directorates | Local community<br>District Health<br>Insurance Funds |
| District | Diagnostic & Treatment Centres<br>Outpatient depts.<br>Specialty physicians | Specialised Services                  | District (first level specialisation)  | District Public<br>Health Directorates                                      | District Health<br>Insurance Funds                    |
| National |   | Development/Education<br>and Research | Specialty<br>(Tertiary)  | Ministry of Health  | National Health<br>Insurance Fund                     |

Source: Mosoiu, D., Mitrea, N., Dumitrescu, M., Palliative Care in Romania, Journal of Pain and Symptom Management Vol. 55, February 2018<sup>(14)</sup>

- **Basic Palliative Care Services** should be provided at a local level to people who have relatively simple, straight forward palliative care needs. The aim is to provide as much care in the persons home locality, whether this is in their home or a community location e.g. dispensaries, GP’s office or hospital outpatient department, depending on the patients and family preferences. Where possible basic palliative care services should be provided through existing professional and lay people who have been trained in the provision of basic palliative care services.
- **Specialist Palliative Care Services** should be provided at a Regional Level to those people who have complex needs. These patients requiring specialist interventions may have one or more of the following characteristics:
  - complex physical and or emotional needs
  - symptoms that are difficult to alleviate, control or fluctuate
  - multiple pathology – co-morbidities that could be either associated or not to their cancer
  - a poor social support network or the need for respite care

The following table identifies the types of services that should be provided at the basic and specialist levels.

| Basic Palliative Care Services  | Specialist Palliative Care Services   |
|---|---|
| <ul style="list-style-type: none"> <li>• Assessment of the patient’s condition and service needs</li> <li>• Assessment of available competent services</li> </ul> | <ul style="list-style-type: none"> <li>• Control of physical and emotional symptoms;</li> <li>• Medical services input from specialist palliative care physicians in relation to care planning</li> </ul> |

|  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• Care planning</li> <li>• Symptom and pain control using recognized tools</li> <li>• for assessing and measuring symptoms and pain</li> <li>• Medication within agreed protocols</li> <li>• Counselling</li> <li>• Monitoring</li> <li>• Terminal care: skilled nursing and medical care and support at the end of life</li> <li>• Education for patients and families.</li> </ul> | <p>performed jointly with the patient, their family, and health care professionals; they include assessment of physical, psychological, social, and spiritual needs, developing and implementing the care plan, monitoring and evaluating care</p> <ul style="list-style-type: none"> <li>• Symptom assessment and management with appropriate medical interventions and medications</li> <li>• Nursing care and help and support with activities of daily living, effective communication and nursing interventions</li> <li>• Therapy services - physiotherapy, occupational therapy, and creative (music and/or art and/or drama) therapy</li> <li>• Pharmacy services - prescription advice, preparing and dispensing medication</li> <li>• Psychological services - counselling, support with pain management and bereavement services</li> <li>• Social services - help with legal and financial issues, obtaining specialized equipment, respite care and/or holiday breaks</li> <li>• Chaplaincy services - spiritual and religious support</li> <li>• Information service - covers a range of information from clinical information (e.g., conditions, symptom control) to social care information (e.g. benefits and resources).</li> </ul> |
|--|---|

• **Type of Palliative Care Services:**

All types of palliative care services should be funded from government funding, regardless of where and how they are provided. Palliative care is often best provided on an outpatient basis, in the patient’s home or in a day centre. It is more beneficial for some patients, and their families, as well as being more cost effective to provide palliative care services in an ambulatory setting than through inpatient beds. **Therefore, funding for palliative care should be made available from government funding to provide palliative care in all of the following settings:**

- GP’s office – through family doctor and GP services
- Patients Home – through palliative home care teams
- Palliative Care Day Centres in hospitals and hospices
- Out-patient palliative care - based in hospitals, stand-alone units, integrated health centres or specialist palliative care centres/hospices
- In-patient beds – specialist palliative care beds in hospitals and hospices
- Respite care – hospitals, hospices and specialist facilities

**Other Costs:**

In addition to the on-going direct care and operational costs of providing palliative care services, the implementation of this strategy requires other investment. Development and capital costs will be required if this strategy is to be implemented. Sources of financing for development

and capital costs should be prioritised from the funding allocation for palliative care that has been identified from the World Bank Health Care Reform Project and/or from other international grants that can be harnessed to support the development of palliative care in Romania. However, if for any reason this funding is not forthcoming, then other sources of government funding should be considered to ensure this important national development strategy is not delayed. This funding should support:

**A National Palliative Care Development Programme** which should be established and funded to co-ordinate and lead the development of palliative care at a national level. Funding allocated to the programme would support the following activities:

- Providing the infrastructure to support the implementation of this strategy, especially the project management of a national programme to develop new palliative care services across the country
- Education and training of health and social care professionals in specialist palliative care
- Education and training of healthcare professionals in basic level palliative care
- Promulgating and disseminating standards of care and care protocols, coordinating peer review of performance and outcomes
- Gathering statistics and sharing data on palliative care need, utilisation, cost etc.
- Surveying the opinions of patients, care givers, fund raisers, volunteers, the public etc. about palliative care
- Communication and national campaigns to raise the awareness of palliative care services and the new palliative care law
- Rolling out a national programme for training volunteer's working in palliative care

**Capital Development Funding** will be required to ensure appropriate premises are developed for new palliative care services, including:

- Building or renovating facilities for new palliative care services (outpatient and inpatient services) – these may be new buildings or existing premises that can be adapted appropriately to ensure they are fit-for-purpose. Some new palliative care services e.g. outpatients or home care teams could be incorporated into the new health and social care centres that are being developed and although this would require some investment, it would not cost as much as building new stand-alone premises
  - Provision of equipment for new palliative care services and cars (for new palliative home care teams)
  - Development of IT systems to support the development of palliative care services
  - The development of a national 24/7 call centre for palliative care patients/relatives
- **Summary of Funding Sources for Palliative Care**

**Operating costs** for palliative care services have several possible funding sources for the medical, nursing and the social components of palliative care, these include:

- Government – Ministry of Health (local authorities), Ministry of Labour and Social Protection (local social authorities), Ministry of Public Administration (local councils)
- Community (Employees 2% tax contribution and donations from the community)
- International Non-Government Organisations
- Foreign Governments
- International Grants (EU, Open Society, etc.)

It is expected that these mixed funding sources will continue in Romania. However, if there is to be a more equal distribution of palliative care services across the country and an increase in the number and types of palliative care services available then the proportion of money that is provided by the government for palliative care services will need to be significantly increased. It is also essential that **all types** of palliative care services are government funded, through either health or social care funding, regardless of where or how those services are provided. Currently, palliative care out-patient, day care services and bereavement services do not receive any government funding. For a modern, comprehensive, cost effective palliative care service to be available for the people of Romania these types of services should be funded through government funds.

**Development funding** - It is acknowledged that it will take many years to fulfil the ambitions set out in this strategy. However, unless development funds can be made available then it will be difficult to begin the work outlined in this strategy. A National Palliative Care Development Programme should be established to co-ordinate the development of new palliative care services across the country, promote and support the education and training of palliative care healthcare professionals, work on palliative care standards and protocols and raise the awareness of palliative care in the population.

**Capital funds** should also be identified to support the capital development required to convert or build premises for palliative care use. Funding from the World Bank loan for improving healthcare in Romania and other grants that can be sought should be used to help support the development of palliative care across the country in a planned and systematic way which aims to achieve the best coverage of palliative care services across the country for the population of Romania.

**PALLIATIVE CARE  
NATIONAL DEVELOPMENT PLAN  
2018 - 2022**

**7. Palliative Care Development Plan – 2018 – 2022**



The Ministry of Health will need to ratify this strategy and development plan. Although some tasks have been completed e.g. developing and implementing the new palliative care legislation, undertaking an analysis of palliative care need in the county. There is still much to do to **implement** this strategy and development plan in full. A range of resources are needed to implement the strategy and both capital and revenue funding will be required to enable the implementation of this strategy and development plan.

### **7.1 The following resources are essential for implementation:**

- **Additional Healthcare Professionals** – this is the most important resource, as services cannot be developed without skilled and competent healthcare professionals. Additional healthcare professionals will be required at all levels to provide basic and specialist palliative care services and to provide training and education to other healthcare professionals/patient and carers.
- **Education and development of GPs in providing basic palliative care** – it is believed that strengthening of local capabilities to deliver palliative care e.g. launching programmes to educate and train GPs and nurses at the local level is essential in helping to ensure more people have access to basic palliative care services.
- **Education and development programmes** for professional staff who want to specialise in palliative care and continuing professional development programmes for those healthcare professionals who are already specialists in palliative care
- **Facilities** - The provision of new or converted/upgraded facilities will be required to begin to implement the improvements in palliative care services. Although this will incur capital costs, but it is hoped that by incorporating some of the palliative care services into new developments that are taking place e.g. the integrated care centres and new out-patients units, the capital expenditure can be minimized
- **Equipment and supplies** - With the increase in demand and development of new services there will be start-up costs for the new services e.g. equipment of out-patient units and cars for home care teams. Also, with an increase in service provision there will be an increase in the need for medication and medical supplies e.g. stoma bags and dressings, etc.
- **Other factors** - Investment will be required to develop an effective infrastructure at several levels including technology for delivering education programmes in palliative care, to enable effective communication and peer-group discussions between palliative care

healthcare professionals across Romania and possibly to provide a 24/7 national call in service for patients, carers and health professionals providing basic services

## **7.2 Additional Palliative Care Services and Staff Required at Regional Level**

The Palliative Care Needs Assessment (2017) identified there is a requirement for a **significant increase** in both palliative care services and healthcare professionals in Romania. The table on page 27 in this document identifies the number of additional palliative care services and staff required at Regional level to meet the palliative care needs of the population. The full Palliative Care Needs Assessment (2017) breaks down the requirements to county level. The Regional Health Service Master Plans <sup>(15)</sup> which have been developed contain information on the additional palliative care services required. This information needs to be used for planning and developing new palliative care services at Regional level.

It is acknowledged that it will not be feasible for Regions to ‘close the gap’ immediately between what palliative care services are currently available and what are required, however, it is essential that the enormity of the challenge does not prevent Government, Regions and Districts from agreeing incremental plans for increasing the palliative care provision over the coming years. Regions will need to consider carefully how they can incorporate the recommendations set out in this national Palliative Care Strategy within their own Regional Health Service Master Plans and how they can integrate the development of new palliative care services with other healthcare improvements taking place within their specific Region.

- **Palliative Care Service Planning Ratios and Criteria**

To assist Regions and Districts with planning new palliative care services ratios for palliative beds and other services are available, these ratios are based on the size of the population they are serving. The national ratios for planning palliative care services and staffing are included in the World Bank Health Reform Project Regional reports (2016), they are also set out in the box on the following page and should be used by Regions and Districts when planning palliative care services in their areas.

| <b>Palliative Care In-patient Beds</b><br><b>25 PC beds per 125,000 population</b>   | <b>Palliative Care Out-patient Clinics</b><br><b>1 PC out-patient clinic per 60,000 population</b>   | <b>Palliative Care Home-based Teams</b><br><b>1 PC home-based team per 40,000 population</b>  |
|--|--|---|
| <b>Staffing ratio</b>  | <b>Staffing ratio</b>  | <b>Staffing ratio</b>   |
| <ul style="list-style-type: none"> <li>• 1 doctor with PC subspecialty per 12 beds</li> <li>• 1 nurse with PC specialty per 8 beds per shift</li> <li>• 1 nurse-assistant per 8 beds per shift</li> <li>• 1 social worker per 25 beds</li> <li>• 0.5 psychologist per 12 beds ;</li> <li>• 4 part-time other staff (physio, priest)</li> </ul> | 1 palliative care outpatient team consists of: <ul style="list-style-type: none"> <li>• 1 doctor</li> <li>• 1 nurse</li> <li>• 0.5 social worker</li> <li>• 2 part-time other staff (physiotherapist, spiritual counsellor)</li> </ul> | 1 palliative care home-based team consists of: <ul style="list-style-type: none"> <li>• 2 doctors</li> <li>• 4 nurses</li> <li>• 1 psychologist</li> <li>• 0.5 physiotherapist</li> </ul> |

As well as nationally agreed service planning ratios the GTL-(PAL) have produced the following criteria to be applied when selecting sites for the implementation of the new palliative care services in Romania. These criteria should be used nationally by Regions and Districts, together with the palliative care service planning ratios, when deciding what palliative care services should be developed and where those services should be located. **Priority in developing palliative care services should be given to:**

- Developing outpatient and home-based palliative care services (*according to patient's preferences and existent human and financial resources*)
- Developing initial services in locations where there are trained physicians willing to work in palliative care
- Counties where there is the greatest palliative care need, according to the annually estimated number of patients needing palliative care (*there are counties with over 5000 patients annually, between 4000 and 5000, 3000-4000, 2000-3000 and under 2000*)
- Developing services in the oncology institutes with a role in care delivery and education (*these are centres with large numbers of potential beneficiaries; it is scientifically proven that early palliative care increases the quality of life of oncological patients and their survival by reducing unnecessary medical interventions*)
- Locations that can provide the infrastructure needed to operate these services
- In-patient Units in the areas where there is a Palliative Care University Chair, in order to provide training/education for the future generations of professionals

- **Roles and Responsibilities for Implementing New Palliative Care Services Nationally**

Implementing new palliative services nationally requires the involvement of people at different levels in the health care system. The table below identifies the roles and responsibilities of the key players in implementing this palliative care strategy and national development plan.

| Palliative Care Working Group and Palliative Care Commission   | Regions and Districts   | Ministry of Health  |
|--|---|---|
| <ul style="list-style-type: none"> <li>• Draft new palliative care legislation</li> <li>• Undertake the palliative care needs assessment</li> <li>• Develop the national palliative care strategy and development plan, setting the priorities and criteria for developing new palliative care services</li> <li>• Advise on approach, types and locations for implementing new palliative care services</li> <li>• Establish education and training programmes in palliative care for all levels of staff</li> <li>• Develop and disseminate national palliative care standards</li> <li>• Provide advice, and expertise to local organisations, managers and clinicians in developing and implementing new palliative care services</li> <li>• Provide a method and process for monitoring and evaluating the implementation of the strategy and development plan</li> <li>• Provide information and reports on the progress of implementing new palliative care services across the country and share learning with healthcare professionals</li> <li>• Produce and up-date the national directory of palliative care services</li> </ul> | <ul style="list-style-type: none"> <li>• Ensure the development of new palliative care services are included in their Regional Health Services Master Plans</li> <li>• Prioritise the type and location of new PC services to be implemented in their local area (<i>using the national criteria as a guide</i>)</li> <li>• Ensure there is integration of PC services with other health services</li> <li>• Financially resource the new palliative care services</li> <li>• Recruit clinical and administrative staff to lead the development and delivery of new PC services</li> <li>• Ensure new PC services are set up in line with national standards for PC</li> <li>• Lead the <b>implementation</b> of projects to establish new palliative care services locally, ensuring a systematic approach to developing each new service is applied</li> <li>• Obtain accreditation for new PC service</li> <li>• Ensure monitoring and evaluation of new service development at a local level</li> </ul> | <ul style="list-style-type: none"> <li>• Approve new palliative care legislation</li> <li>• Approve the palliative care strategy and development plan</li> <li>• Ensure the palliative care strategy and development plan is financed appropriately to ensure the milestones in the development plan can be achieved.</li> <li>• Co-ordinate the wider World Bank Health Reform programme, ensuring there is integration between the different Working Groups</li> <li>• Ensure the palliative care component of the programme is known to other Working Groups (e.g. groups working on developing out-patients and community care)</li> <li>• Communicating the strategy nationally</li> <li>• Review the local evaluations of new palliative care services and, at a national level, identify where there are gaps in PC services across the county to ensure a co-ordinated approach to the future development of PC across Romania</li> </ul> |

## Phase 1. Agreement of the Strategy and Development Plan and Strengthening Education and Training – 2018 - on-going

It is recognised it will take time to implement this strategy, but it important to have clear plan as to how this can be achieved. This section of the report sets out the high-level, phased approach to developing the strategy. There are two objectives of this first phase of the development plan:

**i) Strategy and Development Plan Approval** - This palliative care strategy and development plan needs to be agreed by the Ministry of Health. New palliative care legislation has been agreed and it is now essential that this national development plan is costed, resourced and communicated effectively to ensure the development and integration of palliative care services into the national health system of Romania.

**ii) Strengthening Training and Education in Palliative Care** - The training and development of staff is essential to ensure there are sufficient palliative care health care professionals available to develop and continue to provide palliative care services. Therefore, the first phase of the palliative care development plan will focus on developing palliative care capability. We propose the increase in the number of staff being trained in palliative care should start in 2018 and be on-going:

- **Development of Family Doctors** - A basic package of palliative care, provided by Family Doctors, should be universally available and accessible to every member of the population to ensure equitability. A basic training programme for Family Doctors should be developed which will be available for them to attend from 2019 onwards. A pilot project, undertaken in 2014, <sup>(16)</sup> generated interest from a small number of Family Doctors. A **national approach is now required** to ensure palliative care becomes a key component of the Family Doctor's role and responsibilities. For Family Doctors to become actively involved in providing the basic level of palliative care services at the primary care level they need to develop their knowledge and skills in this area of medicine. Designing, accrediting and delivering a programme of training for Family Doctors in basic level palliative care is an important element of this palliative care development plan. It is recommended that the training should become compulsory for all Family Doctors to participate in over the next five years.
- **Education and Training in Specialist Palliative Care** - Specialist palliative care education and training programmes are already available for doctors, nurses and the multi-disciplinary team. In 2017 after many years of lobbying, palliative care has been included on the list of specialties for nurses in Romania. To enable the development of palliative care services at a national level there needs to be further

investment in specialist palliative care training and education programmes, so there are enough healthcare professionals available to continue to provide the current palliative care services and to begin to establish new services across the country in the future.

## **Phase 2 – Implementing new palliative care outpatient and home care services and planning for future development of palliative care services nationally - 2019 - 2021**

We envisage the work of this second phase of the palliative care development programme will overlap with the with the first phase. The objectives of this second phase are to:

- Begin implementation of new palliative care out-patient and home care teams in areas with a high need for palliative care services
- Commence planning for the longer-term development of new palliative care services in each Region - the focus will be to continue to develop additional palliative care out-patient units and palliative care home care teams; we will also identify possible locations for the development of new palliative care inpatient beds.
- Continue to roll-out the education and training programme programmes started in 2018
- Develop a system for evaluating the new palliative care services which are being set up

There are three important reasons why we are proposing this approach:

- i) There is limited capacity of local staff trained in basic palliative care – *(it will take time to train sufficient staff across the country in providing basic palliative care services, however this is an important part of the strategy and essential for moving PC forward)*
- ii) There is limited capacity of specialist palliative care staff – *(again, time is required to produce palliative care specialists and new services cannot be established with specialist staff who have the appropriate skills and competencies)*
- iii) It is essential we have a clear understanding of the Health Service Master plans for each region so that the development of new palliative care services might be incorporated into some of the existing or new facilities and to ensure that palliative care services become an integrated part of the health system within each Region

During 2018, the Regional Health Service Plans will be completed. This will enable the Palliative Care Working Group to understand the changes proposed by each Region. These Regional Health Service Plans we will also outline where the development of new Integrated Centres and Out-patients will be located, enabling us to make proposals which could locate some of the new palliative care services within these premises.

To start with we believe the most effective palliative care coverage will be gained if we focus on implementing **new palliative care out-patient services and mobile teams first**, with in-patient palliative care provision being developed at a later stage. Through the palliative care needs assessment, we have identified the counties with the greatest palliative care needs and where there are palliative care healthcare professionals ready to set up palliative care out-patient and home care services, using these criteria and the service planning ratios we have identified:

- **27 locations for new Palliative Care Out-Patient Clinics** - Palliative care out-patient services should be provided in each of the three Cancer Centres (Bucharest, Cluj and Iasi) and in the seven Regional Hospitals. We have also identified a further 2-3 palliative care out-patient sites for each county, the specific location of those other out-patient units will need to be agreed, but it hoped some of them may be situated in the new out-patient units being developed as part of the wider health service reform programme.
- **28 locations for new Palliative Care Home-Based Teams** - Palliative care home teams are a model of care which have proven to be a cost-effective way of providing high quality palliative care to people in their own homes who are suffering from life-limiting conditions. Palliative Care Home Teams are necessary to provide a comprehensive palliative care service across the country. This is especially required in rural areas but is also part of an integrated approach to delivering palliative care in urban areas. Some of the new palliative care home teams could possibly be based in new integrated health centres being developed as part of wider healthcare strategy in Romania.

The capital and revenue costs of setting up these new services should be covered by funding from the palliative care allocation of the World Bank project or from funding from the Ministry of Health. **The map on the next page shows the proposed location for establishing new palliative care out-patient and home care teams proposed for 2019-2022**

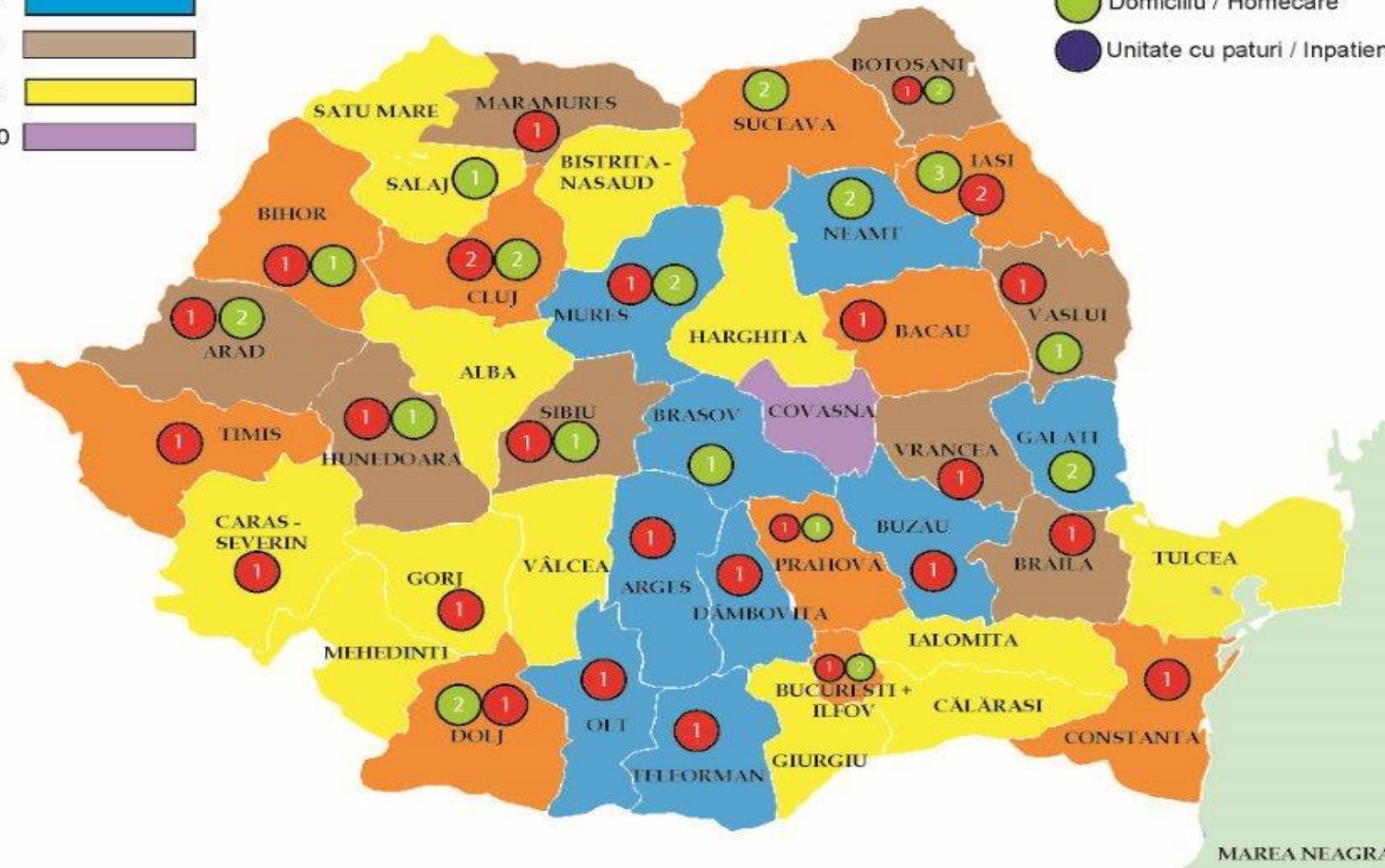
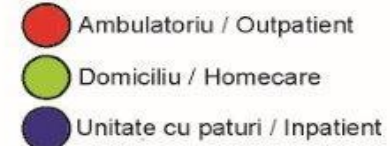
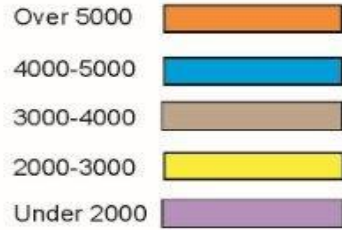
**Project Management and Communication** - To co-ordinate this large national project it is recommended that funding is allocated to provide a Project Manager to support the National Palliative Care Development Programme. The role of the project manager would be to work in collaboration with Regions to support the development of new palliative care services and to lead a campaign to raise awareness of palliative care with the public and healthcare professionals. A dedicated project manager, working nationally with all the Regions, will aid the process of

co-ordinating the implementation of new palliative care services and they would be able to support individual organisations who need guidance to manage projects to develop a new service and assist with the evaluation of the services once they are established. The Project Manager should be funded from the Ministry of Health and they should work closely with the National Palliative Care Commission and the National Development Team, from Hospice Casa Sperantei, so the project is linked in with other palliative care initiatives.



## Proposed development of new Palliative Care Services for the period 2019 – 2021

### THE NEED OF PALLIATIVE CARE (by counties)



### Phase 3 – Evaluation of new palliative care services established in phase 2 and development of plans for implementation additional palliative care services – 2020 – 2022 (on-going)

The objectives of the third phase of this palliative care development plan are to:

- undertake an evaluation of the new palliative care services which were established during phase 2 of this programme
- commence the development of plans for the implementation of additional new palliative care services within each Region
- continue to provide training, education and professional support in basic and specialist palliative care

**Monitoring and Evaluation** – An evaluation criteria and process will need to be developed and once new palliative care services are implemented it will be important they are evaluated, and the lessons learnt from the implementation shared with other organisations who want to set up new palliative care services. The overall progress and the success of the palliative care development plan will also need to be monitored and evaluated.

**Project Management** – The national Project Manager, will be required to co-ordinate the National Palliative Care Development programme and lead the work on communicating and raising awareness of the new palliative care strategy. However, it will be the responsibility of the **Regions and Districts** to develop individual project plans which set out the key tasks for implementing new palliative care services in their areas. The tasks, which need to be undertaken, will be different depending on the type of service and the work that needs to be undertaken to develop each new service. For example, setting up new palliative care home teams will require less time and capital resource than converting or building new premises for in-patient beds. It will be important for each Region to have a plan that outlines where each new service will be located and the activities that will need to be undertaken to set up the new service and ensure it staffed with appropriate trained staff to deliver an effective service.

**Project Support and Education/Training** - At a national level the GTL-(PAL) and the Palliative Care Commission will be able to provide some advice and guidance to Regions and Districts on the requirements, standards and protocols required when establishing new palliative care services. However, it will be the responsibility of the individual Regions to ensure that implementation of new services is delivered effectively. Also, at a national level training and education of newly recruited staff should be available to ensure the continuing professional development

of palliative care staff who are starting up and providing new services. It is possible that a new 'palliative care network' could also be established to provide peer support to managers who are establishing new palliative care services for the first time

### **Palliative Care Development Plan 2018 - 2022**

The diagram below illustrates the proposed objectives and timescale for implementing the national palliative care development plan

#### **Phase 1 - 2018 – 2019**

- Development of PC strategy/development plan
- PC strategy to be approved by MoH and funding secured
- Establish National PC Development Programme and recruit a project manager
- Develop national communication plan for PC strategy
- Commence basic PC training programmes for local staff
- Increase training availability for specialist PC staff
- Identify other activities required to implement strategy

#### **Phase 3 - 2020 – 2022**

- Regions to have produced plans for longer term development of palliative care in their areas
- Development and implementation of additional new palliative care services within each Region
- Continuation of the provision and training, education and professional support in basic and specialist palliative care
- Evaluation of palliative care development programme
- On-going research into how 'best international models' of palliative care can be developed in Romania

**Key Milestones in Developing Palliative Care in Romania**

- 1992 – Setting up of the first Home-based palliative care services in Brasov
- 1997 – Establishment of a Palliative Care Education Centre in Brasov
- 1998 - Establishment of the National Palliative Care Association (ANIP)
- 1999 - Palliative care national training programme for doctors started
- 2001- Oral morphine became available for pain control
- 2002 -The first in-patient Hospice unit was opened in Brasov
- 2002 - Development and agreement of the first national standards for palliative care
- 2003 - Hospice Casa Sperantei recognised as a ‘Beacon of Excellence’ for palliative care in Eastern Europe
- 2005-2007 – New opioids law passed that allows all registered doctors to prescribe medication for pain relief
- 2005 – Palliative care in-patient units introduced and funded in the Frame-Contract with the House of Health Insurances (HoHI)
- 2007 - First public reimbursement by the HoHI for palliative care admissions to inpatient units
- 2007-2008 - Public awareness campaign and national survey regarding palliative care
- 2007 - First palliative care departments in public hospital (Pascani and Stefanesti)
- 2008 - Partnership between Ministry of Health, Hospice and the National Federation of Cancer Patients Associations
- 2008 - 2010 – Palliative care costing project & national impact on funding mechanisms
- 2009 - Introduction of a curricula for palliative care for nurses in basic training
- 2010 - Home-based palliative care services acknowledged
- 2010 - First Master programme in palliative care provided (Brasov Medical Faculty)
- 2010 - Palliative care standards revised
- 2011- Five medical faculties in Romania introduce palliative care in the basic studies curricula
- 2012 - National Strategy for palliative care proposed to the Ministry of Health
- 2013 - Ministry of Health announce commitment towards a National Programme for palliative care
- 2013-2016 - Establishment of a pilot project to develop basic palliative care in community
- 2014-2020 - World Bank project for the reform of health services includes palliative care in programme

- 2017 - Palliative care specialty for nurses acknowledged
- 2016/17 – Palliative care needs assessment undertaken
- 2018 – New palliative care Legislation agreed

**Palliative Care Regulation - (Ministry of Health No. 253/2018)**

**Appendix 2**

**Annex 3 – Palliative Care Beneficiaries**

Art.1. **PC beneficiaries are:** patients of all ages, adults or children with progressive chronic disease, with suffering due to uncontrolled symptoms and/or psycho-emotional, social, spiritual problems and/or high degree of dependence; their families are also PC beneficiaries during patient’s care and for bereavement

Art2. Adult patients that can benefit of specialized PC are in the following categories, without however being limited to:

**1. Patients with cancer**

- a. cancer stage III or IV or II with progressive deterioration, despite anticancer therapy
- b. cancer and performance stage (PS) Karnovsky <70 or palliative performance score (PPS)<70%
- c. cancer and weight loss 5% more in last 3 months
- d. cancer and moderate or severe intensity symptoms
- e. oncological emergencies
- f. relapsed cancer or with progressive evolution after surgery/ radio/chemotherapy
- g. cancer and existential crisis
- h. terminal stage

**2. Heart disease patients, if they present:**

- a. weak response to treatment and
- b. presence of significant symptoms of congestive heart failure at rest and classified by NYHA Class IV

**3. Amyotrophic lateral sclerosis (ALS), if presents rapid progression of ALS in the last 12 months, highlighted by:**

- a. Switching from independent mobility to wheelchair or bedding;
- b. Switching from normal speech to speech that is barely intelligible or even unintelligible
- c. Switching from normal to semi-solid / semi-liquid feed
- d. Switching from the ability to carry out most or all of the daily activities independently to the major need for assistance from the caregiver

**4. Patients with final stage dementia, if the patient suffer from dementia that evolve to:**

- a. stage 7 or more
  - b. moving incapacity without assistance
  - c. dressing incapacity without assistance
  - d. personal hygiene incapacity without assistance
  - e. urinary and fecal incontinence, intermittent or constant
  - f. verbal meaningless communication, only in stereotypical phrases, or the ability to speak within the limit of 6 or very few comprehensible words
- 5. Patients with multiple sclerosis** if presents critical nutritional handicap:
- a. Insufficient oral and fluid intake to keep the patient alive
  - b. Continuous weight loss
  - c. rapid progression of the disease or complications in the last 12 months, highlighted by:
    - i. Switching from independent mobility to wheelchair or bedding;
    - ii. Switching from normal speech to speech that is barely intelligible or even unintelligible
    - iii. Switching from normal to semi-solid / semi-liquid feed
    - iv. Switching from the ability to carry out most or all of the daily activities independently to the major need for assistance from the caregiver
- 6. Patients with Parkinson** if presents critical nutritional handicap:
- a. Insufficient oral and fluid intake to keep the patient alive
  - b. Continuous weight loss
  - c. dehydration
  - d. absence of artificial feeding methods
  - e. rapid progression of the disease or complications in the last 12 months, highlighted by:
    - i. Switching from independent mobility to wheelchair or bedding;
    - ii. Switching from normal speech to speech that is barely intelligible or even unintelligible
    - iii. Switching from normal to semi-solid / semi-liquid feed
    - iv. Switching from the ability to carry out most or all of the daily activities independently to the major need for assistance from the caregiver
- 7. Patients with lung disease** if they present:
- a. dyspnoea
  - b. end-stage pulmonary diseases

- c. hypoxia
- d. progressive weight loss
- e. rest tachycardia >100/mm

**8. Patients with stroke and coma:**

- a. acute haemorrhagic stroke and:
  - i. coma more than 3 days
  - ii. dysphasia
- b. Chronical stage of stroke:
  - i. dementia post-stroke stage 7 or more
  - ii. PS Karnovsky <50%
  - iii. weak nutritional status
- c. coma, with any of the following the in the 3<sup>rd</sup> day of coma:
  - i. abnormal cerebral response
  - ii. absence of verbal response
  - iii. absence of response to pain
  - iv. serum creatinine >1.5mg/dl

**9. Patients with myasthenia gravis:**

- a. stage III or IV according to Ossermann
  - i. stage III generalized acute, progressive, bulbous, and respiratory failure
  - ii. Stage IV with severe chronic development and high resistance to therapy, progression of stage I, II or III in the last 2 years

Art3. Paediatric beneficiaries are children with illnesses that make unlikely the survival until the adult age. These diseases are:

- a. life threatening diseases
- b. life limited diseases
- c. progressive diseases for which at the beginning is possible only palliative treatment
  - i. metabolic storage diseases
  - ii. hereditary degenerative diseases
  - iii. degenerative acquired diseases
  - iv. Non-progressive diseases that lead to constitutional fragility and high susceptibility to complications

Art.4. Paediatric PC characteristics:

- a. PPC address to children with various diseases (art3), some of them being rare diseases for which the experience is limited
- b. frequently, in PPC are assisted children with hereditary disease and may be more children affected into one family. That is why genetic counselling is needed.

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