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# Innovative palliative care for people with cancer: sustainable solutions for the future

## Introduction

The EU Cancer Mission aims to “improve the lives of more than 3 million people by 2030, through prevention, cure and for those affected by cancer including their families, to live longer and better”, by breaking barriers and bringing innovative R&I approaches together with public health policies. Under its objective of quality of life, the Cancer Mission has launched several actions to improve the physical and mental health of patients with cancer and their families.

This Policy Brief Document was developed in collaboration with researchers and experts on palliative care and through a series of workshops. It summarises the results of research projects, providing evidence on the value of palliative cancer care and ways of integrating it throughout the cancer care continuum while addressing inequity of access to it.

Cancer affects millions of people across the European Union (EU) each year. In 2020 there were 2.7 million new cancer cases and 1.3 million deaths from cancer in the EU<sup>1</sup>. Cancer is the number one cause of death for EU citizens under 65, and the second most common cause of death for all EU citizens<sup>1</sup>. It exerts significant physical, emotional, and economic burdens with an estimated societal cost of cancer for the EU in 2018 of €199 billion<sup>1</sup>.

Care for people affected by cancer requires integrated support from families, social networks, health and social care services, and wider society.

Support and care must be provided:

- across the **cancer care continuum**, from prevention, detection, diagnosis, treatment, to survivorship, palliative care, and end-of-life care
- across the **life course**, from prenatal and neonatal care, to children, adolescents and young adults (AYA), to adults of working age and to older adults.

Palliative care is an approach that improves the quality of life (QoL) of adults and children and their families who are facing problems associated with life-threatening illness<sup>2</sup>.

Palliative care is essential, and is a core component of universal health coverage<sup>3</sup>. Palliative care is an important and powerful resource to improve experiences and outcomes across the cancer care continuum and across the life course. It is relevant from diagnosis and through treatment, and into bereavement, not only at the end-of-life stage.

Palliative care is delivered by multidisciplinary teams in primary care, secondary care, and tertiary care, by specialists and generalists, in all health and social care settings, by family carers and other informal carers, and by community networks. A public health approach to palliative care moves beyond individual clinical interventions to empower networks, community support, and society to address or prevent issues associated with life-limiting illness, dying, caring, and grieving.



Figure: Components of palliative care, World Health Organization (creative commons licence)

Recognising the need for innovative and sustainable palliative care, since 2008 the EU has funded 22 research and innovation projects, with a total budget of €110.9 million, to drive innovation in cancer palliative care for children, AYA, and adults. Drawing on evidence from these 22 EU funded projects and expert input, six challenges emerge as requiring urgent attention and action.

## 1. Demonstrate and communicate the value of palliative care

Palliative care improves QoL, reduces symptom burden<sup>4</sup>, and is cost effective<sup>5</sup>. Early palliative care in advanced cancer improves QoL and reduces symptom intensity<sup>6</sup>. Despite the evidence of effectiveness, significant stigma and confusion surrounds palliative care, and it continues to be associated only with the end of life. This means people who could benefit from palliative care are often not able to access it. Education and training about palliative care and its importance is therefore essential for all health and social care workers.

Projects funded by the EU are demonstrating how palliative care can address complex symptoms and improve QoL for people living with cancer. Rehabilitation in palliative care is essential to support people to live well with serious illness<sup>7</sup>. For example, the **INSPIRE**<sup>8</sup> project aims to improve physical function and QoL for people with incurable cancer through the integration of a short-term palliative rehabilitation intervention. The **RELEVUM**<sup>9</sup> project aims to improve the QoL of people with advanced pancreatic cancer by reducing pain and cachexia through AI-guided care plans, alongside chemotherapy treatment. The **PAINLESS**<sup>10</sup> project is testing a neuromodulation

technique to reduce cancer pain and the recently completed **Palliative Sedation**<sup>11</sup> project explored how to relieve refractory symptoms at the end of life, updated a framework for practice, built an online course and an accompanying **e-book**<sup>12</sup> for clinicians, patients and carers.

**Recommendation: Palliative care improves outcomes for person-centred care across the cancer care continuum. This message must be communicated clearly, addressing the associated stigma, fear, and confusion of professionals, patients, family carers, and wider society.**

## 2. Integrate palliative care throughout the cancer care continuum

Palliative care is an essential component of healthcare and the WHO has recommended that it is integrated throughout health systems<sup>13</sup> and for all ages. Despite this, there is substantial variation in provision and access across the EU, for example there are significant differences in the ratio of palliative services per 100.000 inhabitants between Western Europe and Central-Eastern Europe<sup>14</sup>.

The **INSUP-C**<sup>15</sup> project defined integrated palliative care as ‘*bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the care givers (paid and unpaid)*<sup>16</sup>. It set out a series of recommendations to follow for integrating palliative care.

The **PAL-CYCLES**<sup>17</sup> project aims to develop a palliative care transition programme between hospital and the community for patients with advanced cancer. It will facilitate patient-centred communication and continuity of care, reducing unplanned hospital admissions and improving QoL at the end of life. **STRONG-AYA**<sup>18</sup> is a new European network that aims to improve healthcare services, research and outcomes for AYA with cancer. **MyPath**<sup>19</sup> will leverage an innovative digital patient-centred platform to challenge tumour-focused oncology treatment and empower patients to improve QoL and access to care. The **ACTION**<sup>20</sup> project explored advance care planning (ACP) and demonstrated the complexity of developing ACP interventions that influence patient outcomes. Understanding patient preferences for future care and ensuring these inform and shape care remains a significant challenge. The context for end-of-life decision making differs across the EU, with assisted dying in place in some countries and ethical questions and assisted dying legislation being debated in others.

**Recommendation: Palliative care must be integrated across primary, secondary and tertiary care for children, AYA, and adults. It should be included in all cancer control and care strategies and policies.**

## 3. Tackle the inequities that exist in palliative care in cancer

Social, demographic, environmental, geographical and commercial factors influence risk of cancer, outcomes in cancer care<sup>21</sup>, and outcomes in palliative care<sup>22</sup>. The impact of these determinants on experiences in palliative care has been recognised, with calls made to address them<sup>23, 24</sup>.

Access to care across the cancer care continuum is not equitable across the EU. Tackling these inequities requires joint working between palliative care and other specialties such as oncology, but also with policy makers and sectors outside healthcare. Whilst the inequities faced by people living with cancer must be addressed, equity of

access to palliative care for all disease groups must be advocated for. Policies must not inadvertently increase inequity.

The **EUonQOL**<sup>25</sup> project is designing a unified QoL assessment tool that will enable the evaluation of inequities in QoL across the EU. Innovative social interventions are also required, and communities have an important role in supporting people with palliative care needs. EU **Navigate**<sup>26</sup> harnesses the capacity of community navigators, linking them with older people living with cancer and their carers and aims to support them to improve their QoL, well-being and equitable access to care.

**Recommendation: The inequity of access to palliative care services for cancer and all disease groups must be addressed, developing and sharing social interventions that tackle the social and structural determinants of health.**

#### 4. Innovate and implement new knowledge

Innovation is essential for improving care and outcomes for people with palliative care needs. This requires new knowledge to be implemented across routine practice for it to achieve impact for patients and populations.

The **ESMART**<sup>27</sup> project used real-time, remote patient monitoring via mobile devices to support patients whilst undergoing chemotherapy. The trial demonstrated clear evidence that remote monitoring leads to a reduction in symptom burden, distress, anxiety, and support needs. Poor communication between patients and healthcare specialists is known to be a barrier to good care. The **MyPal**<sup>28</sup> project designed an integrated digital health platform for both children and adults to address this barrier. A digital game to overcome the same barriers for children and AYA was also co-designed. They set out a series of recommendations for how digital methods can be sustainably and equitably integrated into care for children, AYA, and adults.

**PACE**<sup>29</sup> explored the complexity of implementing palliative care in practice, focusing specifically on long-term care facilities. The results highlighted the differences in quality of dying across different countries in the EU<sup>30</sup> and developed a set of tools for practitioners and policy makers to implement best palliative care practices widely. The **IMPACT**<sup>31</sup> project looked at the 'knowing and doing' gap by understanding how implementation works. Focusing on advanced cancer and dementia, The IMPACT team developed a set of 23 quality indicators to guide the implementation of palliative care in practice, covering domains such as organisation of care, education of professionals and patient assessment.

**Recommendation: Innovation in palliative care should be supported and accompanied by the dissemination of best practice and policies to support implementation. This will ensure the benefit of innovation reaches all those in need.**

#### 5. Empower patients, carers, and the public to participate in palliative care

Patients, carers, communities, and societies have a fundamental role in palliative care. Enabling and empowering citizens to take up this role, in partnership with healthcare providers, is an important aim of palliative care. The WHO has recently recognised and endorsed the importance of social participation in healthcare<sup>32</sup>.

Patients and carers should be offered opportunities to build skills, knowledge and confidence in caring for themselves and others, enabling them to play an active role in care. The [DIAdiC<sup>33</sup>](#) project developed a psycho-educational intervention to support and empower people living with cancer and their family caregivers. This face-to-face intervention demonstrated improved self-efficacy for the patient, improved coping for the caregiver and improved communication between the patient and caregiver.

Digital and technological innovations can empower children, AYA, and adults living with cancer by removing barriers that can exist to participation, though attention must be paid to equity of access to digital platforms. Projects such as [MyPal<sup>34</sup>](#), [RELEVIMUM<sup>9</sup>](#), and [eSMART<sup>35</sup>](#) transform patients from passive recipients of care to people who can direct and influence their own care, leading to improved outcomes for both patients and services.

**Recommendation: Models of patient, carer, and community empowerment should be developed and supported in palliative care. Best practice from other disciplines should be shared.**

## 6. Anticipate and respond to future needs

Significant changes are taking place across the EU, and these will shape the context and need for palliative care in the future:

### • Dying at home

Studies suggest the majority of people would prefer to die at home<sup>36</sup>, but rates of home death vary across the EU, with higher rates in the north and west, and lower rates in the south and east<sup>37</sup>. Rates of home death are rising, a trend that increased further during the COVID-19 pandemic in many countries<sup>38</sup>. Palliative care services in the community need further development and funding to respond to this rising trend.

### • Support for family carers and informal networks

Family carers and informal networks provide the majority of care and support for people with advanced illness such as cancer. They are integral to improving experiences at these times and to enable people to die at home. They form a key part of the workforce in palliative care and must be recognised and supported.

### • Shortage of health and social care workforce

Europe is experiencing a healthcare workforce crisis<sup>39</sup>, exacerbated by the COVID-19 pandemic. This shortage poses a significant threat to healthcare systems and efforts to improve access and equity in palliative care.

### • Ageing

European life expectancy is rising, with many ageing well and living longer. It is predicted there will be close to half a million centenarians living in the EU by 2050<sup>40</sup>. Numbers of people over 80 with cancer is predicted to increase, bringing new challenges for management and care, often in the context of multimorbidity or frailty<sup>41</sup>.

**Recommendation: The workforce for palliative care includes health and social care professionals alongside family or informal carers and requires urgent recognition and support. The rising trend in home deaths and the ageing population require new models of care and allocation of funding.**

Box – Summary of recommendations

- **Demonstrate and communicate the value of palliative care**

**Palliative care improves outcomes for person-centred care across the cancer care continuum. This message must be communicated clearly, addressing the associated stigma, fear, and confusion of professionals, patients, family carers, and wider society.**

- **Integrate palliative care throughout the cancer care continuum**

**Palliative care must be integrated across primary, secondary and tertiary care for children, AYA, and adults. It should be included in all cancer control and care strategies and policies.**

- **Tackle the inequities that exist in palliative care in cancer**

**The inequity of access to palliative care services for cancer and all disease groups must be addressed, developing and sharing social interventions that tackle the social and structural determinants of health.**

- **Innovate and implement new knowledge**

**Innovation in palliative care should be supported and accompanied by the dissemination of best practice and policies to support implementation. This will ensure the benefit of innovation reaches all those in need.**

- **Empower patients, carers, and the public to participate in palliative care**

**Models of patient, carer, and community empowerment should be developed and supported in palliative care. Best practice from other disciplines should be shared.**

- **Anticipate and respond to future needs**

**The workforce for palliative care includes health and social care professionals alongside family or informal carers and requires urgent recognition and support. The rising trend in home deaths and the ageing population require new models of care and allocation of funding.**

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- <sup>10</sup> PAINLESS <https://cordis.europa.eu/project/id/101057367>
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