

## **Title Page: Lancet Oncology Commission**

### **Title: Integration of oncology and palliative care**

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## Introduction

The overall aim of this commission is to demonstrate why and how palliative care (PC) can be integrated with oncology for adults with cancer, irrespective of treatment intention in high and middle income countries. This integration will combine two main paradigms, the tumour-directed and the patient (host)-directed, by using the most competent and optimal resources from oncology and PC in well-planned patient-centred care pathways.

The two paradigms may be understood as representing two different cultures. Oncology has its root in mainstream medicine, i.e. internal medicine, and is primarily based upon the acute care model. From the mid 1960's hospice and palliative care were established outside the main health care systems often financed by charities. The primary focus was from the start end of life care and care has been provided by multidisciplinary teams targeting the patients and their families. The oncological and palliative care cultures are still mainly living apart, with separate journals, seminars and conferences.

As will be demonstrated, the field of research on integration of oncology and PC is heterogeneous. Most or nearly all studies have been performed in high-income countries and still the variation across countries, systems and settings often limits the generalizability of findings. In a recent Lancet Commission on palliative care focusing on low and middle-income countries it is stated upfront: "Poor people in all parts of the world live and die with little or no palliative care or pain relief".<sup>1</sup> The commission gives a series of recommendations such as how to quantify serious health-related suffering and proposes an Essential Package of palliative care which also may be relevant to apply in high-income countries, for example as a basic benchmark of successful implementation at patient level. It is also recommended an international and collective action to receive universal coverage of palliative care and pain relieve and better evidence and priority setting tools in order to measure the global need for palliative care and implementation policies. Given the empirical basis presented in this commission, the recommendations are primarily focused on high income countries but the findings, experiences and models presented might be highly relevant in other contexts as well.

The WHO definition of PC clearly states that the competence, attitudes and skills of PC should be integrated in health care, in general, and in cancer care, specifically: "*PC is an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, and is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life*".<sup>2</sup> The present paper builds on this definition, which differs substantially from the common perception of PC being synonymous with end of life-care. Studies have shown that hospital-based specialized PC, alongside tumour-directed and life-prolonging treatment, can contribute to better oncology care for patients and families, in terms of better symptom management, quality of life and satisfaction with care, and less psychological distress; some studies even suggest survival benefits.<sup>3-5</sup> Thus, we think it is timely to rethink and reorganize the delivery of oncology and PC to improve treatment and to promote collaboration at the appropriate levels of care. We, therefore, propose models of integration that respectively fit the tasks and responsibilities of the two main hospital categories; i.e. university hospitals (3<sup>o</sup>) and local hospitals (2<sup>o</sup>), as well as community health care (1<sup>o</sup>).

Integration of care is a complex “intervention” based on organizational structure and patient-centred plans. Standardized Care Pathways (SCPs) is a method, a planning tool, for the implementation of such complex processes. The European Pathway Association (EPA) defines SCPs as “a complex intervention of the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period”.<sup>6</sup> SCPs facilitate transitions within hospitals and between health care levels, which should be seamless to ensure the continuity and coordination of care. This commission proposes to use SCPs as a method for integration of oncology and palliative care.

Supportive and palliative care focuses on the patient, the host of the cancer disease. The aim of such care is to prevent, treat and reduce the patient’s symptoms and suffering caused by treatment toxicity and tumour burden and to preserve and improve psychological and social well-being. There have been recent semantic discussions regarding definitions and distinctions between supportive and palliative care. The European Society of Medical Oncology (ESMO) states that supportive care should be available at any stage of the cancer illness, while PC is focused on treatment when cure is no longer possible.<sup>7</sup> The American Society of Clinical Oncology (ASCO) does not specify a particular time for delivery of one or the other<sup>8</sup> and neither ESMO nor ASCO differentiate between the content of supportive and palliative care. In spite of a similar focus, the starting points for palliative and supportive care differed. Whereas palliative care started as end of life care, supportive care initially focused side effects of anti-cancer treatment such as chemotherapy-induced nausea and vomiting, and neutropenia.

Symptom management is a key element of both supportive and PC. Symptoms inform diagnosis and treatment in all parts of medicine and play a central role throughout the entire cancer disease trajectory. They are a particular focus in PC, in which symptom alleviation is the main target for interventions.<sup>2</sup> Symptom assessment is often not performed systematically in oncology practice or routinely incorporated into the clinical decision-making processes.

The World Health Organization (WHO) has defined the term integrated health services as: *“the organization and management of health services, so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and promote value for money”*.<sup>9</sup> In oncology, the multidisciplinary team approach that combines competence and skills in the planning of treatment care has become a standard.<sup>10</sup> This approach represents an integration of disciplines at the hospital level of care, e.g. among surgeons, oncologists, pathologists, radiologists and specialist nurses. The multidisciplinary team can include PC specialists at any stage of the disease trajectory when treatment intention is curative, life-prolonging or palliative. Given the definition of PC, interventions provided by PC have a broad focus and can therefore not be delivered by a single profession. Multiple professions organized in teams are therefore common in PC. The compositions of the teams might vary, partly depending upon local resources and traditions. The internal organization of the teams might also vary, but multidisciplinary, which draws on knowledge from different disciplines but stays within their boundaries,<sup>11</sup> are probably the most common internal organization. The term multidisciplinary teams (MDTs) will therefore be used throughout this commission.

From a societal, ethical and political perspective, the escalating costs of health care represent a major problem. Although spending on cancer care comprises only 5% of the overall health care

budget<sup>12</sup>, these costs continue to rise more rapidly than in other health care areas.<sup>13</sup> The escalating costs can be attributed to the ageing of the population, new and expensive diagnostic and treatment options, more prolonged survival of patients with metastatic disease and a growing public demand for tumour directed treatment at all stages of the disease. The increased complexity and escalating costs also apply to care at the end of life. About one third of the cost of cancer care is spent during the patients' last year.<sup>14</sup> Planning and structure of cancer care and PC has the potential to reduce costs, especially when the complexity of treatment and care increases.<sup>15</sup>

Evidence-based medicine is the norm in oncology practice,<sup>16</sup> but evidence as to when to start and when to stop anti-cancer treatment near the end of life has been lacking.<sup>16</sup> The quality and quantity of research in this area has been questioned<sup>17,18</sup> as is the case with regard to patient-centred outcomes for the newly registered targeted therapies and immunotherapies. The level of scientific evidence is also low with regard to the impact of chemotherapy in most areas of symptom management, including the treatment of pain,<sup>19</sup> although palliative radiotherapy may be highly effective in that regard.<sup>20</sup>

It is especially important during the patient's last year of life that the attention given to the effect of tumour-directed treatment is congruent with the individual patient's perception of benefits in terms of symptom burden and quality of life<sup>21</sup>. Few, if any, trials give guidance for such choices. This has led to the recommendation that a set of criteria (e.g. disease progression, performance status, nutritional status, weight loss and symptom burden) should guide the discontinuation of tumour-directed treatment.<sup>22,23</sup> This could also apply to Phase 1 trials, which may have therapeutic intent, but for which the likelihood of benefit to the individual patient may be extremely small<sup>24</sup>. As the disease progresses, there should be a redefinition of the main outcomes from tumour response to symptom control, preservation of functions and wellbeing.<sup>25</sup>

Shared decision-making is a key element of cancer care, but it has been questioned to what degree patients are able to participate as active partners in the decision-making process when multiple options for tumour-directed treatment are available and when life-prolonging treatment with marginal benefits are offered<sup>26</sup>. Some patients want to live as long as possible and are willing to try intensive treatment, even if the likelihood of benefit is extremely small and the risk of side-effects that may impair quality of life, and reduce residual time at home is high.<sup>27</sup> Active patient participation presupposes sufficient and relevant knowledge of the disease and the treatment options. This can only be reached by the continuous provision of realistic patient-centred information. This requires good communication skills among the oncologists and the palliative care specialists, with the needs and wishes of patients' and families' assessed systematically and used in the decision making processes.<sup>28</sup> It has been found with decision-making for Phase 1 trials that fundamental components of communication and information sharing, including discussion of prognosis and options for supportive care, are often missing from interviews.<sup>29</sup> A more patient-centred focus might be enhanced by an MDT approach, with systematic collaboration among team members from different professions within and across levels of care. This implies an empathic approach by health care professionals with willingness and skills to assess and understand the patient's needs. Since most patients want to spend as much time as possible at home during their last phase of life, health care providers need to understand, accept, communicate and plan for home care.

## Background

In the following section developmental and conceptual issues of relevance for the present focus on integration of oncology and PC are briefly outlined.

### **PC and oncology care - development over last decades**

Cancer care has been criticized for years for its disproportionate focus on the tumour, compared to attention to the patient with the cancer. The concept of hospice care and later PC was introduced partly as a reaction to the lack of a patient-centred focus. Attention to palliative cancer care emerged in the 1970s, partly through efforts of researchers, such as Jan Stjernswärd, who was attached to the WHO at that time.<sup>30</sup> The term PC was probably first coined by the Canadian surgeon Balfour Mount in 1974.<sup>31</sup> At the time, PC had a strong focus on end-of life-care and it is commonly still equated with this time frame,<sup>32</sup> despite its subsequent redefinition. A dichotomized perception of oncology care and PC is outlined in figure 1a. This perception fits with PC as equal to end-of-life care but is not in line with the present definition of PC as formulated by WHO (“applicable earlier in the disease trajectory”). A perception in line with this definition, in which the two are integrated or given in parallel, is outlined in figure 1b.

Supportive care emerged as a concept and a care approach in the late 1980s, somewhat later than PC, but with a similar focus on the host.<sup>33</sup> Supportive care focused on the entire disease trajectory, including when curative treatments, often accompanied by multiple side effects, are still being delivered. Late effects began to receive attention during the 1980s as new health problems in cancer care and spawned the field of cancer survivorship which can be regarded as an extension of supportive cancer care.<sup>34,35</sup>

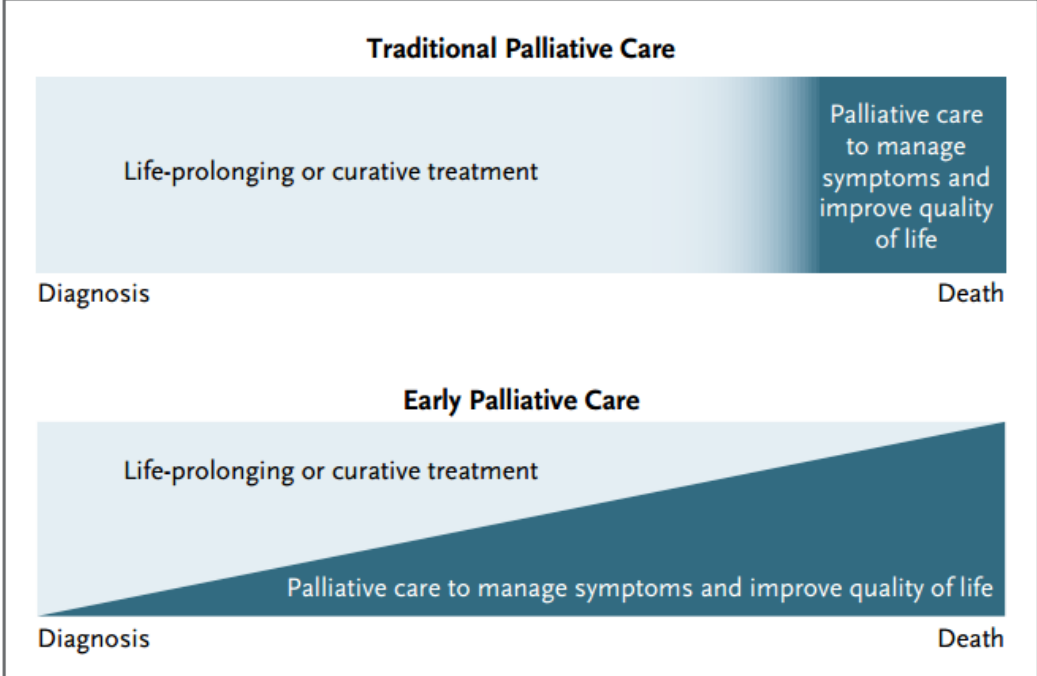
The difference between PC and supportive care is primarily related to differences in the stage of disease to which they are applied, rather than to the treatment itself.<sup>36</sup> This is reflected in the similar definitions of the concepts by the US National Cancer Institute (NCI) and the WHO.<sup>37</sup> According to the WHO definition, PC focuses on patients with a life-limiting disease, while supportive care is applicable irrespective of treatment intention and may also include rehabilitation of cured cancer survivors. Therefore, in our view, treatments of pain, fatigue, physical and psychological distress after curative treatment are best characterized as supportive care.

The content and the professional competence needed to provide PC and supportive care are basically similar, both focusing on the host – the patient living with the cancer disease and/or with side effects after the treatment. PC and supportive care are differently organized across locations, based upon resources and traditions. In some centres, the two are organized as one service, while in others they are totally separated. Independent of organizational structure, the focus on the host with a patient-centred focus is similar. Therefore, when resources permit, integration of PC and supportive care may be most effective in terms of treatment delivery and as a direction to strengthen the patient-centred culture in cancer care delivery.

The latest definition of PC by the WHO (2002), revised from its 1989-definition points to integration of oncology and PC by stating: “PC is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications”.<sup>38</sup>



The integrated care model has more recently also become a topic in cardiology, pulmonology and other specialties. The difference between an integrated model and PC as an end of life care is illustrated in Figures 1a and 1b.



**Figure 1a and 1 b. Traditional versus early palliative care**

**Patients live longer with metastatic disease – need for coordination and planning**

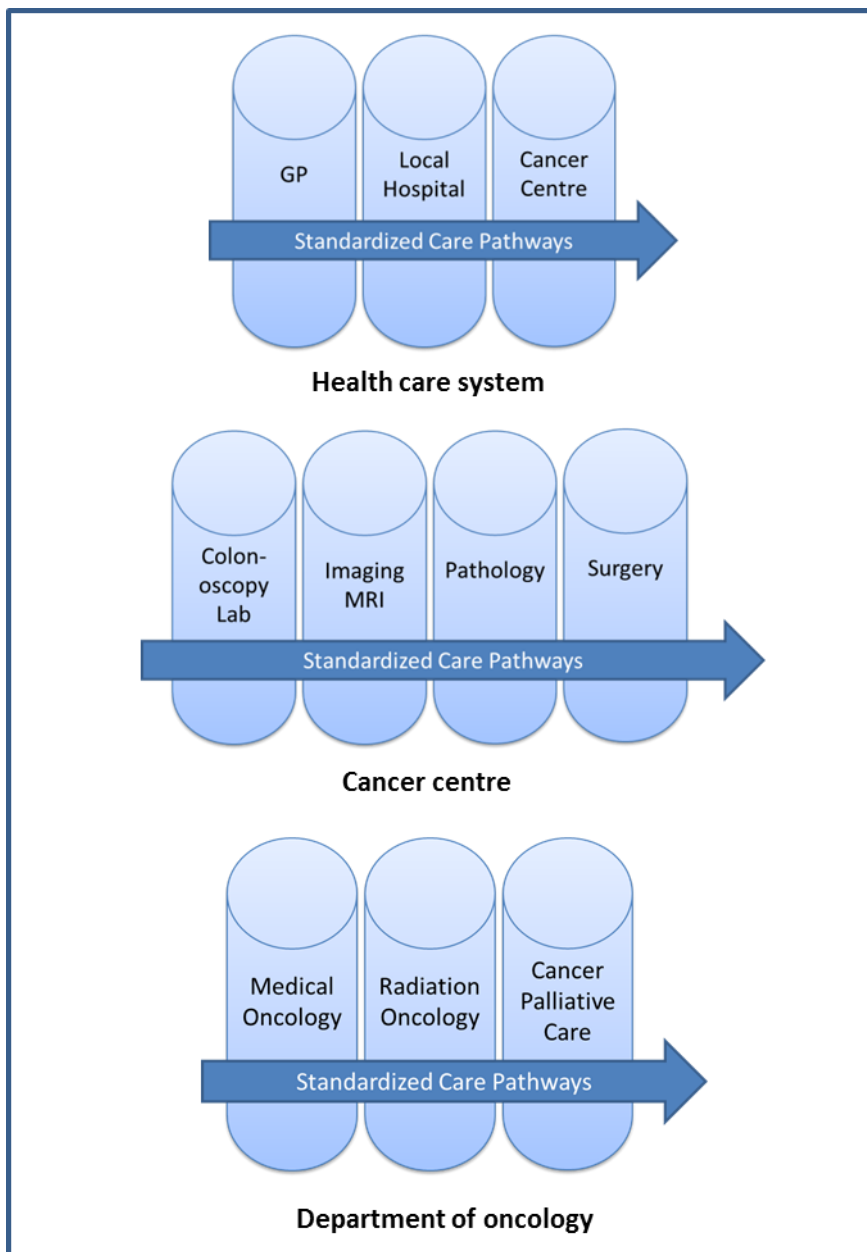
The possibilities for tumour-directed treatments have increased exponentially during the past decade. Multiple treatment lines have become the rule for common cancers, such as breast, lung, colorectal and prostate, and many more patients are now living with metastatic disease. New immune-therapies are being introduced into standard oncology care, with side-effects that differ from those of traditional chemotherapeutic agents. We lack systematic data on the impact of these new therapies upon the host and their clinical presentations. However, we do know that the increase in number of patients living with advanced disease necessarily will have implications on coordination and planning of care by combing the tumour- and the patient-centred approaches.

This development has reshaped cancer into a chronic disease, and cancer was recognised as one of four major types of chronic diseases by the WHO in 2010.<sup>39</sup> The development has also made the terms curative and palliative tumour-directed treatment even more vague and prone to be misunderstood by patients and possibly colleagues. We prefer terms related to treatment intention; curative, life-prolonging or palliative.<sup>40</sup> Probably will an increasing number of patients with advanced cancer die from other comorbid diseases after a prolonged period of tumour-directed treatment. Thus, the chronic care model will become increasingly relevant for oncology-palliative care, but our impression is that the traditional disease model still is the dominating model within cancer care. The chronic care model was launched at the end of the 20<sup>th</sup> century and represents a shift of paradigm within health care.<sup>41</sup> The model emphasises patient-centred elements such as patient empowerment,

patient preferences, and family and social support,<sup>41</sup> and therefore has obvious similarities with patient-centredness although the two seem to have been developed in parallel.

### **Integration in health care**

The availability of new tumour-directed treatments for advanced cancer points to a basic challenge in health care, in general, and in cancer care specifically: how to organize complex care pathways in a flexible and optimal structure involving multiple professionals working simultaneously or in parallel. Health care is currently most often organized in silos of primary, secondary and tertiary levels of care, with levels within each silo as well. Surgical oncology, medical oncology, radiation oncology and cancer PC within the cancer centre are examples of such silos, organized with separate leaders from different departments with individual budgets. Patients and their families may experience great difficulty navigating between and within each of these silos as well as to understand mixed messages about the main focus of care presented by two different cultures within the same department or hospital. As exemplified in figure 2, these silos should be “connected” to provide the varying needs for care of each individual patient. SCP is a method to foresee, establish and administer such connections.



**Figure 2. Health care includes silos at different levels**

In 2007, the WHO Director-General stated that *“We need a comprehensive, integrated approach to service delivery. We need to fight fragmentation”*.<sup>42</sup> The current challenge is to specify the nature of integrated services in different settings and how integration can contribute to the intended aim of ensuring that cancer patients and their families receive the care they need. The WHO Technical brief on integration of health services aimed to show that integrated service delivery is best seen as a continuum involving technical discussions about tasks that need to be performed in order to provide good quality health.<sup>9</sup>

Integration aims to coordinate the activities of professionals with the overall goal of improving patient care. Achieving such coordination requires change at the system level based upon a common understanding and acceptance of the two paradigms in this context. From an organizational perspective one need to take into account the flow of patients between levels (or silos) of the

organization; this refers to the units, sections, departments and/or hospitals. To reach the goal of integration a common understanding of a merging of the two paradigms are probably needed as well as budgetary reallocations and formal or informal changes in the organization may be required. These changes may allow more flexible allocation of human and treatment resources according to the needs defined in the SCPs.

In an influential article, Leutz defined integration as: *“the search to connect the health care system with other human service system in order to improve outcome (clinical, satisfaction and efficiency)”*.<sup>43</sup> He proposed three levels of integration in the same article: linkage, coordination and full integration. In Table 1, examples and understanding of these three levels are provided from a general health care perspective and from an oncology/PC perspective.

<i>Linkage</i>	<ul style="list-style-type: none"> <li>• Patients are cared for in a planned system</li> <li>• Based upon an understanding of special needs (formalized in an SCP)</li> <li>• Work in parallel or in series</li> <li>• Basic understanding of the various professional skills</li> </ul>
<i>Coordination</i>	<ul style="list-style-type: none"> <li>• Patients are cared for in a well-structured plan based upon patients’ needs and the content of the SCP</li> <li>• It operates in separate structures within a system (exemplified by pathology, imaging, surgery, radiation or tumour directed chemotherapy symptom management etc.)</li> <li>• It has been an implementation plan (of the SCP) and follow ups/monitoring of the plan</li> </ul>
<i>Full integration</i>	<ul style="list-style-type: none"> <li>• Resources (competence and skills) are pooled into one unit/section taking from existing systems</li> <li>• The silos are eliminated (partially or totally) and the organization is based upon the SCP</li> <li>• The MDT can as a dynamic structure be an example of full integration as they meet</li> </ul>

**Table 1. Three levels of integration adapted and revised from Leutz.<sup>43</sup>**

The levels of integration as outlined in table 1 can be understood as both static and dynamic. Integration as outlined in Table 1 will also challenge the internal life and individual priorities in cultures and subcultures in both oncology- and palliative care. In order to reach achievable and practical solutions integration can be formalized and made routine in some situations, as with multidisciplinary team meetings (MDT) as one component in a planned structure (the SCPs), while in other situations may be added according to patient needs in order to optimize care.

### **Integration of oncology and palliative care**

The term *integration* has been applied to the interplay between oncology and PC for some decades. It was used in an Editorial in JCO in 2004 that recommended efforts be made to bridge the gap between oncology and PC, in order to provide better care for those dying from cancer.<sup>44</sup> The distinction between integration and early integration has not been clearly defined, but use of the latter term might help to counteract the commonly held belief that palliative care is equivalent to end-of-life care. The strong focus on integration in contemporary oncology and PC has also led to experts formulating consensus- based indicators of integration.<sup>45</sup>

The 2010 Temel et al<sup>3</sup> findings of improved survival and better quality of life with early palliative care paved the way for the integration of PC in oncology, as a means to provide better and more patient-centred care for patients with a life-limiting cancer disease. PC has also been proposed as a means to offset the rapidly increasing costs in oncology, especially in the patients' last year of life, and to address the anticipated shortage of resources due to increasing demands and costs. The findings of the Temel study led to the formulation of an ASCO provisional clinical opinion in 2012, which was revised into a clinical practice guideline in 2017.<sup>16,46</sup> Without using the term early integration, the provisional clinical opinion clearly stated that PC is more than end-of-life care and that patients would benefit from receiving PC, while still receiving tumour-directed treatment, based on a low to medium level of evidence.<sup>46</sup>

**Randomized studies**

The current research on integration between oncology and PC primarily stems from studies of cancer patients in outpatient hospital settings and has recently been synthesized in a review<sup>47</sup>. Other published reviews of the effectiveness of specialized palliative care have mainly been based on mixed populations, without separating the results for patients with cancer. The trials included in the 2017-review have been published from the late 1990s with different designs and endpoints. Table 2 presents the components of integration from the seven randomized trials included in the 2017-review.<sup>47</sup> The components vary considerably across the studies but are systemized in this table based upon components proposed in a recent study.<sup>48</sup>

	Jordhøy 2000 <sup>49</sup>	Temel 2010 <sup>3</sup>	Zimmermann 2014 <sup>5</sup>	Bakitas 2015 <sup>50</sup>	Maltoni 2016 <sup>51</sup>	Temel 2017 <sup>52</sup>	Grønvold 2017 <sup>53</sup>
<b>Clinical structure (*)</b>							
Presence of palliative care inpatient consultation team							
Presence of palliative care outpatient clinic							
Presence of community based / home palliative care							
<b>Clinical processes (*)</b>							
Presence of multidisciplinary specialized palliative care team							
Routine symptom screening in the outpatient oncology clinic							
Administration of systemic cancer therapy (e.g. chemo and targeted agents) possible in patients admitted to PC service							

Follow pre-specified palliative care guidelines							
Early referral to palliative care							
Availability of clinical care pathways (automatic triggers) for palliative care referral							
Palliative care team routinely involved in multidisciplinary tumour conference for patient case discussions							
Communication, cooperation and coordination between PC and oncology service							
Routine discussion of prognosis, advance care planning with goals of care							

**Table 2. Components of integration from 7 randomized trials (colored cell indicates presence of component in trial) (\*) adapted from Hui. <sup>45,48</sup>**

Jordhøy and colleagues published at the turn of this century the results of a cluster-randomized trial of PC.<sup>49</sup> We are not aware of any randomized trials on the effects of PC-programs prior to this publication. Some trials in the 1980s and early 1990s had tried to evaluate the effects of elements included in PC, such as end-of-life care, with negative results.<sup>54-56</sup> These early trials were hampered by methodological shortcomings, such as lack of well-defined primary endpoints, control contamination, recruitment, and problematic attrition and adherence. In their large study of mixed cancer diagnoses, using well-validated instruments, Jordhøy et al circumvented many of these limitations.<sup>49</sup> However, the main focus of this comprehensive trial was integration of community and hospital care for patients with advanced cancer. More patients in the intervention group died at home, compared to the control group, and these patients also spent less time in hospitals and more time at home and in nursing homes. No effect on symptom burden was demonstrated, which was reported in a separate article.<sup>4</sup>

Several years later, Bakitas and colleagues designed Enable II, an RCT to test a telephone-based psycho-educational PC-intervention delivered concurrent with oncological treatment.<sup>57</sup> The program was found to significantly improve both mood and quality of life in a sample of 322 patients with mixed cancer diagnoses. However, a traditional PC-model was not applied, as the study did not systematically include the intervention of a (multidisciplinary) PC-team.

The publication by Temel and colleagues in 2010 is usually referred to as the landmark trial of integration of oncology and PC.<sup>3</sup> They demonstrated that, among newly diagnosed lung cancer patients, early PC not only reduced depression and symptom burden and improved quality of life, but also produced a survival benefit. Finally, the intervention group was found to report improved prognostic awareness and to receive less intensive cancer treatment at the end of life. However, the

study was carried out in a highly specialized institution and some researchers have raised doubt as to its generalizability to other care settings.<sup>58</sup>

In a cluster-randomized trial in 2014, Zimmermann and colleagues investigated early involvement of specialized PC in the treatment of patients with a wide range of advanced cancers.<sup>5</sup> This study provided evidence of benefits on quality of life and symptom burden. Further, it was the first study to explore clinician-patient interactions: a difference with satisfaction with care was found in favour of the intervention group, but no differences were found on other measures of patient/staff interactions.

In the meantime, the initial model constituting the Enable II had been somewhat expanded, and in 2015, Bakitas and colleagues published the findings of the Enable III trial.<sup>50</sup> By applying a fast-track design, this trial was the first to evaluate the optimal timing for introducing PC concurrently with standard oncological care.<sup>50</sup> The only difference between the groups that was identified was longer one year survival for the “early” group. This was a tele-health intervention with an advanced practice nurse, rather than a PC team, initiating and in charge of all patient contact. This raises the question of whether the Enable III is a sophisticated psycho-educational model, rather than a specialized PC-intervention.

In 2016, Maltoni and colleagues carried out a multi-centre randomized trial to evaluate early PC efficacy for patients with advanced pancreatic cancer on both patient-reported outcomes and health care utilization<sup>51</sup>. They reported benefits on quality of life, symptom burden and less time spent in institutions. As such, this was the first European trial to confirm the results of the important North American trials.

The most recent study by Temel and colleagues has again drawn attention to early palliative care, examining the impact of an integrated PC model on newly diagnosed GI (non-colorectal) and lung cancer patients.<sup>52</sup> In addition to improved quality of life and decreased depression, they showed that an integrated PC-model improved the patients’ ability to cope with their prognosis and enhanced their communication with clinicians about end-of-life preferences. They showed that these positive effects vary by cancer types, but the two sub-samples were too small to substantiate these differences.

The Danish PC-trial (DanPaCT) from 2017 investigated the effect of a PC-intervention among patients with a range of cancer diagnosis.<sup>53</sup> Patients were included if they scored above a predefined threshold for self-reported symptoms or reduced functioning. The primary outcome was defined as the individual patient’s main problem, as defined by a screening process. The sample was large with little loss to follow-up. No differences on either primary or secondary outcomes were reported. Grønkvold and colleagues proposed several possible explanations for the lacking beneficial effects, including the lack of structure in the PC-visits and short observation time.<sup>53</sup>

The most recent study relevant in this context confirmed the findings of Temel et al from 2010.<sup>59</sup> However, the intervention was not palliative care per se but consisted of monthly sessions with palliative nurse and inferred more usage of consultations with a psychologist. The study therefore adds to the variability in the content of the palliative services (i.e., the intervention) and of how palliative care and oncology care are delivered, in studies of integration of oncology and palliative

care.<sup>60</sup> Still the added element was definitely patient-centred which is of particular relevance in this context.

The growing literature on integration of oncology and PC has been synthesized in reviews, statements and guidelines, some of which focus specifically on integration, while others more generically on “specialized PC”.<sup>16,58,61-63</sup> However, several issues complicate attempts to evaluate and compile this body of literature. Most of the reviews underline that the heterogeneity in settings, target populations, and study outcomes make it difficult to directly compare trials. Particularly cumbersome is the diversity in intervention content and the PC specific component (Table 2). In addition, the variability in methodological quality across trials was highlighted in a recent meta-analysis.<sup>64</sup> When considering only trials with low risk of bias, the authors concluded that the evidence for the effectiveness of specialized PC-interventions for improving quality of life and symptom burden is relatively weak.<sup>64</sup> However, a 2017-Cochrane review concludes that early palliative care may have more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. The effects are of clinical relevance at an advanced disease stage with limited prognosis, when further decline in quality of life is the rule.<sup>65</sup>

The heterogeneity in study outcomes and methodological quality of studies of the effectiveness of PC are obvious limitations in research on integration. However although the evidence supporting integration of oncology and palliative care might seem somewhat meagre, the recommendation to integrate is strong. This is explained by the overall picture, showing that early palliative care interventions of different sorts have a positive impact on various patient outcomes.

### **Systematic symptom assessment**

In order to facilitate better patient involvement in cancer care and improved patient-centred outcomes, the patients’ “voice” must be heard, in terms of symptoms, functions, quality of life, and preferences for information provision and shared-decision making. The recognition of the patients’ perspectives as valuable or even decisive when choosing how to care, where to care and when to care, represents a major shift in medicine during the last 10-20 years. Patients’ perspectives have now been recognized as valid outcomes in clinical medicine, as endorsed by the National Institute of Health consensus conference.<sup>66</sup> While systematic symptom assessment is an established core clinical activity in PC, directly derived from the definition of PC as stated by the WHO, symptom assessment is still rarely performed systematically and even rarely used actively in the patient decision making processes in present oncological and palliative care practices.

The U.S. Food and Drug Administration (FDA) proposed in 2006 to use the term Patient Reported Outcomes Measures (PROMs) for all measures that can best or only be assessed by asking the patients themselves. By that, the FDA also formally recognized the importance and clinical utility of PROMs by releasing a new Guidance for Industry on these issues.<sup>67</sup> PROMs are therefore an umbrella term covering the patient’s perspective on physical and psychological well-being, and symptoms and treatment effects<sup>68</sup>. The recognition of PROMs as independent outcomes in cancer<sup>69,70</sup> is consolidated by the CONSORT-PRO Extension Statement developed to improve the reporting of PROMs on patients’ evaluation of symptoms, functioning and quality of life<sup>70</sup>. As the patient is the



primary source of information, PROMs supplement clinical observations and objective findings with individual patient information.

Symptom assessment tools are, for these reasons, presently grouped under the umbrella PROMs, which also encompasses other outcomes assessed similarly, such as quality of life and functional status. Symptom assessment is pivotal for palliative/supportive care efforts throughout the whole cancer disease trajectory, and increasingly so as life-prolonging tumour-directed treatment ceases. Still, the infrequent assessment of symptoms is a major factor explaining inadequate symptom relief, with undue suffering among cancer patients approaching end of life. A key symptom in health care is pain, and, according to the international definition by IASP,<sup>71</sup> pain can only be assessed reliably and validly by self-report, not by observations. Several other symptoms, only assessable by patients' report, i.e. as PROMS, are important to consider in the care of cancer patients. These include psychological symptoms such as anxiety and depression symptoms, somatic symptoms, such as anorexia, dyspnea, fatigue and overall quality of life.

Traditionally, PROMs were collected on paper-based questionnaires. New advances in health information technology have promoted the development of electronic tools for the distribution of PROMs. Such new tools allow an effective integration of patient related data from various sources. Further, electronic tools permit distant follow-up of patients who are not hospitalized and can also promote data sharing between care teams at different care levels. Studies in oncology have shown that electronic assessments and rapid presentation of results facilitate communication, is well perceived by patients and clinicians, and may also result in a more efficient and focused use of time.<sup>72,73</sup> A recent qualitative study showed that perceived usefulness may be more important than functional aspects.<sup>74</sup> Still, immediate display of easily interpretable results to the HCP is a crucial factor for successful implementation of electronic registration of PROMs into the clinics.<sup>75</sup>

On this background we find it pertinent to point to a recent study on the effects of systematic symptom assessment by tablet computers in patients with advanced solid tumours. The study demonstrated positive outcomes of systematic symptom assessment in oncology practice. The authors demonstrated that health-related quality of life improved among more in the intervention group and worsened in fewer than among those receiving usual care.<sup>76</sup> In a separate letter the authors also demonstrated improved survival among those having their symptoms assessed systematically.<sup>77</sup> The results of this trial are a strong reminder of the importance and positive effects of systematic symptom assessment in cancer care in general.

## **Standardized care pathways**

Integrated care models can be understood as organizational methods to solve the challenges of management of complex care processes, and particularly so in the growing elderly population. In integrated care, professionals with different competencies and from distinct organizations work together in complex and formalized structures. This model challenges the traditional "vertical organization" of health care, as outlined previously, structured in pillars or silos.

Patients often experience gaps between services when they must shift levels of care or between types of specialization.<sup>78</sup> A different matrix is hypothesized to better meet patients' needs, which are complex and shifting over time, and allow the patient's flow in such complex movements to be more predictable and transparent to them and to their care providers. In order for this to occur,

communication and collaboration among the health care providers must also be predictable, clearly understood, with the roles of team members clarified and agreed upon.

Achieving integration among the different services and levels of health care is by no means straightforward since two different cultures, each with different foci, the tumour-centred and the patient-centred, need to “join forces” and thereby solve the patients’ needs during the development and implementation of the SCPs. Indeed, the greater the number of actors that are involved in a patient’s care, the more difficult the communication and coordination becomes. The development of SCPs is a method for meeting these challenges.

Having its roots in the automobile and production industries, multiple SCPs have been developed and published throughout the recent years, covering a wide area of health services ranging from surgical procedures to complex disease trajectories.<sup>79</sup> Implementation of SCPs ensures that care is organized with the right people at the right time in the right place. Therefore, SCPs can work as a systematic way of organizing integration in the organization to improve patient care and resource utilization. This however, requires that seamless patient flow in a customized organizational model is possible.

A wide range of methodologies have been used in the development of SCPs, mainly without a common framework or international consensus on how to develop them in a standardized and evidence-based way.<sup>80,81</sup> The generalizability of findings is also limited by the plethora of study designs, settings, and proposed pathways. This makes the relevance of individual studies difficult to evaluate and apply to clinical settings that are different from the one in which the specific SCP was developed and tested.<sup>82</sup> In their review, Rotter et al. assessed the effects of SCPs on professional practice, patient outcomes and hospital costs.<sup>78</sup> They included 19 RCTs comparing SCPs to standard practice based on more than 3000 abstracts identified in their search, covering a wide range of medical conditions and surgical procedures. Among the RCTs included, nine gave some form of description on how the SCP was developed and implemented. In those nine studies, the methodology applied to develop an SCP was mainly described in general terms (such as «a protocol was developed by a multi-professional team»). Ten of the studies conducted a follow-up on how health care providers complied with the SCP protocol, but none were performed in a similar way. Only one RCT included described how relevant clinical outcomes were monitored in the SCP-group by the use of computer-technology.<sup>83</sup> A main feature of the RCTs included was that the SCP was applied in a facility-specific manner for a defined period of time, disregarding other elements involved in patient care and follow-up. Further, since the SCPs tested were mainly paper-based, the potential utility of a common and flexible electronic SCP was not evaluated. There is also a high variability with respect to how different SCPs are audited.<sup>82</sup>

## Conclusions

There is now a strong consensus in contemporary cancer care on integration of oncology and PC. In fact, the newly released ASCO guidelines on the topic were for months the most searched article in the Journal of Clinical Oncology.<sup>16</sup> The published RCTs on the subject point to health gains by integration, but what, when and how to integrate is still not established facts. Despite very clear recommendations of integration, this commission has not identified any health care system where the content and the constructs of integration are implemented. This commission will hypothesize that broad implementation plans are needed, adapted to national, regional and local organizations of

oncology- and palliative care as well as their cultures. Local variations in terms of resources and practices also probably play a role.

By acknowledging integration of oncology and PC as a complex process including different parts of the health care system, both horizontally and vertically, and also involving the patient, we propose SCPs as a means for future efforts to promote integration. For the same reasons, this paper will address integration in different panels. Each panel will address different aspects of integration, ranging from how to focus on the patient, to societal changes and new research areas.

#### Introduction of panels

Policy – challenges and frameworks

Societal challenges

Prognostication

Patient-centredness – content methodology and clinical implications

Models of palliative care integration

The role of education: challenges and recommendations

Research

The commission is an international collaboration between 30 experts in oncology, PC, public health and psycho-oncology. In October 2016 a kick-off meeting was held in Milan where panel leaders were appointed, the structure of the commission was decided, and a plan for the work was agreed upon. During the two following years each panel expanded with experts within the relevant field, conducted topical literature searches, and an interactive writing process was conducted. Both administrative and academic organization were run from Norway, by Stein Kaasa, Jon Håvard Loge and Tonje Lundebj.

## Policy - challenges and frameworks

#### Questions to be addressed

What type of recommendations is given for integration at the national and international level on policy and public health at present?

What are the current examples of different practices in organization of palliative care in different national policies in European countries?

What kind of policies and approaches are needed for integration of oncology and palliative care?

#### Introduction

Demographic data demonstrate the undeniable fact of a rapidly increasing cancer incidence and prevalence and an ageing population with multiple chronic comorbidities. A recent publication, presenting various models for extrapolation in high-income countries found that 69-82% of those who die need palliative care.<sup>84</sup> Consequently, an augmented need for palliative care at all health care levels is expected.

Palliative care has been clearly identified as an integrated part of the cancer care pathways by professional international organisations, such as ASCO, ESMO, and EAPC, but also by the European

Union projects, such as the European Partnership Against Cancer.<sup>85-88</sup> In sum these statements clearly indicate that palliative care should be part of national cancer politics and national cancer plans.<sup>89</sup> How this is accomplished in present national politics in Europe will be addressed in the present panel. Further, examples of different practices in organization of palliative care in some European countries are presented and recommendations for future politics are given.

## Organization, development of health policies and health systems

### General aspects on health policies of relevance for palliative care

Health care systems in Europe are generally classified with respect to the role of the state, the role of the health care providers and the role of the payers. This triad is furthermore amended by the closer or looser links with the social care sector. Countries with a strong National Health Service tend to have closer links between health care and other sectors including the social care sector. Health care systems based upon social health insurance systems have a looser link with social care sector and consequently, more often have gaps in the comprehensiveness and continuity of care. Type of system is very relevant for palliative care since the health and social sectors often need to interact, flexibly and fast in order to meet the needs of the patient and the families.

Modern health care systems in Europe build on the experiences of the 20<sup>th</sup> century when the State's responsibility for delivery of health care became a social and political issue. This responsibility was primarily approached in three different ways; the Bismarck system, the Beveridge system and the Semashko system.<sup>90-92</sup> The oldest of these systems, the social health insurance (also called the Bismarck system), originated in 1883.<sup>90</sup> The coverage was gradually extended from industrial workers to other categories of the workforce. In 1940s, Lord Beveridge lead the work on the development of the National Health Service,<sup>91</sup> which became a more comprehensive response to the demands for full coverage, irrespective of employment status. Between the two, in 1928, Soviet Union developed the Semashko system,<sup>92</sup> which was dealing with the organizational aspects of health care rather than the financing or entitlements.

The main differences between the Beveridge and Bismarck systems are the degree of state control over health care and how this control is exerted. In the Beveridge system, the Ministry of Health (MoH) is typically the budget holder and therefore commissioning services through a network of health care providers. In the Bismarck-type of systems, budgets are predominantly with health insurance companies, regulated by the MoH and operating in public interest. The role of the different partners has significantly more weight in Bismarck systems. Although the Beveridge systems seem to perform better in terms of care coordination as health and social care are integrated in a common, welfare stem, this may only be the case at the governmental level. In the Bismarck system, social care and other types of care (related to health but not necessarily inherent in health care) show a large degree of fragmentation as they are financed from different sources, often as cash benefits or entitlements.

An OECD conference in 2011,<sup>93</sup> pointed out that the sharp distinction between these two systems are mainly of historical interest, and that the "pure" Bismarckian era was more or less over, because policies emphasized universal coverage rather than a right of labour. Further, little if any scientific evidence exists on the superiority of one system over the other, specifically regarding coordination of

care, for which no universal definition presently exists.<sup>94</sup>

On the global arena, the resolution by The World Health Assembly (WHA) (governing body of the WHO),<sup>95</sup> on “Strengthening palliative care as a component of comprehensive care throughout the life course” led to a presentation in the WHO on the progress of implementing the resolution. A civil society report requesting e.g. that palliative care should be covered under National Universal Health Coverage plans, and national strategies for palliative care implementation, including universal health professional training, followed the resolution. As much as the systemic approach to organising and financing palliative care is in societal interest and pertinent to population approaches, palliative care is in essence to meet individuals’ needs and therefore must be planned and designed to address those needs. In that sense, palliative care needs to be patient-centred as the primary driver for its planning, assessment of needs, organisation and delivery are patient needs, which should steer the development of adequate services.

### **European over-riding policies and recommendations on palliative cancer care**

In Europe, the European Association for Palliative Care (EAPC)<sup>96</sup> has since its foundation been influential in the promotion, advocacy and development of palliative care in Europe, scientifically, clinically, socially and politically. In 2010, EAPC launched the Prague charter, stating that access to palliative care is a legal obligation and a human right, and thus beyond the established palliative care community.<sup>85</sup> This was followed by the Lisbon challenge, identifying four major objectives related to access to essential medicines, development of health policies that address the needs of patients with life-limiting or terminal illnesses, adequate palliative care training also at undergraduate levels for health care providers and a structured implementation of palliative care.<sup>97</sup> In 2013, the Budapest commitments presented frameworks for palliative care development as a joint initiative by EAPC, International Association for Hospice and Palliative Care (IAHPC)<sup>98</sup> and Worldwide Palliative Care Alliance (WPCA).<sup>98</sup> Key elements were policy, availability, education, and quality.<sup>99,100</sup>

In 2006, the European Palliative Care Research Collaborative (EPCRC) was the first palliative care research project that received funding from the European Commission (EU) under the 6th framework program for research. The promotion and financing of palliative care research within the EU framework represented a major step forward for European palliative care research. Since then, several high-quality projects on oncology and palliative care have received funding, e.g. the IMPACT project developing and testing quality indicators for dementia and cancer palliative care,<sup>101</sup> EUROIMPACT<sup>102</sup> a multi-professional research training program, the ATOME project on access to opioid medication in Europe, and the International Place of Death Study.<sup>103</sup>

The objectives of the EU-funded PRISMA project (7<sup>th</sup> Framework Programme) conducted in nine countries were to co-ordinate research priorities, measurement and practice in end-of-life (EOL) care in Europe, resulting from an identified need for high quality palliative and EOL care and research. The research agenda and subsequent guidance should reflect the European cultural diversity and be informed by public and clinical priorities.<sup>104</sup> Consensus was reached on the following priorities for EOL cancer care research in Europe: symptomatology, issues related to care of the dying, policy and organization of services, and moving from descriptive to interventional studies.<sup>105</sup>

Two EU-funded projects also addressing European cancer politics have now come to an end; the EPAAC (European Partnership on Action Against Cancer)<sup>106</sup> and the European Guide for Quality National Cancer Control Programs (CANCON) (Cancer Control).<sup>89</sup> The EPAAC report on National

Cancer Plans (NCPs) is based on a survey running from December 2011 to April 2012 in the EU Member States, Iceland and Norway.<sup>86</sup> An NCP was defined as a public health programme designed to reduce the number of cancer cases and deaths, with strategies for key areas such as prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research. The survey aimed to map the current level of integration in cancer care, including palliative care, and to develop indicators to monitor the actions of NCPs across countries prior to developing guidelines for preparing or evaluating cancer plans.

The final EPAAC report points to significant variations in cancer control and care within and between EU Member States across the key areas of cancer care mentioned above. The report identified a lack of a comprehensive approach from policy documents addressing the rising needs of cancer patients, especially due to the increasing incidence and prevalence of cancer. Finland specifically prioritized palliative care in its national cancer plan, whereas e.g. Estonia, Greece and Portugal were lacking an appropriate infrastructure to carry out the NCPs adequately, especially with respect to home care and palliative care services. This means that the awareness of the need for palliative care is rising but the political willingness to dedicate adequate resources may be lacking.

The identified inadequacies in policy mentioned above were included in the CANCON project in which the primary objective was to improve overall cancer control throughout the EU.<sup>89</sup> The final guide covers the areas of quality-based cancer screening programmes, better integration of cancer care, community-based cancer care approaches and survivorship.

The main target group for dissemination of CANCON deliverables were policy- and decision-makers at EU and national levels.<sup>107</sup> Palliative care issues were promoted as part of an overall disease trajectory, also pertaining to the primary care level.<sup>108</sup>

In summary, the findings and resolutions presented above represent major assets for the recognition of palliative care as an inherent part of oncology, thereby justifying integration of palliative care and oncology, politically and organizationally. Still, the findings also illustrate a huge divergence across Europe regarding the recognition of palliative care as an integrated part of cancer care at the political level. This contrasts tumour-directed treatments which to a much higher degree are based upon commonly agreed-upon guidelines and treatment algorithms which are accepted as premises for organisation and resource allocation at the political level. By learning from oncology care and its successes, the development of clinical relevant guidelines for organization and implementation of palliative care integrated into “main stream” oncology is rapidly needed and may be a success factor for high quality cancer care in the future.

### **European examples of organisation of palliative care**

The report by the European Parliament on Palliative Care in the European Union found a pronounced heterogeneity in the way in which national health systems care for their dying, as well as the quality and access of the care provided, not only between countries, but also within them.<sup>109</sup> Countries involved in the CANCON project have various policies on palliative care. These policies are often nationally developed and highly influenced by local opinions leaders in palliative care. However it is often referred to recommendations for palliative care published by international organizations, such as the WHO, the European Union or the Council of Europe.<sup>2</sup>

Policies vary on horizontal and vertical integration of services and structures for palliative care.

Palliative care in Belgium, Bulgaria, Denmark, France, the Netherlands, Norway, Slovenia and Spain is provided in various providers' organizations and across all levels of care (Table 3).

<b>Providers</b> <b>Countries</b>	<b>Hospitals</b>	<b>Out-patient clinic / Day-care centres</b>	<b>Nursing homes (and homes for the elderly)</b>	<b>Hospices</b>	<b>Home care</b>
<b>Belgium</b> <sup>110</sup>	+ (PCU*)	+	+		+
<b>Bulgaria</b> <sup>111</sup>	+ (including CCC** and PCU*)		+	+	+
<b>Denmark</b> <sup>112</sup>	+ (including PCU*)		+	+	+
<b>France</b> <sup>113</sup>	+ (including PCU*)	+			+ (including HAD - Hospital at home programme)
<b>Netherlands</b> <sup>114</sup>	+	+	+ (including PCU*)	+	+
<b>Norway</b> <sup>115,116</sup>	+	+	+		+
<b>Slovenia</b> <sup>117,118</sup>	+	+		+	+
<b>Spain</b> <sup>119,120</sup>	+	+			+

**Table 3. Providers of palliative care in some European countries. (+) indicates availability of providers. \*PCU - palliative care units, \*\*CCC - comprehensive cancer centres.**

Hospitals are mostly either specialised cancer centres or general hospitals authorised to participate in some or all parts of oncological care. Out-patient clinics might be organized as part of departments or as special clinics for patients in need of palliative care. In many countries, nursing homes take over the care for those patients who for various reasons are not capable of living in their homes.

In Belgium, France, the Netherlands, Norway and Spain different types of networks and multidisciplinary teams provide coordination and/or care at patients' homes, out-patient clinics and in in-patient departments in hospitals and nursing homes. The level of institutionalisation seems to depend strongly on the specific organisation of health care. Thus, in some countries, such as Bulgaria and Belgium, there is strong dependence on institutional care, whereas in the Netherlands palliative care is often primarily delivered in home settings by GPs and specially trained nurses.

The compositions of the teams that deliver palliative care vary across European countries. In the Netherlands, a large proportion of palliative care is put on the shoulders of GPs, who - among others - run in-patient palliative care units in nursing homes. On the other hand, in many countries palliative care remains a function carried out in hospital settings or in day hospital departments as part of hospitals. The latter policies are likely to become unsustainable for some reasons:

1. Patient preferences, which indicate that patients prefer to be treated close to home when they need palliative care

2. Demographic changes with an increasing number of patients needing palliative care, which cannot realistically all be organized in hospital settings alone

As pointed out already, palliative care in European countries is delivered in different settings, but it is difficult to identify a systematic pattern based upon the health care system in the country. This observation confirms the hypothesis that palliative care is underdeveloped in the health care system and still is too much dependent upon individual initiatives. From the project meetings and interviews on the CANCON, it was identified that in the Netherlands, a patient with a condition that requires only palliative and/or end-of-life care is discharged from in-patient oncological facility and his/her GP and district nurse are informed. Some of the patients who cannot stay and be cared for at home are placed in nursing homes with palliative care units, which are run by additionally trained GPs. In many countries, this would not meet the patient's and/or family's expectations. This is in contrast to the Bulgarian system, where cancer care is exclusively delivered by the so-called Comprehensive Cancer Centres, which exist in all regions.

There is no 'one-size-fits-all' policy in developing different models in palliative and end-of-life care. Still, we observe a significant heterogeneity of services within and between countries. These partly reflect the organisation of health care services but very often, and even more importantly, different societal and political attitudes with respect to palliative care. It seems as if the "mature" systems place palliative care in a more central position than systems with a shorter history. .

When comparing the two analyses of EU and EEA countries' cancer plans in 2011 and 2016, we observe a trend towards more frequently including palliative care as an element of the cancer plans. Still, in most cases palliative care is regarded as an add-on service, receiving less attention than the traditional diagnostic and therapeutic elements of cancer care.

Barriers for integration of palliative care into a comprehensive planning seem to fall in two clusters. One is the fact mentioned above that health systems have different traditional and current attitudes with respect to palliative care. This impedes a more open debate on how to organize, place and staff palliative care as an element of a continuous cancer care. The other cluster seems to be a lack of dedication to secure financial resources and organisation capacity that make palliative care accessible to all patients who need it irrespective of their financial ability to pay for care.

### **US policies on palliative cancer care**

Palliative care was introduced to United States (US) in 1963.<sup>121</sup> It first started as a hospice movement focusing on the provision of home-based care to patients in the last weeks/days of life. In 1973, the first hospice was established in Connecticut. In 1978, the National Hospice Organization was founded. The Hospice Medicare Benefit Program was established by the Tax Equity and Fiscal Responsibility Act in 1982, defining the payment and policies for hospice care in the US. By 2015, there were over 5800 hospice programs across the US.

In contrast to hospice programs that are community-based, palliative care programs reside in acute care facilities. The first palliative care unit in US was established in Cleveland Clinic in 1988. Over time, other cancer centres have developed models of excellence for integrated palliative cancer care, such as the MD Anderson Cancer Center.<sup>8</sup> Since the 1990s, there has been a growing proportion of cancer centres with outpatient clinics to facilitate timely palliative care.<sup>122,123</sup> In 2006, the American Board of Medical Specialties recognized hospice and palliative medicine as a medical specialty,



further promoting the growth of this discipline.

### **Australian policies on palliative cancer care**

Palliative care has had growing recognition in Australia over the last three decades. The sub-specialty was first recognised within the College of Physicians in 1988 and training from that time was available. Specific national policies allowing reimbursement for clinical care were introduced in the year 2000.

There has been a national strategy endorsed by all states and territories since the year 2000. This sought to address access and equity, models of care and the relationship between specialist services and the rest of the health sector including primary care. It has been revised twice since its initial genesis, and has had comprehensive evaluations for its first two iterations. This process enabled conversations that were far more broad-ranging both within the health sector and the community more broadly.<sup>124</sup>

### **Approaches for integration of cancer and palliative care**

Coordination of care, regardless of definition, is demanding, involves a vast number of professionals and multiple transitions from one care level to another during a disease trajectory, which makes collaboration and integration of services paramount. One response to this complex process is the introduction of standardized care pathways, which have been adopted and adapted to cancer care in several countries (e.g. Belgium, France, the Netherlands, Norway and Spain).

Another organisation principle at an even more micro-level is MDTs. This was proposed by one of the EPAAC's working groups as a core element for an effective cancer care policy. A Policy Statement on multidisciplinary cancer care was formulated for implementation by all tumour-based MDTs, to provide patients with the care they need.<sup>125</sup> The MDTs may be a place for integration of palliative care through an assessment and discussion about patient-centred needs at any stage of the disease trajectory. The policy statement is intended to serve as a reference for policymakers and healthcare providers to improve coordination.

The ASCO recommendations<sup>126</sup> of early referrals to specialist palliative care teams and the other listed policy statements on integration of cancer care and palliative care, conflicts with the documented workforce shortage in palliative care.<sup>127</sup> Thus, it is necessary to define the level of palliative care expertise at all health care levels, be it in tertiary specialist centres or home care (see Models and Education). Oncologists, palliative care specialists and other relevant health care professions should be part of all hospital SCPs, whereas primary care workers must possess basic palliative care skills to meet patients' needs. However, an Australian survey reported that a significant number of GPs (31%) felt they had inadequate training and insufficient resources to provide home-based care to advanced cancer patients,<sup>128</sup> which represents a challenge for the educational programs (see Education).

The gap between hospital-based SCPs and the primary care level is well-known but challenging to fill due to different funding and administrative allocation. In practice this gap is often compensated for by informal networks. Bainbridge et al.<sup>129</sup> explored the horizontal integration among professionals in informal palliative care networks. They found that the informal care networks often produce positive

results and that they were well accepted. What was commonly perceived as insufficient was inter-professional communication and evaluative activities. Han and Rayson<sup>130</sup> explored the collaboration between oncological specialists and primary care doctors and their roles in the end-of-life care. They concluded that the following requires further elaboration, reflection and research (Box 1).

#### **Box 1. Required for collaboration between oncological specialists and primary care doctors**

- Defining when end-of-life care begins
- Assessing the patterns and specific components of end-of-life care as provided by different types of oncologists and primary care physicians
- Understanding patient and caregiver preferences for the relative involvement of oncology vs primary care medical specialists at the end of life
- Designing appropriate and validated assessment tools to further understand how end-of-life care should best be managed
- Evaluating the impact, in terms of quality of care and other endpoints, of different models of end-of-life care and understanding how these different models might be implemented in different health-care delivery systems
- Ascertaining best practices and methodologies for integrating primary and oncology specialty care in patients dying of advanced cancer

The disease trajectory of an advanced cancer patient consists of several sub pathways and many patients will be in an incurable state for many years, with large variations in the need of palliative care. During these years several transitions of life expectancy will occur all of which represents multiple challenges and complaints related to lack of communication across care levels, fragmented care, unclear responsibilities etc. Thus, we recommend that assessing patient preferences, and planning the transitions should be focused in early palliative care consultations, use of shared decision making (SDM) as part of the SCPs. This seems pertinent given the fact that 82% of the late palliative care was for end-of-life hospitalization<sup>131</sup> or that only 8% of lung cancer patients in the United States see a palliative care specialist, often to address end-of-life issues.<sup>132</sup> As a rule, patient needs should be assessed as a continuous process since the diagnosis onwards and palliative care needs should not be an exception to this rule.

The work in CANCON therefore did not focus on one particular aspect of cancer care in isolation but rather on (re)-defining the care pathways of cancer patients in order to map all services required to meet patient needs throughout the disease trajectory and beyond.

A recent study from Canada showed that citizens' expectations are high with respect of integrating palliative care standards into the Canada Health Act and thus into the basic processes of care. Importantly, the survey showed that there are strong concerns around the financial accessibility of such care but this is regarded as a condition for successful implementation of such a programme. Furthermore, the majority of Canadians agree that surveys should be conducted among family members (84%), caregivers (82%) and patients (79%) regarding the care received, and 72% of Canadians agree that annual surveys should be conducted to measure and track Canadians' awareness levels of palliative care.<sup>133</sup> For the political level, these findings also support the obligation

for politicians and health authorities at the uppermost level to put palliative on the agenda as an integrated part of the health care system and not as a »hidden« service for the dying patients.

### Costs and cost-effectiveness of palliative care

Major concerns in oncology today are the rapidly increasing complexity of treatment and costs of care, which threaten the sustainability of the present services.<sup>23,134</sup> As pointed out by Isenberg et al,<sup>126</sup> increased delivery of palliative care as recommended by the updated ASCO guidelines,<sup>16</sup> must be accompanied by changes in the health care financing.

An editorial from ASCO-pubs<sup>135</sup> concludes that determining cost-effective methods to care for patients with advanced cancer should be given high priority, based on the rapidly increasing demand for palliative care in an ageing population. However, there is a need to establish valid methods for cost estimates that consider both cost-effectiveness and cost-benefit analyses (outcomes translated to monetary units/dollars). Although studies have shown that palliative care interventions improve both patient-reported outcomes<sup>3,5,57,136-139</sup> and cut costs for second party payers and hospitals,<sup>140-142</sup> most studies are relatively small-sized, and conducted from the health services perspective, not the societal perspective.<sup>135</sup> Thus, they often do not include patient, caregiver and societal costs in the calculations.

Intensive end-of-life care is expensive, but studies fully illuminating the costs associated with integration or not integration of oncology and palliative care are lacking. However, there are findings that indicate that integration is more cost-effective than “treatment as usual”. Early palliative referrals improves end-of-life care in terms of earlier hospice referrals,<sup>143,144</sup> lower readmission rates,<sup>145</sup> shorter length of stay;<sup>146</sup> all contributing to significant reductions in cost. According to Cassel et al. early palliative care is an excellent example of how to improve or maintain quality of health care delivery for patients and caregivers at a lower cost.<sup>147</sup> Further, studies demonstrate that the vast majority of costs in late-stage cancer results from advanced therapy with marginal effects, ICU and emergency admissions, and protracted hospital stays, and not to direct personnel costs.<sup>148</sup> Estimates from the United States and UK indicate 25% of health-care expenditure is related to patients in their last year of life, while end-of-life care takes up 20% of hospital beds.<sup>149,150</sup> In sum these figures and findings indicate expenditures that can be reduced and that integration can serve this function.

The present evidence of better care at lower costs associated with early access to palliative care, makes it necessary to evaluate the policy on subsidies, revenues, payment for patients, reimbursement practice and organization of services to promote integration of oncology and palliative care. Co-payment for patients may be one option but may be unacceptable from a societal point of view, as underserved populations may refrain from using the service. Compulsory palliative care consultations at a certain stage of advanced disease alongside tumour-directed treatment; the time-based model, as opposed to a patient-centric, need-based model as defined by Hui et al,<sup>151</sup> adds cost to the already substantial costs in this group of patients. This is primarily in relation to personnel costs at the tertiary level; e.g. consultations with both oncologists and palliative care specialists, and more time allocated to the consultations. Another option is to make reimbursement conditional on palliative care involvement at a certain stage in the disease trajectory.<sup>126</sup>

However, it must be demonstrated in larger and sufficiently powered cost studies that these additional costs offset savings in other domains of oncology and end-of-life care. Greer et al<sup>152</sup>

analysed cost-data from the Temel study <sup>3</sup> and found that patients in the early palliative care group had higher hospice costs in the 30 days of life, but less costs related to chemotherapy than patients in the control group. Some studies have examined the cost-effectiveness of specialized palliative care, and report diverging results. This is mainly related to differences in financial incentives and reimbursement issues, whether patients are seen on an out-patient basis exclusively, if the unit is located together with other highly specialized teams providing palliative care services and referral and follow-up practice. The latter is an important and political issue in the years to come, as an increasing amount of palliative care must be delivered by the primary health care services. As pointed out previously, this has implications for the education of personnel at the primary health care (see also Education). Systematic palliative care interventions initiated on the specialist levels, but also followed by multidisciplinary palliative care teams, have improved patients reported outcomes and proven cost-effective.<sup>153-155</sup> The recent book by Gomez <sup>156</sup> concludes that home and community-based services are emphasized over building in-patient palliative services.

Researchers have since recently started researching a quantifiable or at least a qualitatively comparable contribution of the different models in palliative care. An example of such a study is by Siouta et al. <sup>157</sup> from 2016. The authors performed a qualitative systematic literature review of empirically tested models in cancer and in other chronic diseases. They included 14 studies, seven models for chronic disease, four for integrated care in oncology, two for both cancer and chronic disease and two for end-of-life pathways. The benefits of the involvement of a palliative care (PC) multidisciplinary team showed: better symptom control, less caregiver burden, improvement in continuity and coordination of care, fewer admissions, cost effectiveness and patients dying in their preferred place. The authors proposed a generic framework for integrated PC in cancer and chronic disease. This framework fosters integration of PC in the disease trajectory concurrently with disease-oriented treatment and identified the importance of employing a PC-trained multidisciplinary team with a threefold focus: treatment, consulting and training.

Limited resources, pressures on cost containment, cost-effectiveness and overall cost control are present in cancer care as well. Consequently, it is necessary to look at the best performing types of care in the whole cancer care trajectory. A study that looked into the evidence on the cost and the cost-effectiveness of PC is a literature review by Smith et al.<sup>158</sup> They carried out a comprehensive review of available international evidence on the cost and cost-effectiveness of palliative care in any setting (hospital-based, home care or hospice-based). Quality of retrieved papers was assessed against 31 indicators, which they had developed for the purpose of this review. The authors identified 46 papers, meeting the inclusion criteria. They found that palliative care is very often less costly relative to the comparator groups and, in most cases, the difference was statistically significant.

**Final reflections**

Barriers	Solutions
Palliative care not being perceived as a needed integral part of the cancer care continuum	Setting up SCPs that cover all cancer care services (envisaged also by National Cancer Control Programs (NCCPs))
Deficient planning of palliative care at the	Adherence to the European Guide for Quality of

national and regional levels	National Cancer Control Programs
Insufficient organizational and infrastructural capacity of palliative care	The need to invest in palliative care infrastructure – partly related to the workforce
Limiting palliative care to respite care and supportive care and often leaving it to the family	Building on infrastructure for palliative care also in outpatient and home settings in order to address the needs of cancer patients
Inadequate assessment of costs and benefits of palliative care	Transparency of direct and indirect costs – and also performing HTA for palliative care procedures

Standards, guidelines and guidance are meant to standardize procedures and SCPs can be used as an implementation tool in order to equalize quality and enable comparative analysis in health care. As much as SCPs are helpful, they might also cause tensions and frustrations at the political level related to struggles to secure an adequate level of human and financial resources. However if high quality cancer care is the goal in a country these tensions and frustrations need to be solved and directions need to be given by the governments based upon a sustainable health policy independent upon who is in position. This approach is strongly supported by all international statements that access to palliative care is a human right.

Given the challenges facing the patients, the care providers and the system as a whole, the bulk of financing should be carried by public funds or at least, the share of public financing of palliative care should not be different from the financing of other health care services in a given system.

In brief, this panel gives reasons to formulate political arguments that can be raised in order to enhance palliative care at the political level:

1. The needs for palliative care are rising and many present needs are unmet
2. Palliative care is part of the cancer care continuum
3. Palliative care is patient-centred and should be delivered systematically
4. SCPs can secure availability of palliative care but presupposes relevant professionalism at all levels and willingness and resources for the implementation
5. The population is fragile, does not demand expensive treatments but lacks public spokesmen.
6. The industry or other strong stakeholders with easy access to the political decision-making processes are focused on other treatment alternatives than palliative care
7. The fragility of patients and their relatives in need of palliative care incapacitates them in the public debate on resource allocation. Public funding is therefore necessary

Still, the main question is – how to ensure that policies on palliative care are effectively implemented? There needs to be a concerted action of cancer care professionals and patients through advocacy efforts making a case especially with respect to the currently unmet needs, which represent a significant burden for the individual, family, health care and, ultimately, on the society as a whole.

## Recommendations

- Convergent policies in all continents on integration of oncology and palliative care need to be developed
  - How to do: The WHO and professional organizations (EAPC, WPCA, IAHP, IONS, ESTRO and ASCO among others) should establish guides to policy makers based upon present best knowledge
  - Timeline: Now
- Organizational structures of early integration of oncology and palliative care in hospitals need to be developed on a global level
  - How to do: Professional organizations EAPC, WPCA, IAHP, IONS, ESTRO and ASCO among others shall establish consensus on structure and implementation plans.
  - Timeline: Now
- Organizational structure of early integration and collaboration between hospitals and community care in oncology/palliative care at global level need to be developed
  - How to do: Professional organizations ESMO, ESTRO, EONS, ASCO, EAPC, WPCA and IAHP among others shall establish consensus on structure and implementation plans.
  - Timeline: Now

## Societal challenges

### Questions to be addressed

What are the societal challenges that may hamper integration of oncology and palliative care?

What are the societal challenges at following levels

- Professional?
- Patient?
- Public?
- Media?

### Introduction

Despite the growing evidence of the benefit for patients and those close to them, and to health care systems, many challenges remain in the better integration of palliative care and oncology. Some of the challenges can be considered as societal, i.e. problems in the interactions and structures within society and the normal patterns of practice. Any people from a community can be considered to make up a society, and anything connected to that group can be described as societal. In this section we consider the challenges at 'societal' levels, professional, patient, public, the media, medical education, which may hamper the better integration of palliative care and oncology.

### Professional: oncologists, palliative care, surgeons, general medicine, primary care

Although much practice by oncologists involves people with advanced cancer, the liaison and integration with palliative care varies considerably. This is despite recommendations by the European Society of Medical Oncology (ESMO) and the Organisation of European Cancer Institutes (OECI) that to be designated, a cancer centre must have integrated oncology and palliative care.<sup>159,160</sup>

A survey of 895 members of ESMO regarding their involvement in and attitudes toward the palliative care of patients with advanced cancer found that although the importance of palliative care was recognized, actual participation levels commonly are suboptimal.<sup>161</sup> 43% of respondents reported that they directly administered end-of-life care often, and 74% reported that they derived satisfaction from their involvement in end-of-life care. Only around a third of respondents collaborated often with a PC care specialist (35%), a palliative home care service (38%), an in-patient hospice (26%), or a psychologist (33%). Yet respondents were involved more commonly in treating physical symptoms, such as pain (93%), fatigue (84%), and nausea/emesis (84%), than in managing psychological symptoms and end-of-life care issues, such as depression/anxiety (65%), existential distress (29%), or delirium (12%). Most respondents, 88%, endorsed the belief that medical oncologists should coordinate the end-of-life care for their cancer patients, but almost half, 42%, felt that they were trained inadequately for this task. Although most of the responding medical oncologists expressed positive views regarding their involvement in the PC of patients with advanced cancer and dying patients, 15% of respondents had pervasively negative views.<sup>161</sup> Similar challenges have been more recently reported among oncologists in other countries, including China, Thailand, the USA and many others.<sup>162-172</sup>

Oncologists' end of life care attitudes can influence their timely palliative care referral and end of life cancer treatment decisions. There is evidence that oncologists often refer patients late in the course of illness,<sup>166,167,173-176</sup> despite believing, as found in recent surveys, that integration of early specialist palliative care in cancer improves symptom control, end-of-life care, health-related communication, and continuity of care.<sup>173,176</sup> A survey of 182 oncologists in the USA from a major cancer centre, found that comfort with the concepts of end of life care was associated with higher rates of specialist palliative care referral and self-reported primary palliative care delivery.<sup>177</sup> A recent systematic review found that the concepts of integration were varyingly defined.<sup>45</sup>

However in many instances decisions against intensive treatments are often made only when death is imminent. A study interviewing Belgium oncologists identified seven categories of barriers which discouraged them from discussing palliative care: oncologist-related barriers, patient-related barriers, family-related barriers, barriers relating to the physician referring the patient to the medical oncologist, barriers relating to disease or treatment, institutional/organizational barriers and societal/policy barriers.<sup>178</sup> Communication, approaches to the management of uncertainty in illness, as well as broader cultures and the focus of research in oncology may have a role here. Sympathetic yet honest communication about the irreversible nature of advanced cancer is important to improve patients' prognostic understanding and, thereby, to allow for adjustment of treatment intensity to realistic goals, to overcome some of patient- and family-related barriers. A qualitative in-depth interview study in Germany found that oncologists reported patients with unrealistic expectations to be a challenge for end of life communication, especially in comprehensive cancer centres.

Oncologists responded to this challenge quite differently, by either proactively trying to facilitate advance care planning or passively leaving the initiative to address preferences for care at the end of life to the patient. A major impediment to the proactive approach was uncertainty about the right timing for end of life discussions and about the balancing the medical evidence against the physician's own subjective emotional involvement and the patient's wishes. These findings may help to explain why end of life communication is often started rather late with cancer patients.<sup>179</sup>

Uncertainty in prognosis and likely treatment outcomes is inevitable in complex illnesses with evolving treatments, like cancer in modern times. With increasingly intensive treatments and population ageing, more people face more complex treatment, care decisions and uncertainty.<sup>180</sup> Yet uncertainty can become a major barrier to effective care, because clinicians delay raising issues or making decisions in an attempt to reassure in the face of uncertainty.<sup>181</sup> A study of decision-making processes during critical care found that decisions were made serially over the whole trajectory, usually several days or weeks. There were four trajectories with distinct patterns: curative care from admission; oscillating curative and comfort care; shift to comfort care; comfort care from admission. Conflict occurred most commonly in the trajectories with oscillating curative and comfort care, and conflict also occurred inside clinical teams. This complex web of discussions means that there is a need for early communication, especially around the values and preferred care outcomes from care of patients and their families. The study also suggested that there should be clearer discussions of a 'trial of treatment', rather than waiting until the 'end of life'.<sup>180</sup>

A further issue impeding integration may be the research focus of oncology, versus that in palliative care. Only a tiny proportion of research spending in cancer is allocated to palliative or end of life care, in contrast to that spent on pursuing oncological treatment. Data on research funding by National Cancer Research Institute partners in the UK, based on studies included in the national Cancer Research Data Base for 2015/6 found that, of the £579.79 million awarded for research into cancer, just 0.33% (£1 925 909) was allocated to palliative and end-of-life care research. In contrast, £207.28 million (36%) was allocated to research into treatment, and £163.11 million (28%) to research into the biology of cancer.<sup>182</sup> This small amount is often spent across multiple projects, meaning that there is insufficient support for evaluative trials, or new palliative treatments.

These figures are similar to those reported for 2010, when only 0.24% of cancer research spending went to palliative or end of life care, although the overall funding for research in cancer increased slightly (from £508 million in 2010).<sup>183</sup> Similarly, in the USA, of the National Cancer Institute's total appropriation for 2010 of US\$5 billion, only 1% was awarded to palliative care research.<sup>183</sup> Data in Australia mirror these findings although, on a positive note, the Australasian Clinical Oncology Research Development program (ACORD) specifically seeks to attract young clinical palliative care researchers to develop their clinical trial protocols alongside young oncology trainees. This focus on research on treatment may further drive oncologists towards tumour-directed treatment, and in valuing cure, over improving quality of life and palliative care. Opportunities for oncologists to develop in teaching hospitals, with a combined career in research and practice, are therefore almost exclusively in the area of cancer biology or cancer treatments, and almost never in palliative care where the funding for individual projects appears to be insufficient to support a substantial fellowship for a PhD or MD. Investment in research into palliative and end-of-life care is urgently required to inform the transition from tumour-directed to palliative care, to improve symptom



control, to deliver cost effective care, and to ensure that choices at the end of life are offered and met, and in turn this will also help to further the integration of palliative and oncological care.

There are some proposals that palliative care would be more acceptable to oncologists if it were renamed supportive care. Surveys among haemato-oncologists and other medical oncologists have reported that these would be more likely to refer to services called supportive, rather than palliative, care.<sup>184,185</sup> However, others have argued that any proposed renaming clouds the more nuanced issues, such as attitudes, resources, and the issues raised above, that together hamper referrals.<sup>186</sup> Supportive care is something that all oncologists should do, and the term is much linked to cancer. Others have proposed renaming the palliative care as 'enhanced supportive care'. The important questions, however, should be around what patients and families feel are appropriate services, not what professionals feel they would like to refer to.

A further consideration is the attitudes of palliative care to oncology. Palliative care services are overstretched, with staff shortages, and insufficient resources to treat all patients. They are often supported by the charitable sector, and in many countries, are not included in mainstream health care funding. These can lead to services being limiting. The US hospice benefit, which reimbursed the provision of hospice care under Medicare, specifically included that patients should have a less than six month prognosis, and that patients in hospice should agree to withdraw from all treatment of potential curative intent.<sup>187</sup> While this definition does not exist in most countries outside the USA, the earlier focus on palliative care on the end of life, can limit referrals. Palliative and oncology clinicians have to recognize the change in the needs of cancer patients, for earlier, more integrated care as a consequent of changes in treatment and disease trajectory. This was clearly expressed at the 67th World Health Assembly, when the World Health Organisation (WHO) passed the first ever resolution on palliative care, recommending national health systems to provide palliative care in conjunction with potentially curative treatment, and not just as an "*optional extra*".<sup>188</sup> The resolution urged member states to develop and implement policies which support the integration of cost-effective and equitable palliative care services in the continuum of care, across all levels.<sup>189</sup> A modern approach to palliative care can also include an integration with oncology and relevant community and hospital services.<sup>190</sup>

### Patients, families, the public and the role of the media

Public priorities when faced with a terminal illness, such as an advanced cancer, would suggest that better integration of oncology and palliative care is important for care and would be preferred. A population based survey of people's priorities for treatment, care and information across seven European countries asked respondents their priorities if 'faced with a serious illness, like cancer, with limited time to live'. Of the 9344 individuals interviewed most people would choose to 'improve quality of life for the time they had left', ranging from 57% (Italy) to 81% (Spain). Only 2% (England) to 6% (Flanders) said extending life was most important. An important minority, from 15% (Spain) to 40% (Italy) said quality and extension were equally important. Prioritizing quality of life was associated with higher education in all countries. The survey included people with different health statuses, but these did not affect priorities.<sup>191</sup> Further components of this survey in the open-ended questions identified a public perception of needs for improved quality of end-of-life and palliative care and access to this care for patients and families, and a recognition of the importance of death and dying, the cessation of treatments to extend life unnecessarily and the need for holistic care to

include comfort and support.<sup>192</sup> Most people in fact would want to know if they had a terminal illness, and factors associated with this wish have been identified.<sup>193</sup>

However, public awareness of palliative care and related services among oncology patients is often limited. One survey in London found that only 19% patients recognized the term 'palliative care', although 68% understood the role of the hospice, and 67% understood the role of Macmillan nurses (specialist nurses providing an advisory palliative care service in the UK). Age-adjusted multiple logistic regression found that the most socially and materially affluent patients had eight times higher odds of recognizing the term 'palliative care' compared with those who were the poorest.<sup>194</sup> A survey in Japan found similar challenges in awareness of palliative care.<sup>195</sup> More recently, an internet search query in the USA, has found that public awareness of the term palliative care is growing month by month.<sup>196</sup>

Uncertainty and communication for cancer patients is also likely to have a role during treatment. In a qualitative study in intensive care, uncertainty was a pervading feature over the trajectory of care. Families were most often involved in decision-making regarding care outcomes and seemed to find it easier when patients switched definitively from curative to comfort care. Some families considered decision-making a negative concept and preferred uncertainty. We found eight categories of decision-making; three related to the care outcomes (aim, place, response to needs) and five to the care processes (resuscitation, decision support, medications/fluids, monitoring/interventions, other specialty involvement). The study suggests a need to support early communication, especially around values and preferred care outcomes, from which other decisions follow, including Do Not Attempt to Resuscitate.<sup>180</sup> Simple tools to understand patients and families priorities and aid communication have been developed, and undergone preliminary testing and many be promising to improve this situation.<sup>197</sup>

Stigmas about cancer are common and present significant challenges to treatment and care,<sup>198-200</sup> including to palliative care and its integration with oncology. Stigma can have a silencing effect. The social, emotional, and financial devastation that all too often accompanies a diagnosis of cancer is, in large part, due to the cultural myths and taboos surrounding the disease.<sup>198-200</sup> There are several reasons that cancer and within this palliative care may be stigmatized.<sup>201,202</sup> Symptoms or body parts affected by cancer can cultivate stigma. Beliefs about treatment can also fuel stigma.<sup>203</sup> Pain, other symptoms or the cancer itself can be seen as a 'test' or punishment, affecting the willingness to use therapies or to be referred to palliative care.<sup>204</sup> Breathlessness and cough are common symptoms but are associated with social withdrawal, non-response of services, and invisibility.<sup>205,206</sup> Depression is a stigmatising symptom in many countries.<sup>207</sup> Negative illness perceptions can increase depression.<sup>208</sup> Some cancers or their treatment cause changes in appearance, which can also be distressing and result in stigma.<sup>209</sup> Fear of dying and the stigma associated with terminal events may also hamper access to palliative care.<sup>210</sup> While it is common that many people report how they grow despite cancer, treatment and through stigma, appropriate support systems and resilience are needed.<sup>209</sup>

News reports about cancer frequently discuss intensive treatment and survival but rarely discuss treatment failure, adverse events, end-of-life care, or death.<sup>211,212</sup> These portrayals of cancer care in the news media may give patients an inappropriately optimistic view of cancer treatment, outcomes, and prognosis, Language in the media likening cancer to a battle or war and frequently conflating

cancer and fear<sup>213</sup> may lead people whose disease is continuing despite treatment, may to feel a failure (losing the war) and reluctant to seek or discuss any alternative. All of these factors may in turn result in difficulty in communication, and a stigma against accepting anything not directed towards cure.

Public communication is probably critical to decreasing cancer-related and palliative care-related stigmas, raising awareness, disseminating education and importantly also in direct patient and family care.<sup>214,215</sup> Wide ranging public education, links into schools, use of modern forms of media, such as social media, twitter and web based for a,<sup>216</sup> and well as more traditional health education are needed.<sup>217</sup> Cultural differences in beliefs in and response to cancer, palliative care, information needs, and end of life care need to be respected and accounted for in this.<sup>218</sup>

Despite the fact that cancer is a major and increasing health problem widespread in older people, paradoxically, older people with cancer are often undertreated when compared to younger patients and excluded from clinical trials.<sup>219</sup> The inequalities do not only pervade new therapies, but also reconstruction surgery, nursing, primary and palliative care. For example, immunotherapy, breast reconstruction, and chemotherapy rates are lower for older patients than for younger patients. In one study, nurses' vision of aging influenced lower support for breast reconstruction: nurses with a negative view of age discriminated more between a 75-year-old patient and a 35-year-old patient (less encouragement for the older patient).<sup>220</sup> Older patients have lower access to in-patient hospice and palliative care services, although this appears to be improving slightly.<sup>221</sup> Older people are more likely to die in hospital and less likely to die at home, often their preferred place of death, when compared with younger patients.<sup>222</sup> A large population based studies found that older lung cancer patients (age > 60 years) had significantly lower chances of receiving opioids than their younger (age < 50 years) peers (prevalence ratio [PR] range, 0.14 to 0.78), even adjusted for comorbidity.<sup>223</sup>

### Barriers and challenges related to death and dying

Despite the fact that everyone eventually dies, death and dying are often taboo subjects, with considerable stigma for people who are dying and those close to them. This is a challenge at a professional level, patient and caregiver level and a societal level. A study of 233 college students used a range of semantic differential adjectives to explore their attitudes toward young and old people who were healthy, ill, or terminally ill. The results identified negative attitudes toward dying people in both young and older age groups, their role was conceptualised as disvalued, indicating a stigma towards those who are terminally ill.<sup>224</sup> Saunders wrote on the need to change these stigma's and focus on living and dying well.<sup>225</sup> Writing in the Lancet in 1984, Wilkes, drew attention to the challenges that these stigmas bring.<sup>226</sup>

Yet stigma's and taboos still pervade society, leading some countries, such as the UK, to launch a 'Dying Matters' initiative in response.<sup>227</sup> As death has become less common in our daily lives, it possibly has become harder to consider our own mortality or that of those close to us. Some have said that there is neglect within oncology with regards to those patients who are dying. Indeed, this may be is a particular problem in oncology and sometimes in cancer nursing, where the focus is on more treatment, on cure, on "fighting the illness", rather than on living and dying well.<sup>228</sup> The emphasis on cure may be helpful when encouraging patients to come forward for screening or early treatment.<sup>229,230</sup> But there are many examples of patients receiving chemotherapy in the last 30 days of life, in many instances when it is not through to be effective.<sup>231</sup> Death often remains a taboo

subject in the clinical encounter.<sup>232</sup> A lack of openness about death has negative consequences for the quality of care provided to the dying and bereaved, with missed opportunities for symptom management and psychosocial support.<sup>225</sup> A lack of transparency can be very hurtful for patients.<sup>233</sup>

A lack of openness often pervades undergraduate and postgraduate education, including in oncology, where many doctors and others feel unprepared to discuss death and dying, deteriorating illness or even to be able to break the news of a death to family members and friends.<sup>234,235</sup> Failing to have those conversations can deny patients and families from making important decisions.<sup>233</sup> These are difficult conversations and not everyone will want to talk about the end of their life, or will want to talk but at different times and stages. This often takes time and it is often difficult to know how to open the conversation. But there is clear evidence that through training and continued support it can be done even in the context of offering further treatment.<sup>236-238</sup> Tools have been developed to help clinicians to ask about and understand patient priorities and these could be a starting point for dialogue.<sup>197</sup>

## Implications

Cancer is one of the most common health issues in society. Worldwide, there were 14.1 million new cases and 8.2 million deaths from cancer in 2012. The most commonly diagnosed cancers were lung (1.82 million), breast (1.67 million), and colorectal (1.36 million); the most common causes of cancer death were lung cancer (1.6 million deaths), liver cancer (745 000 deaths), and stomach cancer (723 000 deaths).<sup>239</sup> An estimated 169.3 million years of healthy life are lost because of cancer. Colorectal, lung, breast, and prostate cancers are the main contributors to total years of life lost in most world regions and caused 18-50% of the total cancer burden.<sup>240</sup> Cancer will increase in all parts of the globe. Currently around 44% of cancer cases and 53% of cancer deaths occur in countries at a low or medium level of the Human Development Index (HDI).<sup>239</sup> Projections to 2030 suggest that if recent trends in major cancers are seen globally in the future, the burden of cancer will increase to 23.6 million new cases each year by 2030. This affects all countries, with an increase of 68% compared with 2012 overall, and 66% in low and medium HDI countries and 56% in high and very high HDI countries.<sup>241</sup>

Although early resolutions regarding palliative care mainly focused on the more advanced stages of disease and the end of life,<sup>30</sup> the WHO mandate on palliative care has evolved and currently extends to include patients in the early phase of all diseases. This evolution of the WHO mandate reflects the evolution of the concept of palliative care as a whole,<sup>242</sup> which consists of: extending care beyond cancer and into more general chronic conditions; promoting early palliative interventions in the clinical evolution of the disease; applying palliative care measures in all settings of the healthcare system; and identifying complexity versus prognosis as criteria for specialist interventions. In other words, the focus of palliative care has shifted from the concept of terminal illness to 'advanced chronic illness with a limited prognosis'; and from a specialty approach, to a national health care system approach.<sup>30,243</sup>

## Recommendations

- Public actions focusing on death as a part of being human
  - How to do: Develop international and national consensus programs (campaigns) on

- being mortal. Engage in the international and national parliaments, patient organizations and professional organizations campaigns.
- Timeline: Now
- Destigmatize palliative care – it is more than end of life care – it is patient-centred care
  - How to do: Develop international and national consensus programs and engage parliaments, patient organizations and professional organizations in the campaigns.
  - Timeline: Now
- Economical resources to palliative care and palliative care research must reflect the needs and the volume of the patients in oncology practice
  - How to do: Establish an international expert panel in developing multinational estimations of needs reflecting the complexity of the patient population.
  - Timeline: 1-2 years
- Raising public awareness of the goals of tumor directed treatment (life prolonging, symptomatic and end of life care)
  - How to do: International and national discussions on information policies and communication in the public domains aiming to raise awareness of the marketing by the medical industry and health care providers
  - Timeline: Now

## Prognostication

### Questions to be addressed

Why is prognostication important in advanced cancer?

What objective prognostic tools are available?

How should prognostic information be communicated?

### The importance of prognosticating in oncology and palliative care

Prognostication is the skill of predicting future outcomes. Most commonly the outcome that is being predicted is the length of survival of the patient, although one can also prognosticate about other clinically relevant outcomes such as symptomatic response to palliative treatment, discharge from hospital or recovery of function. Once patients have received an accurate diagnosis of cancer, frequently the next question is about the likely prognosis.<sup>244</sup>

Oncologists are thus routinely required to prognosticate. At diagnosis prognostication primarily relies on an accurate staging of the extent of disease. All cancer staging systems are based upon the premise that the severity and extent of disease is associated with different outcomes (particularly the risk of death). At diagnosis the stage of disease frequently dictates the preferred course of treatment. Detailed prognostic information about survival associated with each stage of disease can help patients and clinicians to make informed decisions about the best course of treatment.

In palliative care practice the issue of prognosis is also very important, although in these circumstances the question is more specifically about how long patients are expected to live, rather than on predicting their response to further treatment.<sup>245</sup> In routine practice, issues of prognosis are

pertinent to decisions and discussions about place of care, advance care planning and determining ceilings of care.<sup>246-248</sup>

At the interface between oncology and palliative care prognostic questions are most relevant to the decision about whether or not to proceed with palliative chemotherapy. Deaths occurring within 30-days of chemotherapy are increasingly recognised as an indicator of the quality of oncological care.<sup>249</sup> When used appropriately palliative chemotherapy can improve quality of life and survival in patients with advanced cancer.<sup>250</sup> However, when given to patients who are near the end of life, even to those with a relatively good performance status, chemotherapy seldom has benefits and may adversely affect the “quality of death”.<sup>251</sup> Early involvement of palliative care services can reduce the frequency of chemotherapy administration close to death, without any adverse consequences for survival.<sup>3,252</sup>

In 2008 the UK National Confidential Enquiry into Patient Outcome and Death (NCEPOD) conducted a review of deaths occurring within 30 days of systemic anti-cancer chemotherapy treatment (SACT).<sup>253</sup> External review of the notes suggested that the decision to give palliative SACT was “inappropriate” in 19% of cases (due to factors such as poor performance status, lack of realistic prospect of benefit, or end-stage disease). In 27% of patients receiving palliative chemotherapy, external advisors considered that the treatment may actually have caused or hastened the patient’s death. The authors recommended that prior to administering SACT oncologists should fully discuss with patients the aims and likely outcomes of treatment and that this should include a discussion of the option of no treatment. Moreover, for patients with ECOG performance status 3 or 4, they recommended that palliative chemotherapy should only be embarked on with caution and after consideration by a multi-disciplinary team.

There is frequent discordance between patients’ and clinicians’ perceptions about the intended purpose of chemotherapy.<sup>254-256</sup> In one study only 51.9% of 216 patients correctly recognised whether the treatment that they were receiving was either curative or palliative in intent.<sup>256</sup> Similarly it was reported that 64% of patients with incurable lung cancer did not report understanding that their radiotherapy was unlikely to cure them.<sup>257</sup> This mismatch between clinicians’ and patients’ understanding about the indications for their treatment is not confined to oncologists. In once recent study<sup>258</sup> it was reported that 57.4% of patients with metastatic lung, and 79.8% of patients with metastatic colorectal cancer believed that their surgery was likely to have been curative. Moreover there is also evidence that patients with advanced cancer are subject to increasing numbers of radiological investigations<sup>259</sup> and to a higher frequency of artificial nutritional support even in the context of decreased SACT.<sup>260</sup>

### Predicting survival in advanced cancer using prognostic tools

Accurate staging can provide valuable prognostic information; can guide decision making about treatments at the individual patients level; allows for a common international terminology so that different centres can accurately describe the case-mix of their patients and can compare outcomes; and is essential for identifying homogenous populations for entry into clinical trials.<sup>261</sup> However, in the context of palliative care, when nearly all patients have metastatic disease, the usefulness of current staging systems is more limited. In advanced disease “traditional” prognostic factors (e.g. site of primary cancer, number and sites of metastases) may be less relevant as many patients follow a common disease trajectory of increasing debility, anorexia, cachexia, fatigue and decreased mobility;

leading ultimately in many cases to confusion, drowsiness, coma and death.<sup>262</sup> In these circumstances simply knowing that a patient has Stage 4 disease does not help clearly distinguish between those patients with prognoses of days, weeks, months or years. Clinicians frequently rely on their own clinical judgment or intuition to arrive at prognostic estimates. However, systematic reviews consistently show that such estimates are frequently inaccurate and over-optimistic.<sup>263,264</sup>

The most commonly used “qualitative” method of predicting survival in patients with advanced disease is the so-called “Surprise Question (SQ)”. The SQ (“Would you be surprised if this patient died within the next x months?”) used either alone, or as part of the Gold Standard Framework (GSF) proactive identification guidance tool,<sup>265</sup> has been recommended as a way to identify patients who may benefit from referral to specialist palliative care services. A recent systematic review<sup>266</sup> reported that, overall, the SQ was accurate on 74-8% of occasions. Although the positive predictive value of the SQ was low (30%), it performed better at screening out those patients who were not expected to die within a specified time frame (negative predictive value 90%).

In response to the inaccuracy of clinicians’ predictions an increasing number of prognostic tools have been developed specifically for use in palliative care patients with advanced cancer.<sup>245,267-269</sup> There is no consensus about the most accurate or practical tool for clinical use. However, a few of the better validated tools are shown in Table 4 and are discussed below.

Name of tool	Variables included in score	Type of prognostic estimate
<b>Palliative Prognostic Score (PaP)</b> <sup>270,271</sup>	Dyspnoea; Anorexia; Karnofsky performance Status <sup>272</sup> ; Total white cell count; Lymphocyte percentage and Clinician Prediction of Survival	Scores divide patients into three risk groups: A >70% probability of surviving 30 days; B 30-70% probability of surviving 30 days; C <30% probability of surviving 30 days
<b>Delirium PaP (D-PaP)</b> <sup>273</sup>	Delirium; Dyspnoea; Anorexia; Karnofsky performance Status <sup>272</sup> ; Total white cell count; Lymphocyte percentage and Clinician Prediction of Survival	Scores divide patients into three risk groups: A >70% probability of surviving 30 days; B 30-70% probability of surviving 30 days; C <30% probability of surviving 30 days
<b>Palliative Performance Scale (PPS)</b> <sup>274</sup>	Ambulation; Physical activity and extent of disease; Self-care abilities; Oral intake; Conscious level	Patients can be divided into risk groups according to PPS score 10% -100%. Life tables can be used to predict probability of surviving to defined time periods.
<b>Palliative Prognostic Index (PPI)</b> <sup>275</sup>	PPS score; Oral intake; Dyspnoea; Oedema and delirium	Patients are stratified into three groups; survival shorter than three weeks; shorter than six weeks; or more than six weeks
<b>Modified Glasgow Prognostic Score (mGPS)</b> <sup>276-278</sup>	Serum C-Reactive Protein and Albumin	Patients are stratified into three groups with good, intermediate and poor prognoses.
<b>Feliu Prognostic Nomogram (FPN)</b> <sup>279</sup>	ECOG performance status; Serum albumin; Lactate Dehydrogenase; Lymphocyte count and time from initial diagnosis to diagnosis of terminal disease	Using the nomogram a probabilistic estimate can be calculated for survival at 15, 30 and 60 days
<b>Prognosis in palliative care scale – A (PiPS-A)</b> <sup>280</sup>	Performance status; Anorexia; Dyspnoea; Global Health; Breast cancer; Male genital organ cancer; distant metastases; bone metastases; liver metastases; Mental test score; Heart rate; Dysphagia; Weight loss	Categorical survival prediction; “Days”, fewer than 14 days; “Weeks”, between 14-56 days; “Months+”, more than 56 days
<b>Prognosis in</b>	Performance status; Anorexia; Global	Categorical survival prediction; “Days”,

<b>palliative care scale – B (PiPS-B)</b> <small>280</small>	Health; Male genital organ cancer; distant metastases; bone metastases; Mental test score; Heart rate; Fatigue; Lymphocyte count; White cell count; Neutrophil count; C-Reactive Protein; Albumin; Platelets; Urea; Alanine Transaminase; Alkaline phosphatase	fewer than 14 days; “Weeks”, between 14-56 days; “Months+”, more than 56 days
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**Table 4. Summary of characteristics of palliative prognostic tools**

The Palliative Prognostic (PaP) score<sup>270,271</sup> consists of six variables. Partial scores are allocated to each variable and the total score determines whether the patient is in a high, intermediate or low risk group for death within 30 days. The PaP score has been externally validated in a number of studies<sup>268</sup> and the original performance of the tool has been broadly replicated. The total PaP score is more accurate than a simple clinician prediction of survival although somewhat paradoxically, its accuracy may be improved by removing the clinician prediction of survival from the scoring algorithm.<sup>281</sup> A modified version of the PaP (including delirium as an additional prognostic factor), the D-PAP, has also been developed<sup>273</sup> and has been found to be more accurate than the original PaP. One criticism of both the PaP and the D-PaP is that they are heavily reliant on a clinician prediction of survival to generate the overall score. The Palliative Performance Scale (PPS)<sup>274</sup> was developed as a modification of the Karnofsky Performance Status<sup>272</sup> with a focus on those patients with poorer mobility / self-care abilities and the inclusion of other potentially relevant prognostic indicators. A recent systematic review<sup>268</sup> reported that the scale had been evaluated in 18 studies (n = 21 082) in numerous countries and multiple tumour types. In these studies the PPS has demonstrated that it is able to distinguish between patients with differing survival outcomes.<sup>282,283</sup> Prognostic accuracy has not been directly compared to clinician predictions of survival. The Palliative Prognostic Index (PPI)<sup>275</sup> is calculated using five clinical variables. The model stratifies patients into three groups; survival shorter than three weeks, shorter than six weeks, or more than six weeks. It has been validated in a number of studies<sup>284,285</sup> and it has the advantage of not relying on either the clinician prediction of survival nor on laboratory measures (which can be challenging to obtain in palliative care patients). Prognostic accuracy improves if used between 3-5 days after admission to a palliative care unit rather than on admission.<sup>286</sup> It is more accurate than clinician predictions of 30 day, but not 100 day, survival.<sup>287</sup> Perhaps the simplest measure is the modified Glasgow Prognostic Score (mGPS)<sup>276-278</sup> which is calculated from the serum CRP and Albumin levels. The mGPS has been shown in previous studies to distinguish patients with good, intermediate and poor prognoses.<sup>268,288</sup> The scale is simple to calculate and has been widely used in a variety of different cancer types. Its prognostic value is based on its association with the severity of the cachexia syndrome.<sup>289</sup> Feliu and colleagues<sup>279</sup> developed a prognostic nomogram consisting of five variables (ECOG performance status, serum albumin, Lactate Dehydrogenase, lymphocyte counts and time from initial diagnosis to diagnosis of terminal disease) to predict survival at 15, 30 and 60 days. Most recently Gwilliam and colleagues reported the development of the Prognosis in Palliative care Predictor models (PiPS).<sup>280</sup> Two scales, PiPS-A and PiPS-B, have been created so that a prognostic score can be calculated regardless of whether or not blood test results are available. Both scores have subsequently been validated by external groups.<sup>290,291</sup> The PiPS scales produce a categorical output such that patients are stratified according to whether they are likely to live for “Days”, “Weeks” or “Months+”.

Only a few studies have directly compared the performance of the different prognostic tools and no clear pattern emerges. The PiPS tools have been directly evaluated against clinician predictions of



survival. Gwilliam et al <sup>280</sup> reported that the PiPS-B tool was significantly more accurate than a doctor's or a nurse's estimate of survival (but was not statistically significantly more accurate than a combined multi-disciplinary team estimate). The PiPS-A and PiPS-B were also reported to be better at predicting short-term prognoses than the PaP, D-PaP or PPI; but less good than the D-PaP at predicting longer-term prognoses.<sup>291</sup> The same study reported that the PiPS-A and the PPI were the most feasible tools to use in clinical practice (routine data available for >90% of patients). The PaP has been shown to perform better than, or as well as, the PPI <sup>292,293</sup> or the PPS <sup>294</sup> but less well than the Feliu Prognostic Nomogram.<sup>279</sup> Chou and colleagues <sup>295</sup> reported that the PPI performed better than the mGPS in patients with hematologic malignancies under palliative care. A large (n = 1 778) prospective comparative study is currently underway in the UK <sup>296</sup> comparing the accuracy of the PiPS-A and PiPS-B tools with the PaP, the PPS, the Feliu Prognostic Nomogram, the PPI and the Glasgow prognostic score. Importantly this study also includes several clinician predictions of survival (probabilistic and temporal) to act as comparators. The study is due to report in 2019.

Although accuracy is clearly an important factor when weighing the relative merits of different prognostic tools there are also other issues to be taken into consideration. Steyerberg and colleagues have emphasised the importance of conducting studies to assess the impact of prognostic tools on clinical practice and outcomes.<sup>297</sup> The best method of undertaking such studies is a cluster randomised controlled trial but no such studies have been undertaken in the context of palliative care. Impact studies are required to determine whether more accurate prognostication would lead to (for instance); earlier referral to palliative care services; more advance care plans being prepared; more home deaths; less intensive treatment in the last weeks of life; and/or greater satisfaction with communication and with care.

In conclusion, the current state of the knowledge is insufficient to make a definitive recommendation about the best prognostic tool to use. Nonetheless there is good evidence that clinicians' estimates alone are inaccurate and are generally over-optimistic. Therefore they should be complemented by use of "objective" prognostic tools wherever possible.

## Communicating prognosis

For prognostic tools to provide benefits for patients, the estimates that they produce (including the associated uncertainty) and the implications for treatment must be communicated clearly and with empathy so that the information is understood and can be used by the patients. Doing a proper prognostic evaluation and sharing the results with the patient are core clinical skills in an integrated oncology-palliative care. Communicating prognostic information is one of the fundamental communicative tasks in the provision of patient-centred care. For a broader presentation of communication tasks see panel on Patient-Centredness.

Clinicians have a duty to fully inform patients about treatment intent and its risks and benefits, and this is particularly important for SACT as patients often have unrealistic expectations about its potential benefits.<sup>254,298</sup> Although most patients are told that their cancer is incurable, physicians have been found to steer the conversation towards treatment, engage in 'collusion' with patients' false optimism, and sometimes fail to check that their patients have understood the purpose of SACT.<sup>299-302</sup> Studies have shown that 50% or fewer patients were offered alternatives to SACT in consultations and that palliative care was often described by clinicians as "doing nothing" rather than having a more extensive discussion of its potential benefits.<sup>302,303</sup> The increasing number of

chemotherapy lines and novel therapies further adds to the uncertainty facing the informing physician. This points to the need to adhere to one of the basic principles of prognostication; it is not an event but a process.<sup>304</sup> Further, the patients' and the relatives' wishes for prognostic information vary over time.<sup>247</sup> Generally, the patients' wishes for exact information decreases as death approaches but is in general ambivalent.<sup>247</sup> Involving the patients in a continuous discussion on their prognosis might influence on their alternative future goal settings, to be other than survival.

There are a range of patient, physician and institutional barriers to clear communication about prognosis and palliative care in oncology. Oncologists describe a cure culture in which they are 'trained to treat' and so can feel that stopping SACT is a sign of failure, often resulting in discussions about hospice being delayed until all treatment options have been exhausted.<sup>305</sup> Physicians report a lack of confidence in this communication, particularly related to uncertainty about prognosis, leading to concerns that an inaccurate prediction could reduce patient trust.<sup>306</sup> They also express concerns that breaking bad news could lead to depression and a loss of hope in patients.<sup>307</sup>

Despite these perceived barriers, clear communication about prognosis early in the disease trajectory must be the aim within oncology. Contrary to the concerns of many physicians, it is possible for patients to maintain hope following the disclosure of a poor prognosis.<sup>308</sup> Mack and Smith<sup>309</sup> argue that this is a common misconception and point to evidence that, honest discussions, even where the news is bad, contribute to better physician-patient relationships that foster hope. A narrative review found that avoidance of prognostic discussions can lead to mistrust, anxiety, poorer quality of life, and family distress.<sup>310</sup>

Perhaps not surprisingly given the focus on quality of life in palliative care, satisfaction with communication is higher for bereaved relatives in hospice settings than hospitals.<sup>311</sup> Earlier integration of palliative care specialists may therefore increase patient prognostic awareness and improve patient and caregiver satisfaction. In RCTs integrating palliative care from diagnosis, including regular appointments with a palliative care specialist, Temel and colleagues found that early palliative care interventions could improve quality of life, prognostic awareness and communication about end-of-life preferences.<sup>3,52,312</sup>

In addition to the involvement of palliative care specialists early in the disease trajectory, oncologists need practical advice on communication strategies to integrate early and honest discussions about prognosis and palliative care into their own practice as part of a standardised care pathway. There is some guidance available on strategies that can be employed during conversations about prognosis and other end-of-life issues, see Box 2.

**Box 2. Australian clinical practice guidelines for communicating about prognosis and end-of-life issues include the following.<sup>313</sup>**

- Assess what the patient already knows and the level of detail they want
- Tailor the information to the individual and their family: pace provision of the information depending on the individual, use non-technical language, consider the family's individual needs
- Acknowledge uncertainty and avoid giving exact timeframes. Be honest without being blunt
- Explore and acknowledge emotions
- Encourage questions, check understanding and emphasise continuing care

In a review and synthesis of best practices, Bernacki and Block<sup>310</sup> suggest using a conversation guide to ensure key topics such as goals, fears and trade-offs (i.e. prolonging life through intensive treatment vs quality of life) are covered. Several discussions may be needed to allow a staged disclosure that develops prognostic awareness,<sup>314</sup> and to adapt information provision as the disease progresses and the patient's communication preferences change.<sup>27,315</sup> Raising these issues early in the disease trajectory allow the time needed for such staged disclosure. From the patient perspective, adjusting their hopes and expectations for the future from where they are to the factual situation is for most a process that takes time. The type of conversation guide suggested by Bernacki and Block<sup>310</sup> may be particularly useful as a starting point for clinicians with little experience of prognostic conversations. For those who will be having regular prognostic discussions, more focused communication training about cultivating prognostic awareness may be appropriate.

Systematic reviews of training to improve clinicians' end-of-life communication and communication with cancer patients have shown some positive results, such as increasing expressions of empathy, increased use of open ended questions and improved clinicians' self-efficacy and comfort with these conversations.<sup>316,317</sup> However more evidence is needed about the impact of training on patient satisfaction, whether positive impacts are sustained over time and on other outcomes such as quality of patient death.<sup>316,317</sup>

## Barriers and solutions

Accurate prognostic information is needed by patients and clinicians to help inform treatment decisions. Clinicians' survival predictions are frequently inaccurate and over-optimistic. Moreover, professionals working in oncology often lack confidence in communicating poor prognoses and related uncertainty, resulting in these conversations being delayed or omitted and in patients having unrealistic treatment expectations. Some of these barriers could be overcome by the use of objective prognostic tools to complement clinical intuition, although further research will be required before definitive recommendations can be made. Earlier integration and increased joint-working between oncology and palliative care may improve the quality of communication and reduce the frequency of futile treatments in patients approaching the ends of their lives. Evidence based communication guidance and training (as part of a wider integration of palliative care and oncology education, see Education) to provide practical strategies for communicating prognosis and uncertainty would reduce barriers to prognostic awareness amongst patients.

## Recommendations

- Prognostic communication about life expectancy should occur early in the disease trajectory as a part of early integration of palliative care.
  - How to do: Teach oncologists and palliative care physicians how to convey prognostic information, establish national and international indicators of patient involvement in the prognostic process
  - Timeline: 1-2 years
- Develop new prognostic tools to predict survival, symptom control and maintenance of functions (physical, mental and social) during cancer palliative care.
  - How to do: Allocate research resources and establish international collaboratives to develop the prognostic tools Timeline: 1-2 years

## Patient-centredness – content, methodology and clinical implications

### Questions to be addressed

What is patient-centredness?

What are the main elements of patient-centred care in practice?

How do we involve the family?

Communication – a necessary tool for patient-centred care

What are the barriers and solutions to succeed?

### Introduction

Patient-centredness has been defined by the Institute of Medicine (IOM) as “*care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions*”.<sup>318</sup> This approach is recommended in all areas of medicine but its content and methods have been considered particularly appropriate in cancer care.<sup>319</sup> Central to this approach is patient-centred communication that aims to 1. foster healing relationships, 2. exchange information, 3. respond to emotions, 4. manage uncertainty 5. make decisions 6. enable self-management.<sup>320</sup> Patient-centred care is dynamic and should address the patients’ physical, psychological, social and spiritual needs at all stages of the disease.<sup>318</sup> These needs must be documented dynamically as they may change over time and shall be used in the decision-making process in consultations, MDT meetings or other clinical decision points.

There has been increasing attention to the concept of value-based care in cancer, which refers to the quality of care achieved modified by the cost.<sup>321</sup> However, until recently patient-reported outcomes were not included in the evaluation of the quality of cancer care and the clinical focus tended to be disease-centred rather than patient-centred. This has contributed, at least in high-income countries, to the overutilization of some cancer treatments, including those that are futile, and to the rising cost of cancer care.<sup>322</sup> The utilization of patient-reported outcome measures (PROMs) in both clinical trials and in clinical care has facilitated the shift to greater patient-centredness in cancer care.

Systematic symptom assessment is an important component of patient-centred care since many symptoms are overlooked unless they are assessed systematically. The positive effects of systematic symptom assessment on the patients' quality of life and possibly also survival, have been demonstrated in recent publications.<sup>76,77</sup> However, in spite of the overwhelming evidence of the benefits of systematic symptom assessment, implementing such assessments in routine cancer care has been slow, due to concerns about its feasibility, benefit, cost, and the lack of a strong enough system of implementation without economic and/or professional incentives and a patient-centred focus.<sup>73,77,323-325</sup>

Adequate communication skills are necessary in order to provide patient-centred care. Patient-centred communication can be learned<sup>326</sup> and must be regarded as a professional skill, rather than merely as a personal attribute. This competence is needed in order to assess symptoms, provide information about diagnosis and disease progression and to discuss options and patients' preferences for treatment and care.<sup>320</sup> Such skills are of importance throughout the entire cancer trajectory but may be particularly relevant when the treatment intention is non-curative and/or when the biological effects of tumour-directed treatments may be minimal and the adverse effects on quality of life may be substantial. Recent evidence suggests that there may be significant deficits or shortcomings in the emotional engagement and communicative skills of oncologists with their patients.<sup>327</sup> Evidence also suggest that both empathy and communication skills can be improved with training.<sup>326,328</sup>

Patient-centredness has been central to contemporary palliative care since its emergence in the 1960s. At that time, the patients did not receive palliative care until near the end of life, when it was clear that symptoms, needs, concerns and relationships would be the primary targets for interventions. It is now recognized that palliative care may be of value from the time of diagnosis, but the focus on patients and families has remained central to palliative care. Quality of life and symptom alleviation are primary targets of treatment in palliative care, and communication and shared decision-making (SDM) are considered essential methods of practice.

SDM has been defined as: *"an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences"*.<sup>329</sup> SDM is a process that involves both the patient and the physicians and helps to ensure that there is informed consent and patient autonomy in decision-making. SDM presupposes that the patient has knowledge of the disease, of the intended effects and toxicity of treatments, of the expected survival and of the symptom burden, with and without the proposed treatment. SDM requires a trusting relationship between the patient and the health care providers, as well as communication skills on part of the health care providers. Such skills are needed to facilitate the appropriate, timely and sensitive sharing of relevant information and to support patients in expressing their preferences and views and in making truly informed choices.<sup>330</sup>

Advance Care Planning (ACP), a special variant of SDM, focuses on the patients' priorities for the future including being able to die in accordance with their personal values and wishes. ACP is an important aspect of contemporary cancer palliative care,<sup>330</sup> recommended to take place early in the course of treatment when cure is not an option. Engaging patients and families in ACP can help them

to reflect on and to manage the transitions that lie ahead and to set treatment goals that are consistent with their values and preferences.<sup>331</sup>

The integration of palliative care and oncology highlights the importance of patient-centredness including skills in communication, SDM and ACP. Although there should be some division of responsibilities between oncologists and specialists in palliative and supportive care, communication and interaction between them is important to support a common understanding of the disease and the treatment. The “back-feeding” of the observations of palliative medicine specialists to oncologists may help to ensure that patients are truly informed and without unrealistic expectations about the goals and results of the tumour-directed treatment and therefore they can meaningfully participate in SDM.<sup>332</sup>

This panel builds on the IOM definition of patient-centredness in which a central component is to “... ensure that patient values guide all clinical decisions”. Symptom assessment, SDM with its special variant, ACP, and care for the caregivers are key elements of patient-centred practice. Communication skills are central in order to practice patient-centredness. These skills and barriers to and solutions to patient-centred practice barriers will be discussed.

### Patient-centredness in the oncology setting

Cicely Saunders established modern palliative care, highlighting the importance of active listening to patients’ needs, and making patients’ views visible and recognizable in the care processes.<sup>32</sup> She also introduced the concept of total pain<sup>333,334</sup> which infers a broad understanding of the patients’ needs during a life limiting disease. In these ways, she was a pioneer in patient-centred care, although this term had not yet entered the medical lexicon. With the advancement of modern surgery, chemotherapy, and radiotherapy, targeted therapies and, more recently, immune therapies, cancer treatments have often become combinations of modalities administered by different specialists, each with its own risks and benefits. Navigating such complex systems and participating in SDM requires ongoing communication and support of the patient and the family by oncologists and the other participants in the treatment teams.

Contemporary cancer care has some characteristics of special relevance for promoting patient-centredness as a means to improve care. Cancer is no acute disease and most patients experience cancer as a chronic disease although the public perception of cancer is probably close to the acute disease model.<sup>335</sup> The chronicity of cancer stems from the fact that many patients undergo life-prolonging treatments for years or are cancer survivors with manifest or latent late effects. The chronic disease model has become even more relevant during the last decades with the advancement of modern surgery, chemo- and radiotherapy, targeted therapies and recently various types of immune therapies. Cancer treatments are often combinations of different treatment modalities administered by different specialists, and each treatment carries its own risks and benefits. Navigating through such complex systems therefore become a core task in itself, which the patient cannot be expected to solve by himself.

The patient and eventually his family, in order to be actively involved in the care planning, must understand and accept the reality of the situation and the different options at hand. Many patients’ disease understanding is far from their medical reality when their cancer journey starts or even when they come to breaking points such as tumour progression at a later stage. Combined with the distress

accompanying the cancer disease trajectory demonstrated repeatedly,<sup>336</sup> the physicians meet patients who are often misinformed or under-informed with compromised decision capabilities due to distress. They are therefore at high risk of accepting treatment proposals with uncertainties which they are not aware of. This places a special responsibility upon the physicians as they can start treatments in patients who are not truly informed about the treatments' risks and benefits. The high percentages of patients misinterpreting palliative radio- or chemotherapy as curative support this understanding.<sup>337</sup>

### Box 3. Main elements of patient-centred care

- Respect for patients' values, preferences, and expressed needs
- Coordination and integration of care
- Information, communication and education
- Physical comfort – relieving bothersome symptoms
- Emotional support – relieving fear and anxiety
- Involvement of family and friends

Patient-centred care is a broad approach that must take into account both the person and the disease, with attention to individual values, needs, resources, needs and preferences. The health literacy of the patient<sup>338</sup> i.e. the ability to obtain, read, understand, and use healthcare information, may vary widely across patients and must be taken into account in communication and SDM. A variety of factors, including anxiety related to the life-threatening circumstance, language, culture, and recent immigration all may affect health literacy and the ability of patients to participate in decisions about their care. The fragmented nature of the cancer care system, with multiple levels of care, providers and locations also presents major challenges to coordinated care and the development of comprehensive treatment plans.<sup>339</sup>

### Shared decision-making (SDM)

SDM is a central component of patient-centred care. It is highly relevant in all phases of cancer treatment, but becomes increasingly important as the disease progresses. At such times, decisions often become more complex, with trade-offs between life quantity and life quality. SDM is an active process, requiring the exchange of information and opinions in order for patients to make decisions based on their values and preferences and on their understanding of the best available medical evidence.<sup>340</sup> This means combining the tumour-directed and the patient-centred approach to care and weighing the benefits and risks of starting, changing, continuing or stopping tumour-directed treatment. Decisions about selecting one treatment option over another may also be difficult, since there is often little or no empirical data that indicate greater value for one regimen over another.

<sup>341,342</sup>

A variety of factors unrelated to the value of care may affect SDM, including those highlighted by the fields of behavioural economics and the psychology of decision-making.<sup>343</sup> Decisions about starting, continuing or discontinuing chemotherapy or other cancer treatment may be difficult to make because of insufficient, uncertain or even conflicting empirical data and because they are made under circumstances of emotional strain. In this situation, available statistical and clinical data may

not be used<sup>344</sup> and some clinicians may find it easier to prescribe another round of chemotherapy than to engage in a conversation about futile treatment.<sup>322</sup> Further, the “last-case bias” may operate in which decision-makers are more influenced by recent experiences than by remote events. Reimbursement practices may also directly or indirectly influence institutions and providers toward “grey zone” chemotherapy that is costly, but of uncertain benefit. Patients and providers may both tend to be “treatment focused” in such situations of uncertainty,<sup>345</sup> hoping that treatment will prolong survival and/or because physicians are uncomfortable having conversations regarding prognosis.<sup>345</sup> Correcting misbeliefs about quantity of life and introducing alternative treatment goals, such as preserving quality of life, require communication skills and are most appropriate within the framework of SDM.

Physicians are legally and ethically obligated to provide information in a way that enables patients to be active and informed partners in the decision-making process and to promote their participation in decision-making.<sup>346</sup> A process to accomplish such SDM can be described in four steps; 1) *awareness of equipoise*, 2) *discussion of the benefits and harms of options and their probabilities*, 3) *elicitation of patients’ concerns and expectations*, 4) *partnership and participation*.<sup>347</sup> Only the second step seems to be common in cancer clinics,<sup>348</sup> where most attention is typically paid to the “objective” biological aspects, consistent with the tumour-directed approach. Little attention is often paid to the host, i.e. patient’s preferences, symptoms, quality of life and care, and to the option of no tumour-directed treatment.

Despite being a central element of patient-centred care, SDM is not explicitly included as an integrated part of oncology guidelines.<sup>16,22,348</sup> A premise of SDM is that the oncologist and the palliative medicine specialist must both be aware of the patients’ prognosis and the risks and benefits of treatment choices in patients with advanced cancer.<sup>349,350</sup> Patients may have unrealistically positive perceptions of their prognosis and effects of tumour-directed treatments and be willing to continue or to start therapy with minimal or no likelihood of therapeutic effect and a high risk of side-effects.<sup>337</sup> The use of intensive and non-beneficial treatment at the end of life is both extensive and expensive,<sup>25,260</sup> although such treatments often reduce quality of life and time spent at home.<sup>254</sup> Paradoxically, physicians tend to choose less intensive treatment for themselves at end-of-life than they offer their patients.<sup>351</sup>

A common misunderstanding is that SDM implies leaving decisions to the patient. As demonstrated in Table 5, there are different degrees of SDM, partly depending on the different choices at stake. The process, *the making*, is the main component of SDM.

	Physician’s premises	Patient’s premises
<b>Physician makes the decision</b>	Physician makes the decision without access to patient’s preferences	Patient lacks competence to give informed consent
<b>Physician limits the patient’s preferences</b>	Physician clarifies available treatment options	Patient wants a treatment that is not available



<b>Physician makes decision in collaboration with the patient</b>	Physician recommends a defined treatment	Preferences and wishes for shared decision-making might vary
<b>Patient makes the decision during the consultation with their physician</b>	Physician presents equivalent/similar treatment alternatives	Preferences and wishes for shared decision-making might vary

**Table 5. Examples of different degrees of SDM**

To promote SDM, the doctor must encourage patients and caregivers to participate in consultations and decisions regarding the care, *determine* situations where this is critical, and *inform* patients about the benefits and disadvantages of available treatment options. This must include balanced prognostic information about best and worst case scenarios, *responding* to patients' concerns and their understanding of the information, which helps to reach *an agreed-upon treatment plan*.<sup>352</sup> This approach largely corresponds with the 5-steps presented in Table 6. Patients' and caregivers' assertive behaviours and physicians' facilitative behaviours interact to promote patient participation over time.<sup>353</sup> This complexity explains why a single, unidimensional intervention is less likely to work.<sup>354</sup>

<b>1</b>	<b>Determine situations in which SDM is critical</b>	<b>Complexity depends on treatment intent and options</b>
<b>2</b>	Acknowledge that decisions are to be made to the patient	Increasingly important with sensitive issues
<b>3</b>	Describe treatment options, including risks, benefits and uncertainty associated with options	Avoid hastened decisions, make sure patients are fully informed
<b>4</b>	Elicit patient preferences and values, and make sure the patient understands the information in her/his perspective	Listen carefully and convey information in a language that matches the patient's cognitive level
<b>5</b>	Agree on a plan for the next steps in the decision-making process	Agree that the plan may be revised depending on the disease development

**Table 6. Five steps in shared decision-making, Adapted from Politi et al**<sup>340</sup>

The literature on outcomes of SDM in palliative care remains scarce and findings are inconclusive.<sup>355</sup> However, in a range of studies in different groups, SDM has been associated with better quality of life and treatment and consultation satisfaction, better affective-cognitive outcomes, and decisions that are more in line with the patient's pre-consultation treatment preference. A recent study<sup>356</sup> showed that 49% of 102 cancer patients preferred shared treatment decision responsibility, whereas 29% preferred to leave the decision to the physician, the latter significantly associated with more advanced age and greater distress. This corresponds to another study reporting that about 50% of patients with advanced cancer preferred to be involved in SDM, whereas the remaining 50% were almost equally divided between active (making the decisions by themselves) and passive (the physician making the decision for them) approach.<sup>357</sup> Such attitudes may change over time in either direction, pointing to a need for individualization and flexibility in communication and in care

planning. More research has been conducted on the use of decision aids finding increased knowledge, greater patient engagement and decisions more consistent with patients' preferences.<sup>358</sup>

There is little evidence about patient preferences concerning communication and information as an aid to shared decision-making in palliative oncology.<sup>359</sup> Most patients (90-95%) are more willing to obtain information about diagnosis, prognosis and treatment options than about palliative care (63%).<sup>360</sup> However, about 50% wish to participate in treatment decision-making as time passes, and patients with more pain are more likely to change their preference towards being more involved.<sup>361</sup> Most patients with advanced cancer say they want honest, sensitive communication about end-of life issues. This helps patients and their families to prepare, make informed decisions, and also to avoid potentially burdensome medical treatments near death.<sup>362</sup>

The role of family and caregivers is important in the SDM process through the disease trajectory. Two thirds of patients with advanced cancer want family members to participate in the communication and the decision-making.<sup>360</sup> However, caregiver preferences may not be concordant with those of patients<sup>363,364</sup>, especially regarding information when death comes closer.<sup>349</sup> Some cancer patients may want to "spare" family members from the emotional strain of receiving bad news and it has been found that distress in caregivers of patients with advanced cancer is greater than in patients themselves.<sup>365</sup>

A successful implementation of SDM in clinical practice relies on training physicians to engage with the patients and to provide the right information at the right time. Several decision aids exist to facilitate this process,<sup>22,340</sup> and the stepwise approach presented here, represents a systematic approach. Further, specifically defining SDM as a part of the standardized care pathways, may promote its implementation in clinical practice at the organizational as well as the individual patient care level.

## Advance care planning (ACP)

ACP can be considered a special variant of SDM, focusing on the patients' voluntary participation in discussing their future care with their care providers. ACP should be an integral part of the care and communication process and of the regular care plan review. ACP differs from regular care planning by focusing on an anticipated deterioration in the individual's condition approaching death. ACP developed from advance directives, which have been used in the USA and other countries since the mid-1970s.<sup>366</sup> From the mid-1990s there was a shift from standardized legal forms to an ongoing and flexible process and from the focus on refusal of treatments to promoting statements of preferences and wishes, paving the way for ACP.<sup>366,367</sup> ACP has received growing attention since that time and is currently an important issue in palliative care internationally.<sup>330,368</sup> In Europe, efforts to promote ACP have been focused on patients with life-limiting illnesses, rather than on the general public.<sup>369,370</sup> While advance directives are specifically directed at refusing treatment when individuals are no longer able to express their wishes, ACP concerns also future care in a broader sense.<sup>368,370</sup>

A recently published consensus definition of ACP describes it as *"a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help to ensure that people receive*

*medical care that is consistent with their values, goals and preferences during serious and chronic illness*".<sup>371</sup> The word 'process' underlines that the planning is not a one-time event, but usually evolves over time through a series of conversations, and therefore that ACP documents should be updated regularly.<sup>368,370,372</sup> Although the definition does not specify who should take part in the ACP process, ACP discussions commonly involve the patient, family, informal caregivers and health care professionals. This discussion can be conducted by the primary care or oncology team or by the palliative care team, depending on the skills and resources that are available.

The ACP process starts by exploring the patient's health-related experiences, concerns, and personal values, and his/her understanding of ACP and readiness to engage in it. Not all patients want such a plan or are able to formulate their wishes for future care, which is, in itself, is valuable information for planning of care. Next, the current disease situation should be discussed in order to obtain a common understanding of treatment and care options and their advantages and disadvantages. ACP may also include discussion and completion of an advance directive or living will, depending on the national legislation. The advance directive will typically address specific interventions, such as cardio-pulmonary resuscitation or tube feeding, in a future scenario of incapacity. Finally, encouraging the individual to share thoughts and preferences with family and friends is an important part of the process.<sup>368,370,372</sup>

Different forms and templates for ACP documents have been proposed and many are freely available on the internet.<sup>373</sup> There is an ongoing debate about whether ACP should be based on open or scripted conversations.<sup>330</sup> The use of a template may ensure that most relevant areas are presented to the patient, although strict adherence to a guide may restrict the free exchange of thoughts, and reduce ACP activity to a tick-box exercise.<sup>370</sup> A semi-structured interview guide may avoid these dangers.<sup>374</sup> ACP ensures that the care is more likely to be in accordance with the patient's preferences than if it is not performed.<sup>375</sup> It has also been shown to decrease life-sustaining treatment at the end of life and to increase the use of hospice and palliative care and to prevent unwanted hospital admissions.<sup>362</sup> Comprehensive ACP programs seem to be more effective in making end of life care coherent with patients' preferences than just completing a written advance directive.<sup>376</sup>

Although there are still unresolved questions as to the optimal ACP system and how to assess its impact and effectiveness, ACP is coherent with patient-centred care and therefore relevant for the early integration of palliative care and oncology although many countries presently do not have any legislation regarding ACP.

### Assessing the patients' perspective systematically

Symptoms, preferences and patient-reported outcomes have been labelled differently in recent decades. The U.S. Food and Drug Administration (FDA) has proposed the term Patient Reported Outcomes Measures (PROMs) for all measures that can best be assessed by patient self-report.<sup>67</sup> PROMs is an umbrella term covering the patient's perspective on well-being, symptoms, subjective treatment effects and side effects.<sup>68</sup> The CONSORT-PRO Extension Statement, aiming to improve the reporting of PROMs on symptoms, functioning and quality of life,<sup>70</sup> further consolidates PROMs as independent outcomes in cancer.<sup>69,70</sup>

The patient perspective and experience cannot be replaced by clinical observations and examinations performed by the oncologist or by the palliative medicine specialist. In ordinary consultations, many

bothersome symptoms are not identified or addressed.<sup>377</sup> However, PROMs can be used to highlight the patient's experience and to bring the "patients' voice" into the clinical consultations. The benefits of routine PROM assessment in clinical practice are well documented. These include improved patient-physician communication,<sup>378-380</sup> increased physicians' awareness of patients' physical and psychosocial functioning,<sup>381-383</sup> improved patient well-being,<sup>76,379</sup> and a more efficient and focused use of time.<sup>382</sup> Regular use of PROMs makes the physicians aware of symptoms they did not know bothered their patients.<sup>383</sup>

Symptoms are essential information for the primary cancer diagnosis and for follow up care during curative and life prolonging treatments. Still, systematic symptom assessment is not part of routine oncological care,<sup>381,384-386</sup> even though this is frequently employed in clinical trials.<sup>387</sup> For patients with advanced cancer, for whom symptom management is a central goal of care, systematic use of PROMs is even more important and is a prerequisite for optimal symptom management.<sup>318</sup> Relieving burdensome symptoms is therefore a core task within patient-centredness and a special obligation on part of the physicians.

Insufficient and unsystematic assessment of symptoms is a major factor explaining inadequate symptom relief in cancer patients. Inadequate pain control has been documented in up to 50% of the cases, despite strong efforts to improve pain treatment.<sup>388,389</sup> Clinical studies of patients with cancer have found systematic use of PROMs to improve a range of symptoms.<sup>382</sup> The discrepancy between research outcomes and those in clinical care is probably explained by the rigorous diagnosis, documentation, treatment and follow-up in clinical studies, which are often not conducted in regular care.

For patients with limited life expectancy, the balance between treatment effect and tolerance of therapy, based on toxicity and adverse effects, is crucial in the treatment decision-making. Toxicities and adverse effects are mandatory to report in clinical trials by such systems as the Common Terminology Criteria for Adverse Events (CTCAE) developed by the National Cancer Institute.<sup>390</sup> These criteria have, until recently, been rated by the physicians, although many are symptoms that are best reported by the patients. This recognition has led to the development of a PROMs-version of the CTCAE, the PRO-CTCAE.

The most feasible and reliable form of PROMs is via standardized and methodologically sound self-report questionnaires, traditionally paper-based. New advances in health information technology have led to the development of electronic tools (e-tools) for the collection of PROMs. Electronic data collection permits dynamic assessment i.e. automatically tailored questions for individual patients based on the patients' previous scores on given symptoms. This results in fewer repetitive and irrelevant questions, thereby reducing patient burden. Several electronic questionnaires (e-PROMs) now exist, with a user-friendly interface and immediate aggregation, storage and transfer of patient scores, for direct use in the clinical encounter and possibly integration with other clinical data in the electronic patient record.<sup>391</sup> In the oncological setting, electronic assessment and rapid presentation of results to the clinician facilitate communication, are well accepted by patients and clinicians, and may result in more efficient and focused use of time.<sup>72</sup> A recent qualitative study showed that perceived usefulness might be more important than functional aspects regarding applicability.<sup>74</sup> Still, immediate display of easily interpretable results to the physician is a crucial factor for successful

implementation of electronic registration of PROMs into the clinics.<sup>75</sup> Nevertheless, the most important obligation on the part of health care providers is to actively use PROMs tools, discuss the scores with the patient, explain potential interventions and make the patient an active partner in the decision-making process.

Systematic symptom assessment by either paper-based or electronic assessment tools (PROMs) ensures registrations of burdensome symptoms, also such symptoms patients do not report spontaneously unless asked, specifically anxiety and depression. These may not be spontaneously reported by patients, particularly if they perceive that they will not be regarded as relevant to their cancer care. Still, the symptoms reported by the patients with PROMS must be addressed in the clinical encounter and used in the decision-making processes. Often symptom intensity, the most common symptom assessed in the assessment tools, must be supplemented with other symptom characteristics in order to decide about intervention. The duration of the symptom, its meaning and the distress associated with it may best be elucidated in a follow-up clinical interview. This may be initially conducted in an oncology clinic but may also be assessed by the specialized palliative care or psychosocial oncology team. The latter may be able to conduct a more in-depth assessment and provide more specialized care

## Caregiver involvement

Patient-centred care and SDM aims also to involve the family members. It should be routine in clinical care for patients to be asked to identify their significant others, and to provide information about the nature of their relationship with them, strengths and limitations in their ability to take on complex cancer caregiving, and how much information about the medical situation they can and should and can receive. Further, caregiver problems, such as serious illness or emotional or economic problems need to be assessed.

Caregivers are often actively involved by cancer patients in decisions about their care and treatment, particularly those focusing on the end of life. Patients choosing to participate in SDM have been found to prefer to share this experience with their family members.<sup>392</sup> Caregivers, including family or friends, often provide care for cancer patients, although many may not be well-prepared to do so. The burden of such caregiving on caregivers may also be substantial and reduced quality of life, distressing symptoms such as insomnia, fatigue, anxiety and depression, and financial stress have been shown to be common among them.<sup>393,394</sup> The strain on caregivers may have increased in recent years, as cancer care has shifted towards more outpatient and home-based care. Moreover, with cancer being more prevalent in the elderly, many caregivers of advanced age and may suffer from substantial health problems of their own. Therefore, involvement, training and support of caregivers are key components of modern cancer care.

Caregiver resources and the quality of the support for the patient and the caregiver support may be decisive in determinations about the place of care, when the disease progresses, and the location of death.<sup>395</sup> The family as informal caregivers of patients is often the patients' main source of emotional and practical support, although the burden and challenges of disease may create or intensify family conflict. Such conflict, which can obstruct or complicate treatment planning, may benefit from intervention. These disagreements and tensions may be easily recognizable, but can be challenging

and time-consuming to resolve. Palliative care physicians and teams can help to support caregivers in addressing these conflicts though engagement of specialized psychosocial oncology may also be of value. The updated ASCO Clinical Practice Guideline on integration of palliative care and oncology emphasizes that services by multidisciplinary palliative care teams complement existing programs, and that “Providers may refer family and friend caregivers of patients with early or advanced cancer to palliative care services” .<sup>16</sup>

Studies of the effects of early provision of palliative care on caregiver satisfaction with care, quality of life and emotional distress have produced conflicting results. One Norwegian study<sup>396</sup> showed an overall positive impact on quality of life, in line with a study using specialty trained PC clinicians in patients with a poor prognosis.<sup>397-399</sup> The ENABLE-III study by Dionne-Odom, is probably the first RCT examining a specific palliative care intervention for family caregivers of patients with advanced cancer.<sup>400</sup> The intervention group received three structured weekly telephone coaching sessions, monthly follow-up, and bereavement calls compared with usual care in the control arm. The results showed lower depression scores at 3 months in the intervention group.

Two consecutive meta-analyses have examined the effect of different interventions on various caregiver outcomes in a total of 79 RCTs with family caregivers of cancer patients.<sup>393,394</sup> Results from the first analysis indicated that these interventions had small to medium effects on caregiver burden, caregivers’ ability to cope, their self-efficacy, and aspects of their quality of life.<sup>394</sup> In the period covered by the second analysis (2010-2016), the number of trials had increased substantially corresponding to a huge variety of formats and types of interventions. This make comparisons and conclusions about efficacy thereby difficult but indicate that caregiver interventions can vary and probably should be flexible.<sup>393</sup> What should be remembered is that caregiver satisfaction in most RCTs of early introduction of PC is at best defined as a secondary outcome, and therefore can be interpreted as a complementary effect of improved patient care, and not the result of specific interventions directed at the caregivers.

Qualitative data from trials of early palliative care have identified certain aspects of palliative care that may influence the caregiver satisfaction; e.g. building rapport, establishing a relationship with patients and family, focusing coping and providing realistic information about prognosis.<sup>332,401</sup> The content of the early and subsequent palliative care visits, identification of key issues and timing of when to address these, were regarded as reasons for favourable outcomes in one study.<sup>332</sup> Statements expressed in another study gave important clues to how incurable cancer affects the family and ways that helped them cope.<sup>401</sup> Statements like:” It is the family that’s going through it” and “Talking with the palliative care physician was immensely advantageous” clearly illustrate these points.

## Communication – a key to patient-centredness

Oncologists and palliative care specialists face difficult communication situations through the trajectory of cancer, including breaking news about disease progression and non-response to tumour-directed treatments. A strong focus on better communication as part of early palliative care promotes patient-centred care, and results in better prognostic awareness and higher patient satisfaction.<sup>5,312</sup>

Patient-centred communication is a key asset for implementing SDM in oncology practice. As mentioned the main characteristics of patient-centred communication are attention to patient's affective states, values, needs and preferences.<sup>346</sup> Patient-centred communication aims to create a dialog between the physician and the patient and therefore the clinician must be able to monitor and consciously adapt the communication to meet the patient's needs. When this does not occur, the communication easily takes the form of a monologue which is provider-centred and not patient-centred.

### Box 4. Communication in the cancer care setting shall help the patients to: (Adapted from Epstein RM, Street RL, Jr.)<sup>320</sup>

- Receive bad news
- Handle the emotional impact of a life-threatening illness
- Understand and remember complex information
- Communicate with multiple health professionals
- Understand statistics related to prognosis
- Deal with uncertainty while maintaining hope
- Build trust that will sustain long-term clinical relationships
- Make decisions about treatment, possibly including participation in clinical trials
- Adopt health-promoting behaviour

The key tasks to be solved by patient-centred communication span the whole cancer trajectory, but common features to all phases are exchanging information, responding to emotions, fostering healing relationships, managing uncertainty, making decisions and enabling patient self-management.<sup>352</sup> Patient-centred communication transcends medical issues and also includes practical issues such as clarifications of responsibilities and who to contact.<sup>310</sup> Key communicative tasks to be solved in advanced cancer are presented in Table 7.

### Key communicative tasks

- Eliciting the patient's report of symptoms
- Communicating prognosis while maintaining hope
- Making decisions about tumour-directed and intensive medical treatments – particularly about starting and stopping criteria
- Making decisions about future care including hospice care
- Responding to the emotions of the patient, the family and caregivers
- Helping the patient navigate the transition to end-of-life care

**Table 7. Advanced cancer - key communication tasks to be solved**

Communication includes both sending and receiving information with both verbal and non-verbal elements. Both parties must repeatedly change roles from sender to receiver; being the receiver, i.e. performing active listening, is challenging for many physicians. Indeed, one of the most-cited studies of physicians' communication demonstrated that GPs interrupted the patient on average 18 seconds after the patient had started talking.<sup>402</sup> Physicians must be willing to "see" patients as whole persons and providing them with information that is understandable and useful from their perspective. They must also be prepared to discuss the end of life, although the words "die" and "death" are generally avoided by oncologists, who may be uncomfortable engaging in meaningful discussions about the end of life.<sup>403</sup> A common belief is that honesty undermines hope, although there is evidence that honest but empathic communication may actually help to preserve morale and psychological well-being.<sup>233</sup> Finally, both parties also need to share knowledge and understanding and must have suitable perceptual and linguistic skills to produce effective communication behaviours that are appropriate to the situation.

For patients, good enough communication with their physicians can help to make them feel understood, participate actively in the interaction, improve their understanding of the disease and treatment options, cope better and to experience trust in their physicians and in the health care system. Patient-centred communication can also result in a treatment plan that is concordant with patient preferences and values. It is essential that the physician and the patient establish a common understanding of the current situation as the starting point for patient involvement. A prerequisite is that the information and answers are communicated in a way and in a language that match the patient's cognitive and intellectual abilities and that it take into account the patient's emotional state at the time of the consultation. Hence, provision of sufficient information requires knowledge about how to convey the information in an understandable manner at the right time.

With more complex clinical conditions and therapeutic opportunities, patient-centred communication is especially salient.<sup>404,405</sup> Nevertheless, inadequate communication about prognosis and treatment choices is common,<sup>349,350,406</sup> although listed as a key dimension of patient-centred communication.<sup>318</sup> Moreover, critical information about prognosis and treatment options is often not discussed during life-prolonging treatment, and may lead to unrealistic patient expectations regarding cure.<sup>3,312,352</sup> Much too often, these discussions typically take place late in the disease trajectory, often in the last month, which is too late for patient and family to benefit from referral to palliative care.<sup>407</sup>



The tendency of physicians to avoid honest communication is not supported by empirical research. Parker et al found that up to 90% of patients with advanced cancer want information about the disease, treatment options, symptom management and life expectancy.<sup>349</sup> There is accumulating evidence showing that early discussions about care goals in advanced disease improve end-of-life outcomes.<sup>310</sup> Further, patients who have discussed the future with their doctor before the disease is too far advanced, report greater well-being and have fewer unwanted intensive interventions in the last weeks of life, with no detrimental effect on survival.<sup>3,362</sup> An earlier integration of oncology and palliative care with patient-centred communication also enhances patient and family involvement, guides the decision-making and promotes realistic expectations for the future, and is therefore an important improvement of general oncology care.<sup>401</sup>

Communication skills can be taught to medical undergraduates and postgraduates, but discussion of prognosis and at relevant time-points must be part of oncology and palliative care training. Such discussions presuppose detailed knowledge about prognosis, including the uncertainty inherent in a prognostic evaluation. Empathic communication about prognosis and about uncertainty are communicative skills that should be mandatory in the curriculum for oncologists and other clinical specialities treating cancer patients (see Prognostication and Education).

As outlined in the scheme for SDM, treatment options should be explained simply and clearly. Most topics are emotionally loaded for the patients and family members. Learning how to elicit and respond to the emotions during and still carry the consultation forward is a skill that physicians must acquire. Very few learn these skills by themselves, some improve by an open professional culture focusing treatment of the patients, and most probably need specific training like an athlete that needs training to improve.

Training in SDM as a method in clinical practice and on how to maintain, develop and share fundamental communication skills is needed at regular intervals for oncologists, palliative care specialists and other health care providers to foster patient-centred communication<sup>332,408</sup>. Empathic listening, flexible and attuned responsiveness to the shifting needs of the individual patient and to patients' and caregivers' emotions are important skills that can be improved through learning.<sup>310,314,401,409,410</sup> The best methods for improving communication skills are not yet established.<sup>411</sup> However, interventions such as communication skills training with role play and feedback, e-learning, group discussions, modelling, case evaluations and coaching are some of the most commonly used strategies. Overall, strategies that involve activity and practice are most efficient.<sup>411</sup> Although less common, interventions aimed to influence the patients' behaviour include encouraging them to use prompt lists which can be combined with patient and oncologist coaching.<sup>412,413</sup> Although evidence about their usefulness in palliative care patients is limited, they could help to engage patients and physicians in more active and deep interaction.<sup>340,414,415</sup>

## Psychosocial Care

The prevention and alleviation of psychological and social distress in patients with cancer and in their families and support for their personhood has been a central goal of palliative care from the time of its inception.<sup>416</sup> Indeed, palliative care emerged, in part, to the neglect in modern medicine of the human dimensions of suffering.<sup>417,418</sup> Nevertheless, there has been much less attention in palliative care to training and the systematic delivery of psychological and spiritual care, compared to physical

interventions, for which there are well developed protocols and guidelines. This contrasts recent findings on depression being the main factor associated with poor QOL in patients with advanced cancer.<sup>419</sup>

Symptoms of depression,<sup>336</sup> demoralization,<sup>420</sup> and spiritual distress<sup>421</sup> are common in patients with advanced cancer and longitudinal research has shown that, without intervention, these symptoms tend to worsen with greater proximity to death.<sup>422</sup> There is a growing evidence base for the effectiveness of psychological interventions to alleviate depression and other manifestations of distress in patients with advanced disease. These interventions include supportive-expressive group therapy,<sup>423</sup> Meaning Centred Psychotherapy,<sup>424</sup> Problem-Solving Therapy and behavioural activation<sup>425</sup> and Dignity Therapy.<sup>426</sup> However, psychosocial interventions and skills are not well integrated at present into either oncology or palliative care.

A recently developed approach to psychological care of the patient with advanced disease that is integrated with cancer care and with palliative care is referred to as Managing Cancer and Living Meaningfully (CALM).<sup>427</sup> This intervention is intended to provide patients and their caregivers with reflective space to communicate their experience and to address the major decisions, burdens and adaptive challenges of advanced and progressive disease. Palliative care, oncology and psychosocial care providers can be trained to deliver this intervention and such training has the potential to enhance their ability to engage empathically in sensitive conversations and to create reflective space. An international training program for health care providers is now underway<sup>428</sup> for this intervention which has been shown to alleviate and prevent depressive symptoms, to reduce death-related distress and to enhance the capacity of patients to communicate with their family and their health care providers.<sup>429</sup> This program infers training of members of the multidisciplinary palliative team. The palliative care multidisciplinary team is set up in order to address the complexity of problems facing the patients and their families. Patients' problems are often complex and cannot be solved by a single profession alone. Some problems are best addressed by specific members of the team, such as financial problems that often needs the competence of a social worker. The effects of a multidisciplinary approach have been demonstrated but perhaps not fully utilised.<sup>430</sup> Although a broader patient-centred approach on part of the physicians seems pertinent, other members of the team are often in better positions to provide the care. The CALM approach is therefore promising in terms of its focus on skills needed to provide patient-centred care.

#### Box 5. Psychological domains - content

Treatment decisions and communication with health care providers

Renegotiation of personal relationships and self-concept

Reframing priorities and the sense of meaning in life

Fears, hopes and plans related to impending mortality

### Barriers and solutions

At present the delivery of cancer care is more provider-centred than patient-centred.<sup>431</sup> This applies to the system as a whole, including institutions, payment systems, infra-structure and professional

cultures. In sum, these factors represent substantial barriers towards making care more patient-centred.

On the macro-level, the focus on promising new cancer therapies is prominent. This focus can be traced in present research priorities (see Societal Challenges) and also mirrors the priorities and marketing activities of the drug companies. It has been stated that the ultimate goal of contemporary science is immortality,<sup>432</sup> and, if correct, this represents a strong driver for further strengthening the focus on the tumour. These factors also create expectations both within and outside the medical community and effects priorities at all levels within health care and in politics. The public opinion and thereby the expectations of patients, are also influenced and contrasts the reality facing a substantial proportion of them and their families, namely that their cancer is incurable. In our view, these factors with their unilateral focus on the tumour, represent barriers against a focus that includes both the tumour and the patient.

Oncology as a medical specialty has its roots in internal medicine while palliative care has its roots outside mainstream medicine. This has created different cultures with different foci; the tumour and the host. A culture is characterized by sharing the same values including taboos, and acts as an “invisible” but commonly shared guidance for social interactions for those sharing it.<sup>433</sup> Cultures also create borders. This contrasts legislation which is open and explicit, making legislations easier to discuss and change. Bridging the two cultures in oncology and palliative care is therefore a challenge which is traceable at all levels in health care including daily activities at wards, departments and hospitals.

One prominent characteristic of the medical culture is the perception of the paternalistic doctor deciding over life and death. This is communicated at medical schools, and also fulfils the expectations of the students. The majority of them start at medical school with an “inner picture” of the physician as the person who is in power over life and death. The most challenging parts of teaching communication skills to medical students are to motivate them for the training and to teach them to systematically explore the perspective of the other, the patient.

The tabooing of death is another observable trait of the medical culture. The word is seldom used,<sup>403</sup> and many medical schools do not teach palliative care or end-of life care at all. The lack of exposure to these topics during the formative years as students or freshmen have consequences for performing clinical tasks such as discussing tumour-directed treatments with a patient who has limited life expectancy or providing care which includes death as the endpoint. Euphemisms are commonly used by the physicians when topics are perceived as challenging, often without checking if the information is understood by the patient. This protects the physician from challenging communicative tasks in which he often lacks or does not have the correct answer but when open negotiations with the patient would have been preferable.

Even if most patients with advanced cancer express a preference for realistic information and realistic discussions about treatment options and prognosis,<sup>362,434</sup> it must be acknowledged that barriers for high-quality conversations exist on the patient side as well. Patients may be reluctant to ask questions, express their feelings, do not want to admit that they are unsecure or that they do not quite understand the options and the implications. Two tongues – one towards the oncologist the

other towards other health care providers is documented in qualitative studies in patients approaching the end of tumour-directed treatments.<sup>435</sup> This points to a very important and common trait among patients with advanced cancer; they are ambivalent both wishing to live and wanting to live a good a life as possible. This ambivalence is also commonly observed in relation to wanting information about prognosis when this is poor.

There are examples of how the medical culture has changed in response to new dogma. The best described is probably the change from hiding to disclosing the cancer diagnosis described earlier. In an editorial commenting upon the study of Novack<sup>436</sup> which confirmed disclosure to be the preferred practice, informed consent as a prerequisite or inclusion of patients into trials was pointed to as the most possible explanation for the change of attitude.<sup>437</sup>

When asked, doctors are generally positive to use PROMs, but this is still much more common in palliative care units compared to general oncology units, primarily because of the enhanced focus on symptom management in palliative care. Frequently cited barriers towards the use of PROMs are time-constraints, cumbersome use, difficulties related to interpretation and logistical problems.<sup>385,438</sup> Other factors including resistance to change of an established system, lack of strong enough implementation, no economical and/or professional incentives and absence of patient-centred focus also play a role. These factors are basically the same for all organizational changes, and represent a challenge when implementing all types of new practices. Paradoxically, introducing new drugs or new technologies do not seem to meet the same resistance to change. It is reasonable to assume that the economic strength of the producers of drugs and new technologies therefore plays a role.

To enhance a patient-centred approach, the following factors apply on the organizational, professional and personal, levels: a) implementation of a patient-centred approach and communication plan into the SCPs, b) willingness to change behaviour and incorporate this into clinical practice and c) a mutual understanding and internalization of the content and values of a patient-centred approach among all health care providers involved in the care

The problems of sharing information within and between health care organizations have been recognized as a barrier to the implementation of ACP. Other barriers include competing demands of other work for health care professionals, and the emotional nature of these types of conversations. Specially trained staff using a structured approach has been shown to facilitate implementation.<sup>439</sup> Also, prompts in the electronic health record can increase the rates of documentation.<sup>440</sup> At the patient level, factors influencing the uptake of ACP are complex, including previous illness experiences, preferences and attitudes. Generally, cancer patients are more open to ACP than patients with non-malignant diagnoses.<sup>441</sup> However, one systematic review suggested that cancer patients value more the shared decision-making and communication elements of ACP than the avoidance of excessive medical treatment at the end of life.<sup>392</sup>

Other strategies to enhance patient-centredness are elaborated upon in other panels and include economic incentives, organization, and education.

## Recommendations

- Patient-centred care (focusing on the host) must be an integrated part of all cancer guidelines and all treatment/care plans early in the disease trajectory until end of life care
  - How to do: Societal and political demands at national and international levels initiated by WHO and professional organizations and patient advocacy groups
  - Timeline: Now
- Implementation of routine use of PROMs in all settings of patient care
  - How to do: Develop PROMs for use in electronic patient record systems and assure that the information is used in the decision making processes. Implement incentive driven indicators for the use of PROMs
  - Timeline: Now
- Shared decision-making (SDM) and advanced care planning (ACP) must be integrated as a mandatory part of all standardized care pathways (SCP)
  - How to do: Refine the methods for SDM and ACP internationally and adapt to national needs and norms. Implement incentive driven indicators for the use of SDM and ACP
  - Timeline: 1-2 years
- Involvement and assessment of the family as a part of early integration of cancer palliative care
  - How to do: Develop methods (tools) for involvement and assessment internationally, and adapt nationally and implement indicators to monitor implementation
  - Timeline: Now
- Develop the content and the basic method of SCP for use as a tool for early integration of palliative care into oncology care in hospitals and community care
  - How to do: International research on method development, complementary intervention strategies/plans, training of health care personnel and resource set with continuous funding
  - Timeline: Now
- Mandatory training of oncology and palliative care specialist in patient-centred care including patient-centred communication
  - How to do: Refine (and further develop) methods for training to be supplemented by international and national accreditations
  - Timeline: 1-2 years

## Models of Palliative Care Integration

### Questions to be addressed

What current models exist to describe how palliative care can be successfully and comprehensively integrated into oncology care?

Which model is best placed to reach patients across all areas of the cancer care trajectory (community, outpatient and inpatient settings)?

What is the role of the primary care/community team in the delivery of palliative care for patients with advanced cancer (Primary Palliative Care)?

What is the role of the oncology team in the delivery of palliative care (Secondary Palliative Care)?

How can we best utilize the skillset of specialist palliative care teams for patients with advanced cancer (Tertiary Palliative Care)?

How can we optimize communication and standardise transitions between Primary, Secondary and Tertiary palliative care services?

## Introduction

The overall aim of integration of health care services is to coordinate care among providers and across settings, so that patients and their families have access to the care that they need when they need it, resulting in improved health outcomes.<sup>43</sup> Thus a key question is: how should integration or collaboration occur between the two disciplines, oncology and palliative care? Internationally, a series of different organizational models have been developed, some of which have been tested in clinical studies. Although the content, structure (internally as well as externally) and professional competence within these models varies considerably, there are also important common themes. The aim of this panel is to present and discuss models of care and propose future organizational models.

Over the last decade, several studies and models of care have addressed how palliative care can be moved from a focus exclusively on end-of-life, to a focus on early integration within the cancer care trajectory. As previously highlighted early integration of palliative care has been shown to improve quality of life, satisfaction with care, symptom control, mood, and illness understanding.<sup>3,5,49-53</sup> As a result, early palliative care is now widely endorsed by a number of influential international organisations as the standard practice of care for patients with advanced, incurable illness.<sup>16,88,442</sup> The question is no longer whether and why integration of palliative care is worthwhile, but how this can best be accomplished to optimize the goal of better patient-centred care.

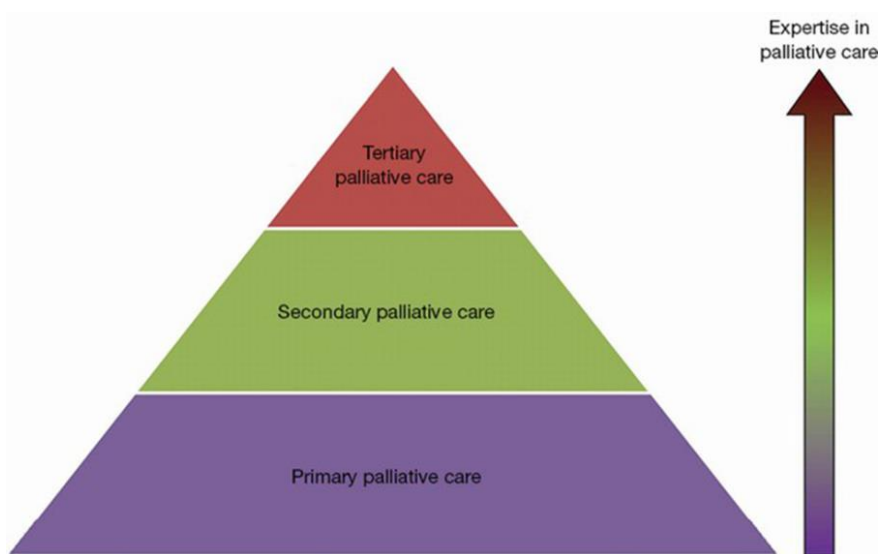
Although integration is important for all aspects of health care, it is of particular importance for patients with advanced cancer, who have complex problems that are best managed by MDT.<sup>443</sup> Within the hospital setting, MDTs can span a variety of providers including physicians (such as surgeons, pathologists, radiologists, medical and radiation oncologists and palliative care physicians) as well as other healthcare providers (including pharmacists, social workers, occupational and physical therapists, spiritual care providers, music and art therapists). In addition, over the last few decades, cancer care is increasingly delivered in outpatient rather than inpatient settings.<sup>444</sup> For this reason, it is increasingly recognized that primary care, including GPs and community nurses, has an important role to play in cancer control, and that communication between MDT providers across all settings and disciplines is necessary to improve patient care.<sup>445</sup> The MDT approach should ideally link oncology and palliative care services in the hospitals and also involve and communicate with primary health care providers as needed. Consideration of how to optimally plan and collaborate between oncology and palliative care services should form an essential component of patient-centred care.

## Models of integration – the broad picture

Existing models of palliative care integration into oncology care can be broadly classified as conceptual or empirical. Conceptual models outline broad theoretical principles, while empirical models depict how these can be put into action in specific settings.

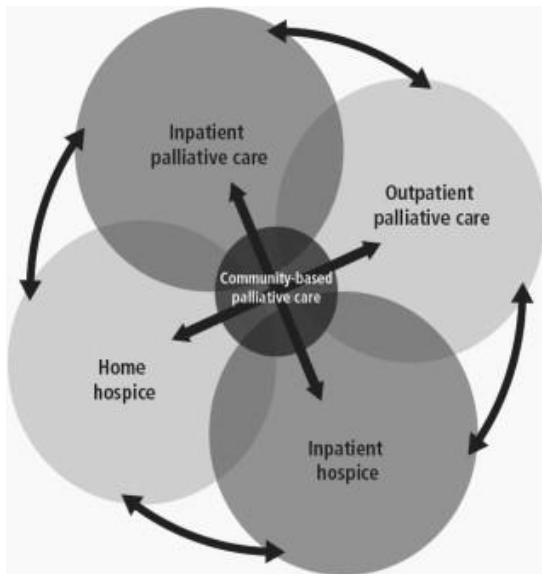
The conceptual models can be classified broadly into time-based, provider-based, and setting-based models.<sup>151,446</sup> The most well-known conceptual model of palliative care integration is **time-based**. This model contrasts the traditional provision of palliative care only at the end of life with a contemporary model where palliative care is introduced at diagnosis, and gradually increases over time until the time of death and bereavement (Figure 1a and 1b)). Non-integrated care, where care is “handed over” to palliative care teams when the patient’s disease no longer responds to tumour-

directed treatment, is counterpoised with integrated care, where palliative care teams provide advice throughout the course of the illness. Other conceptual models are **provider-based**. These classify palliative care conceptually as primary/secondary,<sup>447</sup> or primary/secondary/tertiary,<sup>448</sup> based on level of complexity, and propose the involvement of different care providers at each level (Figure 3). While tertiary palliative care is consistently depicted as being provided by specialized palliative care physicians, there are variations in the classification of primary and secondary palliative care. Primary palliative care is provided by family physicians in some models<sup>449</sup> and oncologists in others<sup>447</sup>. Similarly, some models specify that SPC is provided by oncologists<sup>450</sup> and others classifying SPC as care provided by palliative care specialists in non-tertiary settings.<sup>449</sup> These models emphasize differential competence of providers in palliative care, with increasing levels of competence required to deal with more complex issues.



**Figure 3: Conceptual model of palliative care delivery based on provider expertise**

The third conceptual model of palliative care integration is **setting-based**, where delivery of care is based upon the setting where care is provided. The main setting for care in these models is ideally proposed to be in the community, with palliative care being provided primarily in the patient's home, rather than in the hospital (Figure 4).<sup>446</sup> This community-based care may be provided either by the patient's family physician, with support from a palliative care team,<sup>446</sup> or by a specialist, community-based palliative care team.<sup>451</sup> There is an emphasis on facilitating smooth transitions in care between inpatient, outpatient, home and community hospice settings.



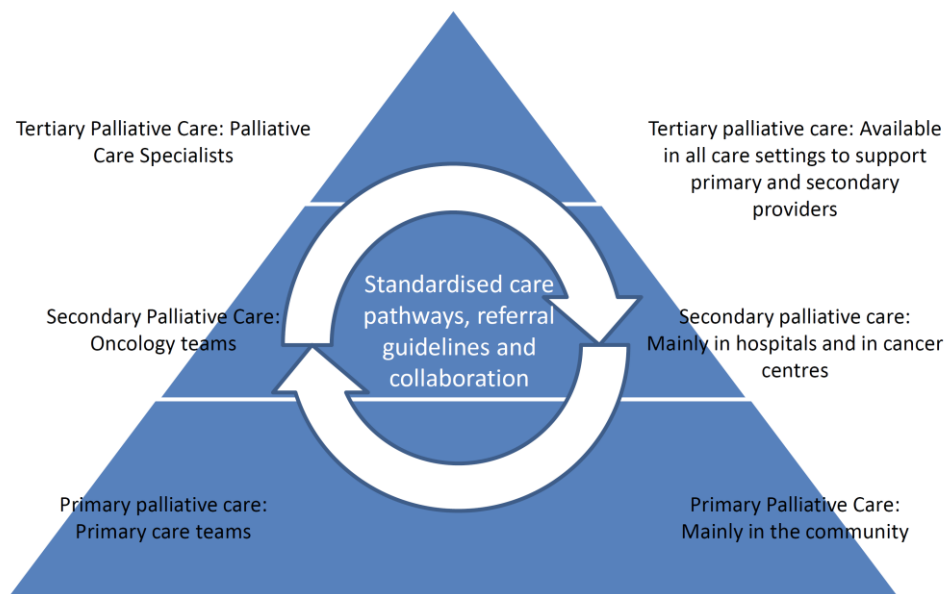
**Figure 4: Conceptual model of community-based palliative care provision. Kamal AH, et al. <sup>446</sup>**

These conceptual models identify important factors related to organization, professional competence and timing as a part of the care pathway, which should be considered when describing and defining integrated oncology and palliative care across all settings. However, none of the existing models specifically describe the detailed mechanics of how patients move among primary and specialized levels of care or among care settings and how communication occurs among providers. Furthermore, none of these models outlines how care is provided within the organizational structures of the oncology health care system. Full integration requires defined processes such as clinical care pathways, referral guidelines or pooled resources, to provide truly integrated care.<sup>43</sup>

The remainder of this section will focus in greater detail on a provider-based conceptual model of primary (PPC), secondary (SPC) and tertiary palliative care (TPC) provision, delivered by generalists, oncology teams, and specialized palliative care teams, respectively (Figure 5).

This model crosses settings and is not time-specific, but emphasises the need for oncology and palliative care to be fully integrated across all settings and levels. Through the use of standardized care pathways and referral guidelines, it is more likely that patients can access the right care is provided at the right place at the right time. It is grounded in the concept that the majority of palliative care can, when the treatment goals are cure or life prolongation, be provided by oncologists with basic competence in palliative care. Palliative care specialists should provide consultation for complex problems.<sup>8</sup> Within this larger model, we review some examples of empirical models of palliative care within each level of care.





**Figure 5: Proposed model of optimal oncology palliative care provision based on integration across providers and settings**

Primary Palliative Care: community-based care provided by GPs

Secondary Palliative Care: more complex care provided by oncologists

Tertiary Palliative Care: complex care provided by multidisciplinary specialist palliative care teams

## Primary, secondary and tertiary palliative care integration

### Primary palliative care

Primary palliative care (PPC) has been defined as the core skills and competencies that all clinicians should feel comfortable providing to patients with advanced cancer and their families. These include basic assessment and management of physical, psychological, social, spiritual and practical problems; communication related to prognosis and advance care planning; appropriate referral to available community-based supports; and bereavement care for the family.<sup>8</sup> While primary palliative care can occur at any clinical setting, it is best provided in the community, both in outpatient settings for those patients well enough to attend appointments, and in the home setting. Home-based care is particularly important in this context, as it prevents unnecessary visits to the emergency department and hospital admissions, and enables a home death.<sup>452</sup>

PPC is best provided by multidisciplinary teams that may include general practitioners, home care nurses, personal support workers, and case managers.<sup>453</sup> Whilst PPC in some countries is delivered by palliative care or hospice specialists, family physicians and general practitioners are well-placed to provide PPC. Their therapeutic relationship with their patients and families may span many years, giving them a unique perspective into their patients' values and priorities, potentially including preferences for end-of-life care and advance care planning.<sup>454</sup> Since a large proportion of cancer patients have uncontrolled symptoms from the time of diagnosis,<sup>455</sup> it is imperative that family

physicians are sufficiently competent to embark on an initial symptom management plan. As cancer progresses, patients often express a preference to receive care at home and to die at home, if possible,<sup>456</sup> which may be facilitated by PPC providers.<sup>457</sup> In addition, these physicians support families during bereavement, offering excellent continuity of care that is highly valued by patients and their families.<sup>458</sup> There is wide variability internationally in the engagement of family physicians and general practitioners in palliative care from less than 50% in some countries such as Canada and Japan,<sup>459,460</sup> to up to 85% in the United Kingdom, the Netherlands and Australia.<sup>461-463</sup>

The literature around the integration of PPC into oncology is limited. As cancer care becomes more specialised, many family physicians lose contact with their patients for the duration of their cancer treatment; this is often compounded by poor communication between cancer specialists and family physicians, making it challenging for family physicians to re-engage with patients at the end-of-life, or to recognise when patients are entering the final stages of their illness.<sup>445,464,465</sup> Other barriers to the provision of PPC include time constraints,<sup>174,466,467</sup> insufficient reimbursement,<sup>467</sup> and limited palliative care training or expertise.<sup>63,468</sup> Out-of-hours support for community-based patients can be particularly challenging.<sup>469</sup> Home-based palliative care is often seen as labour-intensive, poorly remunerated and difficult to coordinate, especially outside of regular office hours, or when family physician offices are far from their patients' homes.<sup>445,454,461</sup>

Multiple initiatives have enabled the provision of PPC, both among family physicians and in collaboration with SPC and TPC providers. In some European countries (such as Ireland, the Netherlands, UK and Denmark), out-of-hours cooperatives have been set up to lessen the burden on individual family physicians to provide round-the-clock care for their patients;<sup>469,470</sup> these are generally well-received by patients and practitioners alike.<sup>471</sup> Educational initiatives around the core skills of PPC at the medical student and postgraduate learner level are vital, as are Continuing Medical Education programs, as discussed in Education panel. The development of collaborative partnerships between primary and tertiary palliative care providers is recognised as a vital component of promoting and supporting PPC, as further discussed below.<sup>454</sup>

In the Netherlands, the general practitioner (GP) and home care nurse are the main providers for community-dwelling patients with cancer and palliative care needs. Nurse case managers have recently been introduced in some areas. To ensure continuity of care, the case manager collaborates with the patient, their informal carers, and the medical professionals involved in the care of the patient (GP, oncologist). The case manager provides advice to patients and their informal carers and refers them to other care providers as necessary. As well, the case manager may offer palliative care advice to other healthcare providers, including the GP and the home care nurse.<sup>472</sup>

### **Secondary palliative care**

Secondary palliative care (SPC) refers to the care provided by the oncology team in the specialist health care system to both inpatients and outpatients. Because oncology teams are based for the most part in hospitals and cancer centres, these are the main settings for secondary palliative care. Cancer care itself is multidisciplinary, and involves medical specialists from medical, radiation and surgical oncology, as well as specialized nurses, social workers, psychologists, psychiatrists, dieticians, physiotherapists and occupational therapists, among others.<sup>473</sup> All of these require core clinical competencies in palliative care, as described below.

Important strides have been made in promoting SPC as a part of oncology care programs. ASCO has formally endorsed early palliative care<sup>16</sup> and has published a number of clinical guidelines for palliative care in oncology.<sup>8,474</sup> Several other international bodies have made efforts to formalise the role of oncologists in providing SPC. Among these, a partnership between ASCO and the American Academy of Hospice and Palliative Medicine (AAHPM) has produced a consensus statement using a Delphi process on high-quality palliative care delivery in US medical oncology practices<sup>475</sup> (Table 8). In this statement, they recommend that oncologists should provide regular systematic symptom assessment at least monthly, as well as conducting a basic assessment of psychosocial wellbeing and of faith group, and assessing caregivers for distress if they accompany patients to the appointment.<sup>475</sup> SPC also includes assessment of prognostic understanding and communication of prognosis to the patient and primary care provider. Patients with complex or uncontrolled symptoms should be referred to TPC services as available.<sup>475</sup>

Palliative Care Domain	Endorsed elements of secondary palliative care in oncology practices
<b>Symptom Assessment/ Management</b>	<ul style="list-style-type: none"> <li>• Monthly symptom assessment using a validated quantitative instrument</li> <li>• Educate patients about the cause and management of existing symptoms</li> <li>• Instruct patients how and when to contact the clinic during and after hours for new or worsening/poorly controlled symptoms</li> <li>• Assess the effectiveness of adjusted medication by the next clinical encounter</li> </ul>
<b>Psychosocial Assessment/ Management</b>	<ul style="list-style-type: none"> <li>• Conduct an initial, basic psychosocial assessment</li> <li>• Assess distress with a validated quantitative instrument initially and after any clinical change (e.g. cancer progression)</li> <li>• Manage distress at a basic level with supportive, empathetic statements and validation of the patient’s experience. Otherwise, patients should be referred</li> </ul>
<b>Spiritual and Cultural Assessment/ Management</b>	<ul style="list-style-type: none"> <li>• Document patient’s faith</li> <li>• Provide patients with a framework to consider their goals and hopes along with the likely medical outcome(s) of their illnesses and support those goals</li> <li>• Assess and document preferences for communication and language</li> <li>• Provide translation services</li> </ul>
<b>Communication and Shared Decision Making</b>	<ul style="list-style-type: none"> <li>• Assess patients and families for preferences regarding (1) how they want to receive information regarding the patient’s cancer, prognosis, treatment risks/benefits, treatment plan, and bad news; and (2) who participates in the decision making and to what extent</li> <li>• Provide oral and written documentation of the treatment plan to the patient and family with specific details regarding expectations for (1) disease control, (2) effects on symptoms and quality of life, (3) length and frequency of treatment, and (4) the frequency of and rationale for disease reassessment.</li> <li>• Assess the patient’s and family’s understanding of the patient’s illness, prognosis, and goals of care at diagnosis, disease progression, and with changes in the treatment plan</li> <li>• Openly acknowledge and address mistakes as soon as they are noticed</li> </ul>
<b>Advance Care Planning</b>	<ul style="list-style-type: none"> <li>• Begin advance care planning at the diagnosis of advanced cancer, starting with assessing the patient’s and family’s readiness to discuss advance care planning and any concerns they might have</li> <li>• Code status, living wills, advanced directives, health care surrogate, and out of hospital “do not resuscitate” orders should be discussed, completed and documented as soon as possible</li> </ul>

<b>Coordination and Continuity of Care</b>	<ul style="list-style-type: none"> <li>• Coordinate care with primary care, hospice, hospital, and nursing home</li> </ul>
<b>Appropriate Palliative Care and Hospice Referral</b>	<ul style="list-style-type: none"> <li>• Describe the difference between hospice and palliative care to patients and families as soon as possible after an advanced cancer diagnosis</li> <li>• Conduct routine patient assessments to determine need for palliative care or hospice referral</li> <li>• Refer patients with a prognosis of 3 months or less and/or an Eastern Cooperative Oncology Group performance status of 3-4 to hospice</li> <li>• Collaboratively agree upon referrals with the patient/family</li> </ul>
<b>Carer Support</b>	<ul style="list-style-type: none"> <li>• Obtain permission to speak with primary caregiver(s) and to include them in conversations about the patient's care</li> <li>• Assess caregivers attending clinic visits with patients for distress at least once</li> <li>• Inform caregivers how to contact the clinic in routine and emergency situations</li> <li>• Provide information about local and online caregiver resources</li> <li>• Provide bereavement follow-up in the form of a phone call and/or condolence card and information regarding local bereavement resources</li> </ul>
<b>End-of-Life Care</b>	<ul style="list-style-type: none"> <li>• Have processes to evaluate patient symptoms, advise medication changes to patients and family, and provide on-call coverage 24 hours per day, 7 days per week</li> </ul>

**Table 8. Essential elements of secondary palliative care. Adapted from Bickel et al <sup>475</sup>**

Despite these guidelines, oncologists continue to vary in their perceptions of their role in providing SPC. Some provide no palliative care and refer all patients to tertiary services; others see themselves as solo providers of simultaneous oncology and palliative care, and do not refer to TPC; still others refer to tertiary services only in complex clinical situations.<sup>174</sup> At the SPC level, patients may associate cancer treatment directly with hope, and a singular interest in pursuing active anticancer treatments can impact on the delivery of appropriate palliative care.<sup>179</sup> An additional complicating factor may be that some patients prefer to receive more positive messages from their oncologist regarding their cancer, linking this with a greater compassion on the part of the physician.<sup>476</sup>

In an effort to improve integration and promote both secondary and tertiary palliative care provision, ESMO has developed designated centres of integrated oncology and palliative care based on 13 rigorous criteria across clinical, research and educational domains.<sup>88</sup> A recent survey of all active ESMO designated centres identified high levels of routine symptom screening and goals of care discussions among oncologists, although less attention was paid to advance care planning and end-of-life discussions, which were more likely to be addressed by the palliative care services.<sup>159</sup>

### **Tertiary palliative care**

Tertiary palliative care (TPC) is provided by physicians and other multidisciplinary team members with specialist palliative care training. These teams may include specialized palliative care physicians, nurses, social workers, spiritual care providers, occupational and physical therapists, and pharmacists, among others. Clinical guidelines recommend that inpatients and outpatients with advanced cancer and/or high symptom burden should receive dedicated palliative care services early in the disease course concurrent with cancer treatment.<sup>16</sup> However, with shortages of TPC specialists worldwide, it is more practicable to limit the provision of TPC to the subset of patients whose care needs are the most complex and are not adequately met by primary or secondary level providers. It

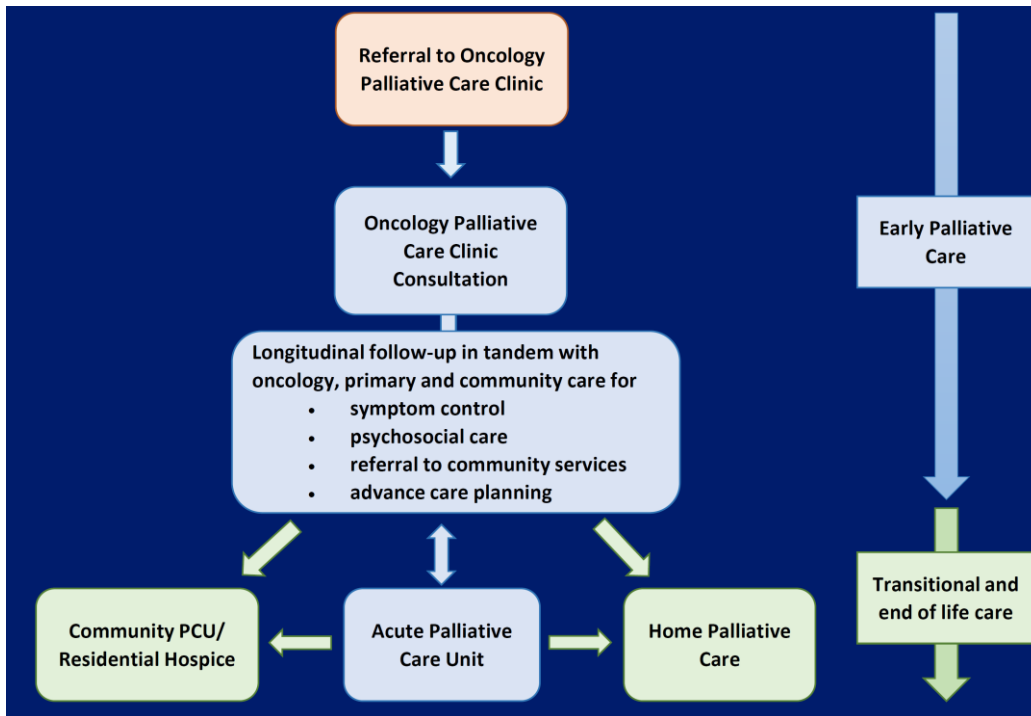
is therefore important to have mechanisms of determining which patients would benefit most from consultation by TPC services.<sup>477</sup>

TPC should be available to all patients with cancer, regardless of prognosis, and available to PPC and SPC providers on a consultant basis in all settings, including for inpatients, outpatients, and in the community. Where resources are limited, palliative care services provide care mainly as consultation services for inpatients.<sup>122</sup> Acute palliative care units for the specialized management of complex symptoms and psychosocial concerns are limited to a minority of tertiary care hospitals and hospices.<sup>443</sup> In the community, longer term palliative care units, hospices and palliative care home consultation services provide valuable support to patients at the end of life. More recently, it has been recognized that full integration, especially for patients at earlier stages of their illness, is only possible through an outpatient palliative care program.<sup>174,444,478</sup> Development or expansion of TPC services should consider the unique needs, philosophy and culture of the broader institution, with input sought from key stakeholders across clinical and managerial levels.<sup>479</sup>

### **How to integrate tertiary palliative care?**

Availability of TPC for outpatients is of paramount importance for integration into standard oncology care, as most of oncology care, including for patients with advanced disease, occurs on an outpatient basis. Several models of outpatient TPC care have been proposed, including mobile teams, freestanding palliative care clinics, and embedded clinics.<sup>480,481</sup> A mobile team, where outpatient palliative care consultations in oncology clinics are performed by the inpatient consultation service on a same-day bases, is feasible if there are few consultations. However, outpatient palliative care clinics are more efficient on a larger scale, and allow patients to be seen by a number of multidisciplinary team members working together in the clinic.<sup>478,482,483</sup> The most robust evidence for early palliative care is for palliative care clinic interventions, and has shown that these clinics improve quality of life, symptom control and mood.<sup>3,5,64</sup> Embedded clinics offer opportunities for oncologists and palliative care clinicians to collaborate and coordinate care, and allow rapid access to palliative care teams. However, there are also challenges with this model, including finding adequate clinic space, fatigue on the part of patients with longer clinic visits, and involvement of only one discipline – usually a single physician or nurse.<sup>151</sup>

Several models of integrated TPC programs have been described. In 1995, the palliative care program in Edmonton, Canada, was one of the first to report their practice, which consisted of an inpatient palliative care unit housed within an acute hospital setting, as well as a consultation service and an outpatient clinic. From the outset, a strong emphasis was placed on the use of standardised assessment tools, wide-ranging education and research initiatives, and close integration with family physicians to enhance PPC provision.<sup>484,485</sup> These elements of care were similarly emphasized in subsequent reports of successful TPC programs in Lausanne,<sup>486</sup> Milan,<sup>487</sup> Cleveland,<sup>488</sup> Houston,<sup>489</sup> Trondheim,<sup>49</sup> and Toronto,<sup>490</sup> with the latter two also publishing successful randomized controlled trials illustrating the effectiveness of this model of care.<sup>5,49</sup> The model of palliative care at Princess Margaret Cancer Centre serves as one empirical example and is described in Figure 6.



**Figure 6: Tertiary palliative care based on referral to a palliative care clinic**

Hannon B et al.<sup>478</sup> Referrals are made by the patient’s oncologist. Care is integrated and collaborative across acute and community care settings. Ultimately, care is transferred to home, hospice or a palliative care unit.

### **Barriers to integration of tertiary palliative care**

Several areas are identified consistently within the literature as barriers to fully integrated oncology and palliative care services, across system, organisational, and clinical levels. Lack of institutional recognition of the value of TPC services has limited the development of new services. Palliative care services are infrequently afforded the same priority as other areas of cancer detection and treatment at executive or managerial levels. A new initiative from the Union for International Cancer Control aims to address this issue, identifying palliative and supportive care as one of the four essential pillars of cancer treatment and care (along with cancer data for public health, early detection and diagnosis, and timely and accurate treatment).<sup>491</sup> ESMO designated centres also strive to boost the status of integrating high quality palliative care services within oncology.<sup>492</sup>

Closely connected to this is the problem of adequate funding to support integration. Although oncology leadership tends to agree that integration is beneficial, funding to support program expansion often lags behind. A survey of members of the Multinational Association of Supportive Care in Cancer, the European Association of Palliative Care, and ESMO found that only 17% of respondents felt their institution was likely to increase palliative care funding; 49% felt it was unlikely their institution would increase inpatient palliative care beds; and respondents were neutral regarding future palliative care team hiring plans.<sup>443</sup> Despite several studies demonstrating the cost-effectiveness of palliative care teams,<sup>158</sup> this does not seem to factor into budgetary considerations at the oncology level.

Lack of trained medical and nursing personnel and poor reimbursement for palliative care physicians have also been cited as barriers to the access and development of TPC, even within cancer centres and ESMO designated centres of integrated oncology and palliative care.<sup>443</sup> At the individual oncologist level, there remains significant heterogeneity in referral practices to TPC teams due to factors ranging from personal opinions to structural issues. For example, for some oncologists practicing secondary palliative care, especially in community practice, the additional reimbursement afforded by this may limit their willingness to fully integrate with palliative care teams or refer to TPC services.<sup>443</sup> In an effort to standardise referral practices, the use of specific criteria to trigger automatic referral to palliative care teams alongside concurrent oncology care have recently been proposed; the success of these criteria has yet to be explored.<sup>151,493</sup>

Ongoing stigma and misconceptions about the term palliative care are frequently quoted as barriers to integrated services.<sup>494</sup> Because of its historical association with end-of-life care and medical futility, the name itself is often cited by oncologists and patients as an obstacle to early referral<sup>167</sup> (see Societal Challenges). In one centre, the outpatient palliative care service has been renamed “supportive care”, which has been associated with earlier referrals.<sup>495</sup>

## Human resources & clinical competencies

In order to deliver high-quality, integrated palliative care, an inter-disciplinary approach is required. The competence of PC needs to be placed into context in the cancer plans, such as participating as active and integrated partners of the MDTs. As mentioned previously, this includes not only physicians and nurses but also social workers, spiritual care providers, physiotherapists, occupational therapists, psychologists, psychiatrists, and pharmacists, amongst others. Inclusion of these can be provided by the PC specialist physician based upon the needs addressed in the MDTs. Access to and close links with community-based nursing and allied healthcare providers is also essential to ensure seamless transitions between care settings.

In terms of clinical competencies, PPC providers should have core skills in assessing and managing physical and psychological symptoms, as well as knowledge to use SDM in daily clinical practice which also includes ACP for patients with short life expectancy and planning, coordinating and providing end-of-life care in patients’ homes when feasible.

Core teaching on pain and symptom management as well as end-of-life care has been recommended for medical students in the UK and the US;<sup>496,497</sup> initiatives such as the Canadian LEAP program (Learning Essential Approaches to Palliative and End-of-Life Care)<sup>498</sup> provide multidisciplinary PPC training for all healthcare providers (see Education).

For SPC, wide variations exist in terms of the training and competencies of individual oncologists, often based on the clinical setting within which they work. Many physicians working within designated centres of integrated oncology and palliative care are dual-certified in both oncology and palliative care (65% in a recent study).<sup>159</sup> These centres were also more likely to have access to a broad range of multidisciplinary clinicians.<sup>159</sup> Mandatory rotations in palliative care and modules in symptom management, communication skills and up-dated skills in SDM and ACP have been recommended to improve SPC competencies. At minimum, competencies should include basic assessment of pain and other symptoms; assessment of psychosocial, spiritual and cultural needs for

the patient and family; appropriate goal-based communication; skills in using SDM/ACP; and coordination of end of life care (See Education).

TPC services should be led by clinicians with specialist palliative care training and certification where available. As of today most countries with such a certification have organized it as a dual certification. For cancer centres that mean specialist certification in both oncology and palliative medicine (see Education). As consultants, these clinicians should have appropriate training in the management of complex symptoms and problems throughout the disease course and bereavement. Palliative Care is now recognised as a medical specialty or subspecialty across 18 European countries as well as the USA, Canada and Australia <sup>499</sup> (Also see Education.)

## Care Transitions and Collaboration: moving among levels of care

A number of common facilitators to successful integration across primary, secondary and tertiary palliative care have emerged. These include structures and tools for transitions between levels of care as well as for collaboration among disciplines. Although there may be some overlap of roles, clarity and clear division of each team's respective responsibilities is necessary to ensure a consistent message for patients.<sup>174,500,501</sup>

Referral guidelines or other types of predefined structures such as PC incorporated in detail in the SCP can clarify which patients and when they are likely to benefit from referral to TPC services. In a recent study using a Delphi process, international palliative care experts reached consensus on 11 major criteria for outpatient palliative care referral in cancer centres, based on stage of disease, prognosis, and clinical problems. These criteria can also be used as guides when detailed SCPs are developed in oncology. These criteria were categorized into needs-based and time-based criteria (Table 9).<sup>477</sup> As well, consensus was reached that referral should be based on both automatic referral and clinician-based referral, with only 7% agreeing that referral should be based on automatic referral alone.<sup>502</sup>

### **Needs-based criteria**

- Severe physical symptoms (e.g., pain, dyspnoea or nausea scored 7–10 on a ten-point scale)
- Severe emotional symptoms (e.g., depression or anxiety scored 7–10 on a ten-point scale)
- Request for hastened death
- Spiritual or existential crisis
- Assistance with decision making or care planning
- Patient request
- Delirium
- Brain or leptomeningeal metastases
- Spinal cord or cauda equina compression

### **Time-based Criteria**

- Within 3 months of diagnosis of advanced or incurable cancer for patients with median survival of 1 year or less
- Diagnosis of advanced cancer with progressive disease despite second-line



**Table 9. Needs based and time-based criteria for referral to tertiary palliative care. Adapted from Hui et al.<sup>477</sup>**

SCPs have been suggested as a potential means of recognising transition points in care, and of ensuring high-quality care regardless of the clinical setting. For example in Canada, Cancer Care Ontario has developed collaborative care plans based on Palliative Performance Status (PPS) for “stable” (PPS 70-100), “transitional” (PPS 40-60) and “end-of-life” (PPS 0-30) stages. Lessons learned from the use of SCPs in end-of-life settings indicate that these pathways should be detailed while also flexible in addressing individual needs; should not be a substitute for empathic care of the patient; and need to be coupled with ACP, comprehensive education and training in palliative care.<sup>503,504</sup> Further research is needed to assess their effectiveness in earlier stages of disease.<sup>190,505</sup>

The development of strong, collaborative relationships among primary, secondary and tertiary providers are essential for truly integrated care. Among PPC and TPC providers, these may include mentorship and advisory programs facilitating ready access to TPC teams, including out-of-hours support; inviting PPC providers to engage in discharge planning discussions or family meetings for shared patients prior to home discharge; and maintaining excellent communication between community- and hospital-based teams through shared electronic records. These partnerships may help to improve family physicians’ confidence in providing PPC and in recognising transitions in care.<sup>454</sup>

Collaboration between SPC and TPC providers in cancer centres should be a part of the MDTs and/or be encouraged by joint rounds and tumour boards, as well as by combined palliative care and oncology educational activities for trainees.<sup>48</sup> Sharing support staff (such as allied health professionals or nursing staff) can act as a bridge between services.<sup>174,501</sup> Joint patient consultations, proximity of palliative care clinics to oncology clinics (or palliative care clinics embedded into oncology clinics), and the involvement of palliative care teams in tumour boards or cancer committee meetings may be superior to communication via email or phone.<sup>174,500</sup> In addition to the clinical advantages offered by such collaborative models, there are also potential financial advantages associated with pooling resources, especially in the early stages of palliative care program development.

Collaboration can also be facilitated by technology and clinical tools. Symptom screening has been established as a standard of care in all cancer centres in Ontario, Canada,<sup>506</sup> is proven to be effective in routine oncology practice<sup>76,507</sup> as well as in pilot projects in primary care practices.<sup>508</sup> This can serve to encourage systematic assessment and management of symptoms by oncologists, and trigger timely referral to TPC programs. Joint electronic patient records or mutual access to patient records, among all levels of care providers can improve information transfer among care providers in the hospital and in the community.<sup>509</sup> Telehealth is also being explored as an intervention to improve communication in palliative care, particularly for those living in rural regions.<sup>510</sup>

## Conclusion

We have presented conceptual models of palliative care integration as well as principles, competencies and resources necessary to achieve integration in various settings. There is no single model of palliative care integration that is tested in clinical studies or used in any health care system.

This heterogeneity can indicate that palliative care integrated in oncology is in its infancy. It is an urgent need to, based upon the high quality studies to agree upon models that fit the different health care systems in high and middle income countries . The overall goals are that these novel organizational models will meet the needs of all patients in all settings and circumstances. However, a successful model of integration needs to incorporate primary, secondary and tertiary providers, span settings (inpatient, outpatient, community), and specify how movement between these levels occurs in a systematic fashion. Although there is now sound evidence for early TPC involvement for patients with advanced cancer, evidence is lacking for models of PPC and SPC provision, as well as for care pathways bridging levels of palliative care. Research in these areas should be prioritised.

**Recommendations**

- Establish integrated specialized palliative care/oncology services at cancer centers according to figure 5
  - How to do: Develop integrated models, train personnel, make palliative care mandatory at the MDT, and give economic incentives
  - Timeline: 1-2 years
- Establish multidisciplinary community teams for early integration
  - How to do: Develop models for community teams and evaluate the models in research projects
  - Timeline: 2-5 years
- Community and hospital based services must be integrated.
  - How to do: Establish formal contracts on integration and payment plans (resource setting)
  - Timeline: 1-2 years
- Basic early palliative care must be embedded into the oncology programs
  - How to do: Palliative Care must be a mandatory part of oncology training. Revise national content of oncology training programs and give international recommendations
  - Timeline: Now

**The role of education: challenges and recommendations**

**Questions to be addressed**

- What are the main international educational strategies that can promote integration of oncology and palliative care?
- What should the curricula include to promote integration of oncology and palliative care?
- What are the educational barriers and facilitators for integration of oncology and palliative care?
- How can educational activities be further developed to promote the integration of oncology and palliative care?

## Introduction

Several of the previous panels have pointed to education of health care providers as a key factor for promoting integration of oncology and palliative care both on the clinical and the organizational levels. This is in line with recommendations from authors, stakeholders and bodies.<sup>45,511,512</sup> There is at present an unmet need for basic and specialist competence in palliative care at all levels of health care; tertiary, secondary and primary, which calls for increased educational efforts.

Integration of oncology and palliative care requires close collaboration and exchange of information between primary, secondary, and tertiary palliative care providers (see Models). The tertiary palliative care (TPC) specialists are often located in comprehensive cancer centres and/or university hospitals, and are commonly also engaged in academic activities as research and education. The skillset of TPC specialists is essential to support primary and secondary providers. These premises expand the responsibilities of TPC beyond the cancer centre setting through education and mentorship programs aiming to upskill primary and secondary health care providers.

The heterogeneity of the organizational models described in Models does not allow for drawing conclusions on what kind of competence and skills that best promote integration. Further, we were not able to identify reports, policy statements or articles at an international level specifically addressing how education programs can promote integration of oncology and palliative care or what they should include except for general statements about palliative care.

In this panel we therefore describe available international educational strategies and recommendations in palliative care, contents of oncology and palliative care curricula, educational barriers and facilitators. We also discuss how education can promote integrational models. Medical education from undergraduate to post-graduate levels is the primary focus being aware of the fact that palliative care shall be delivered by multidisciplinary teams including health care providers with qualifications in other disciplines than medicine. Still, expanding the panel to education for all the other important health care providers in the multidisciplinary team would definitely exceed the limits for this panel. With a focus on medical education, principles and content is also considered of value for education of other health care providers as well.

This panel is based upon available information regarding palliative care education (specialization and post-graduation programs) such as the EAPC Atlas of Palliative Care in Europe,<sup>499</sup> EAPC Atlas of Palliative Care in Latin America<sup>513</sup> and the website Global Directory of Education in Palliative Care of The International Association for Hospice and Palliative Care.<sup>514</sup> Further information was gathered from medical societies' papers, websites supplemented by a systematic review of literature using the MESH terms *palliative or palliation, oncology or cancer, education and the words integrative or integrative* in the title/abstract. The search yielded 23 articles considered of relevance for this panel. Of those, 12 were informative articles (consensus/panels/indicators/recommendations/discussion/debate/state-of-art) regarding integration of palliative care and oncology), four were descriptions/evaluations of multidisciplinary curriculum/specialist education, four presented professional perspectives/opinions, two surveys focused on guidelines and service management, and one was a systematic review about early integration.

## Educational strategies

International agencies and professional associations have developed and promoted policies and projects including educational strategies and recommendations to improve palliative cancer care. WHO has recognized that national actions are necessary to strengthen palliative care education and that it includes “ensuring that education about palliative care (including ethical aspects) is offered to students in undergraduate medical and nursing schools and health care providers at all levels, in accordance with their roles and responsibilities and as part of human resource development.”<sup>2</sup>

The European Association for Palliative Care (EAPC)<sup>96</sup> has launched a recommendation of three levels of palliative care education that can serve as a basis for integration,<sup>515,516</sup> (see Table 10).

- PC\* approach at a basic level (level A; undergraduate and postgraduate)
  - integrate PC methods and procedures in general care, for all health care professionals
- General palliative care at an advanced level (level B; postgraduate)
  - for professionals involved with PC, but not as their main occupation; e.g. oncologists
- Specialist PC (level C; postgraduate)
  - for professionals working solely in PC whose main activity is complex problems requiring specialized skills and competencies

**Table 10. Three levels of palliative care education\*PC=palliative care**

Another example of an integrative approach is originating from the European Society for Medical Oncology (ESMO), which has developed designated centres of integrated oncology and palliative care based on rigorous criteria across clinical, research and educational domains promoting both secondary and tertiary palliative care provision. To date, close to 200 centres from 41 countries have achieved this designation.<sup>517</sup>

## Accreditation of palliative medicine

In general, certification in palliative medicine falls into three categories, depending on the post-graduate educational system of the different countries: specialty, subspecialty and general competence in the field. All three categories require a basic medical degree; however, subspecialty in palliative medicine also requires a clinical specialty degree in another medical area. Certificate of competence refers to formal educational courses in the field of palliative medicine approved by national health authorities and medical societies, but not necessarily a recognized new specialty in some countries.<sup>499</sup> The supplement of the EAPC Atlas of Palliative Care in Europe collected information on education and certification in palliative care from 18 European countries, Australia, Canada and the United States.<sup>499</sup> As expected, variations were demonstrated in type of certificates, demand for clinical practice, theoretical content and length and whether research was a mandatory component (Table 11).

The integration of palliative care into oncology may be highly dependent on the level of accreditation. Thus, the different models of integration generally originate from countries with some kind of accreditation of palliative medicine and availability of TPC. Palliative medicine achieved specialty/subspecialty status in the UK in 1987, USA in 2006, and Canada in 2016.<sup>518,519</sup> Palliative medicine has also been established as a specialty in multiple countries in the Asia-Pacific region, including Australia, New Zealand, China, Japan, Taiwan, Malaysia, Singapore and India.<sup>520</sup> Other

countries in Europe, Asia, Latin America and Africa are actively working toward some kind of accreditation. In some countries, such as the UK, Ireland, New Zealand and Australia, palliative care is a full medical specialty requiring a minimum of three to four years of postgraduate training to achieve certification. In other countries; e.g. Canada, the United States, France and Germany, palliative care is organized as a medical subspecialty.<sup>521,522</sup> Other educational programs are directed towards medical specialists associated with some kind of accreditation, which include the Japanese Palliative Care Emphasis Program on Symptom Management and Assessment for Continuous Medical Education (PEACE)<sup>523,524</sup> and The Nordic Specialist Course in Palliative Medicine.<sup>525</sup> The latter is a joint venture between the Associations for Palliative Medicine in the Nordic countries (Denmark, Sweden, Norway, Finland and Iceland) and has resulted in a theoretical specialist training course in six modules over two years combined with a clinical stay at a specialized palliative care unit. However, in Finland palliative medicine has recently become a speciality and in Sweden a subspecialty. Denmark and Norway may also be moving towards higher levels of accreditation.<sup>499</sup>

The heterogeneity in specialty status with a lack of clearly defined competencies for palliative care physicians is probably associated with variability in the content and quality of care delivered and represents a challenge for the advancement of clinical palliative care. Further, as it can be depicted from Table 11 - especially looking at clinical practice and theoretical training - the classification and definitions of a speciality and a sub-speciality differ considerably between countries. A substantial proportion of those attending the programs are oncologists who have been recruited for the subspecialty model for palliative medicine, which may enhance integration.

Country	Accreditation	Denomination in English	Clinical practice in years	Theoretical training	Research
<b>Australia/New Zealand</b>	Specialty	Palliative Medicine (medical specialty)	3	NS	1-3 projects
<b>Canada</b>	Subspecialty	Subspecialty of Palliative Medicine	2	350 hours	1 project
<b>Czech Republic</b>	Subspecialty	Palliative Medicine	1	12 months	NS
<b>Denmark</b>	Special denomination	Competence in the field of Palliative Medicine	2	6 weeks	1 project
<b>Finland</b>	Special denomination	Special Competence in Palliative Medicine	2	150-270h	1 project
<b>France</b>	Special denomination	Diploma of Complementary Specialised Studies in Pain Medicine and Palliative Medicine	2	170 hours	1 project
<b>Georgia</b>	Subspecialty	Palliative Care and Pain Medicine	0-5	75 hours	NS
<b>Germany</b>	Subspecialty	Palliative Medicine	1	40 hours	Not required
<b>Hungary</b>	Subspecialty	Subspecialty in Palliative Medicine	1	80 hours	NS
<b>Ireland</b>	Specialty	Certificate of Completion of Training as Specialist in Palliative Medicine	4	Varying between the different universities	Not required
<b>Israel</b>	Subspecialty	Palliative Medicine Sub-Specialty	2	NS	NS
<b>Italy</b>	Special denomination	Master's Programme in Palliative Care for Specialist Physicians	0-5	1500 hours	1 project
<b>Latvia</b>	Special denomination	Special Competence in Palliative Care	2	400 hours	80 hours
<b>Malta</b>	Specialty	Palliative Medicine	Most of the training acquired	Most of the training acquired abroad	Not required

			abroad		
<b>Norway</b>	Special denomination	The Formal Competence Field of Palliative Medicine	2	180 hours	1 project
<b>Poland</b>	Specialty	Specialisation Program in Palliative Medicine for Physicians	2	NS	1 project
<b>Portugal</b>	Special denomination	Palliative Medicine Competence	1	400 hours	3 project
<b>Romania</b>	Subspecialty	Diploma of Complementary Studies in Palliative Care	0·25	2 months	NS
<b>Slovakia</b>	Special denomination	Specialisation Study in the Field of Palliative Medicine	0·5	NS	NS
<b>Sweden</b>	Subspecialty	Subspecialty in Palliative Medicine	2·5	120 hours	Not required
<b>United Kingdom</b>	Specialty	Certificate of Completion of Training as Specialist in Palliative Medicine	4	Varying between the different universities	Not required
<b>United States</b>	Subspecialty	Hospice and Palliative Medicine Certification	1	Varying between the different universities and states	Varying between the different universities and states

**Table 11. Accreditation of Palliative Medicine Education. Modified from Bolognesi et al 2014<sup>526</sup> and Centeno et al 2015<sup>522</sup> NS: not specified**

## Palliative care and oncology curricula for physicians

Several documents specify a framework for competence for physicians, developed by their respective national medical associations. Our literature review demonstrated that education in palliative medicine is generally recommended to be included in undergraduate and post-graduate curricula, updated by continuing education, lectures, courses, and conferences. The EAPC Steering Group on Medical Education and Training has published prototypes of postgraduate and undergraduate curricula for palliative medicine; in 2009 and 2013, respectively. In addition, rotation of trainees and fellows is common and supposed to promote integration<sup>151,444,474,516</sup> (Table 12). Thus, it is recognized that curricula in palliative medicine may facilitate integration of oncology and palliative care from an early stage in the education.<sup>527</sup> The European Association of Palliative Care (EAPC) recommends that the curricula at medical schools should cover six domains, achieving six overall learning goals.<sup>527</sup> Recommended educational goals include experiential learning, active techniques, multi-professional learning, and experience in PC and must cover more than 40 hours in total. It should be included in the exams and teaching should be performed by palliative care specialists and professional groups other than doctors (nurses, psychologist, chaplains etc.) integrating ethical and, psychological social and existential issues. Additionally, education in palliative care should be removed from oncology and anaesthesiology, and taught as an independent subject.

Educational strategies	Levy et al.; 2014 <sup>474</sup>	Gamondi et al.; 2013 <sup>516</sup>	Hui, Bruera; 2015, 2016 Hui et al.; 2015 <sup>45,151,444</sup>
<b>PC* in undergraduate curricula</b>	X	X	X
<b>Lectures and curricula on PC for oncology professionals</b>	X		X
<b>Oncology rotations for PC fellows</b>	X		X
<b>PC rotations for oncology fellows</b>			X
<b>Conferences on PC for professionals</b>	X		X
<b>Continuation education for practicing oncology professionals</b>	X	X	X
<b>PC skills formal examinations</b>	X		X
<b>Combined PC and oncological educational activities for fellows and trainees</b>			X
<b>Post-graduation in PC</b>		X	X

**Table 12. Suggested educational strategies to improve competences \*PC: palliative care**

The aforementioned survey by Bolognesi<sup>526</sup> demonstrated a wide variety of subjects, present in the post-graduate palliative care specialization programs in Europe. Examples of subjects were pain and symptom management, pharmacology of opioids and other essential drugs, psychosocial issues, ethical issues, communication, team working, organization of delivery of care, end-of-life care, normative and legal issues, oncology, non-malignant diseases, supplemented by community palliative care, culture, language and religion, grief and bereavement plus applied teaching from other disciplines, including radiology, psychiatry and public health. Thus, specialist palliative care curricula should provide sufficient theoretical and practical knowledge and skills to handle oncological emergencies, i.e. clinical detection, emergency management and referral to specialists (e.g. radiotherapy, neurosurgery) for spinal cord compression, pathological fractures, raised intracranial pressure, superior vena cava obstruction, hypercalcemia, etc. Secondly, knowledge about prognostication of different cancer diseases, chemotherapy lines and radiation therapy should be implemented in the curricula. However, there exist no over-all recommendations on the exact



amount of oncological teaching in post-graduate palliative care accreditation programs and the actual amount is probably highly variable in different countries.

The American Society of Clinical Oncology (ASCO) have deliberately included current best evidence of palliative care in oncology curricula, aiming at enhancing oncologists' understanding of the basic principles of palliative care, while acknowledging that complex scenarios and refractory suffering should be referred to palliative medicine specialists.<sup>447</sup> The third edition of the Recommendations for a Global Core Curriculum in Medical Oncology outlined specific competencies for oncologists related to supportive and palliative care, was published in 2004 and updated in 2010 and 2016, and was endorsed by ASCO and ESMO, Box 6.<sup>528</sup> However, there exist no over-all statistics of the amount of palliative care teaching in post-graduate oncological accreditation programs and the actual amount is probably highly variable in different countries.

**Box 6. Main objectives of the Recommendations for a Global Core Curriculum in Medical Oncology.**

- to screen, assess, prevent and manage symptoms of patients with cancer such as pain, fatigue, anorexia, anxiety, depression, breathlessness and nausea
- to communicate effectively with patients and families about illness understanding and coping with it, prognosis, difficult decisions, end-of-life and its preparation including psychosocial and existential dimensions
- to recognize the role of cancer rehabilitation, including physical therapy and nutrition
- to recognize the importance of culturally competent, multidisciplinary care that also includes the families
- to understand how to integrate palliative interventions in routine multidisciplinary cancer care
- to recognize the difference between burnout, compassion fatigue and depression
- to ensure timely referral to specialist palliative care teams

The National Cancer Institute has developed EPEC-O (Education in Palliative and End-of-Life Care for Oncology), a multimedia curriculum that can be used as a self-study tool or presented by seminar or webinar.<sup>529</sup> Further, the North-western University Feinberg School of Medicine offers the EPEC Trainer conferences that are 'train-the-trainer' courses to facilitate wide dissemination of the curriculum via 'Certified EPEC® Trainers'.<sup>530</sup> The Accreditation Council for Graduate Medical Training in the US has also mandated competency in hospice and palliative care for medical and haematological oncology fellowship programs.<sup>467</sup>

In addition, educational curricula have been organized as the Pallium Canada's Learning Essential Approaches to Palliative and End-of-Life Care (LEAP and LEAP Onco)<sup>498</sup> and the Virtual Learning Collaborative (VLC) a web-based education module under development by ASCO and American Academy of Hospice and Palliative Medicine (AAHPM).<sup>531</sup> Moreover, US and European organizations, such as the National Comprehensive Cancer Network (NCCN) and European Society for Medical Oncology (ESMO), have published clinical-practice guidelines on palliative care.<sup>331,474,532,533</sup> These initiatives represent a step towards in the integration processes. Moreover, an international Delphi survey identified four major educational strategies, related to post-graduate oncology programs.

These were a didactic palliative care curriculum for oncology fellows provided by palliative care teams, continuing medical education in palliative care for attending oncologists, combined palliative care and oncological educational activities for fellows and trainees, and routine rotation in palliative care for oncology fellows.<sup>151</sup>

#### Box 7. Existing curricula - Key Messages

Large variations between countries

Little systematic content in most countries

Few standardized programs

Are present recommendations too broad?

The heterogeneity in education programs, i.e. the competence defined as needed in palliative care, probably mirrors the heterogeneity in organization and as well as what is delivered in clinical palliative care across countries and maybe even within countries. The present recommendations have similarities, but perhaps more striking are the variations which create a broad scope.

### Educational barriers and facilitators for integration of palliative care and oncology

Lack of education and training and the common perception of palliative care as being end-of-life care only, have been identified in different settings.<sup>151,511,512,534,535</sup> Further, a recent review stated that education (in addition to policy and implementation) represents a key barrier to palliative care integration in the US.<sup>534</sup> The education barrier is both of quantitative and qualitative nature. The quantitative aspect includes the insufficient numbers of health care workers with adequate training and education for providing palliative care at their level in the health care system. The latter is not confined to the US settings only. The qualitative aspect includes the large variations in content across countries both regarding undergraduate and postgraduate education and training.

These workforce-related issues represent significant barriers, as palliative medicine is the fastest growing medical specialty/subspecialty world-wide.<sup>536</sup> It is important to acknowledge that this is not only related to low staffing levels, but also to the level of competences and practical skills, inadequate training in communication, lack of knowledge about the quality of the health care delivered by other professions or specialists, and resistance to refer patients to specialized palliative care or hospices.<sup>450,537,538</sup> Therefore, expansion and support of educational programs for newly educated as well as midcareer physicians are crucial in order to meet the workforce shortage in palliative medicine.<sup>534</sup>

Proposals exist on how to develop and enlarge the contents of curricula for oncologists and for palliative care specialists at different levels of specialist education. However, budget constraints and absence of administrative support can hamper the development of educational and training programs intended to enhance integration. Despite the fact that Europe is considered the pioneer region of palliative care, a descriptive EAPC study of undergraduate medical education in Europe (43 countries) identified low investments in education.<sup>539</sup> In only 30% of the countries palliative medicine was taught in medical schools, being a compulsory course in six (14%), with 40% of the countries

having a full professorship in palliative medicine.<sup>540</sup> The study did not explore the reasons for these low numbers. Knowledge of oncology and palliative care congruent with the level of care that is given, constitute the underlying premise for integration of palliative care and oncology. Thus, this must be compulsory in all curricula from under- to postgraduate and specialist education programs.

In a recent study exploring attitudes and beliefs among oncology trainees regarding palliative care, 67% believed that a mandatory palliative care rotation was important; those who had completed palliative care rotations were more aware of the role of palliative care services than those who had not done so (96% versus 74%).<sup>541</sup> Further, a survey of Canadian oncologists found that oncologists were more likely to refer to TPC services when they had completed a rotation in palliative care.<sup>167</sup> Thus, being part of a larger, multidisciplinary team alongside palliative care colleagues allows oncologists to share the burden of complex care delivery, potentially also preventing burnout and compassion fatigue.<sup>166</sup> Oncologists' willingness to engage with palliative care services correlates positively with self-reported comfort around managing end-of-life issues.<sup>177</sup>

The integration of oncology and palliative care should be a two-way street. A clinical rotation is essential for integration of these disciplines, because it could help oncology fellows to acquire knowledge of the basic principles of symptom management and communication, understand when referral is appropriate, and build a working and research relationship with the palliative-care team. A rotation could also help to destigmatize palliative care, and might result in increased interest among oncologists for sub-specialization in palliative oncology. The latter may enhance recruitment to an emerging discipline. As many palliative care specialists have another background than oncology, clinical rotation the other way round to oncology is also warranted. Similar to the way in which patient care might be improved by educating oncologists in palliative care, rotations in medical and radiation oncology for palliative-care fellows, to increase their familiarity with the natural history of cancer, cancer-treatment modalities, and the complex decision-making process surrounding cancer treatment at the end of life, could be of benefit. Such rotations might also help palliative care specialists and oncologists nurture a mutual understanding, strengthen their partnerships, develop common clinical pathways for their patients and enhance research collaboration.

To ensure and justify the investments in the integration of oncology and palliative care, future research should study the effectiveness of different teaching methods in palliative care education and the benefits of uni- and multi-professional education. There is a need to document the effect of how education and training programs impact treatment, patient care and organizational issues, e.g. care, economy, collaboration, and map the delivery and effects of undergraduate and postgraduate education on promoting palliative care integration. Health care organizations increasingly require evidence for the impact of education, so a robust evidence base to justify the cost and time of delivering education in palliative care must be established.

TPC specialists are often located in comprehensive cancer centres and/or university hospitals, and are commonly also engaged in academic activities. Therefore, leveraging the skillset of TPC specialists to support primary and secondary providers of PC and expanding the scope of TPC beyond the cancer centre setting through education and mentorship programs may help to upskill primary and secondary providers and clarify the respective roles of each. Further, the TPC specialists working in comprehensive cancer centres or in close conjunction with oncological departments must have skills and competence in oncology. The level of skills has to a little extent or not at all been concretized

but include skills and knowledge making them capable to handle oncological emergencies, to prognosticate different cancer diseases and have sufficient knowledge about chemotherapy and radiation therapy that enables them to cooperate with the oncologist in deciding the optimal treatment proposal for each patient.

As has been demonstrated, there is a substantial heterogeneity in education programs in palliative medicine at all levels and across countries and perhaps also within regions. This in itself represents a substantial barrier for further integration of oncology and palliative care. One may speculate if this is related to the immaturity of palliative care as a medical activity, lacking recognition of the added value of including palliative care in the standard treatment lines, financial issues or difference in scope, the tumour versus the host, between oncology and palliative medicine. In line with others<sup>320</sup> we think a shift of paradigm towards models based upon patient-centred care is highly warranted at all levels. Education programs should reflect this. Patient-centred care does not exclude targeting the tumour but makes a combined approach, the tumour and the host, the focus for the health care that need to be taught. In our view, it is a general challenge that contemporary medicine strives to include the patient in education and practice. Models are available such as shared-decision making, but these are still strangers in most medical curricula.

Communication skills are mandatory in order to provide patient-centred care. For patients with advanced cancer the patient-centred approach is of pivotal importance to ensure best possible care whether oncological or palliative. Training and education to improve physician-patient communication as part of patient-centred education programs should therefore be emphasized in curricula across different specializations. Communication must be learnt and consequently be part of all curricula in basic, intermediate and specialist medical education. Further, oncologists and palliative care specialists should receive specific communication training on regular intervals, to maintain and develop their skills, and to share fundamental skills.<sup>332,408</sup> Several methods are available for teaching communication to clinicians such as communication skills training with role play and feedback, e-learning, group discussions, modelling, case evaluations and coaching are some of the most used strategies. Overall, strategies that are active and involve practice seem to be most efficient.<sup>411</sup>

## Recommendations

- Palliative medicine must be accredited as a specialty or sub-specialty in all countries
  - How to do: Public awareness of the needs and national/international recommendations of accreditation. Adapt the accreditation from successful countries
  - Timeline: Now
- Palliative care must be mandatory taught in specialization in medical oncology, radiation oncology, clinical oncology and surgery oncology
  - How to do: Develop minimum volume and content requirements including mandatory clinical rotation in palliative care
  - Timeline: Now
- Develop international teaching programs on when and how to integrate oncology and palliative care
  - How to do: Require program development at health care providers' level as well as from professional organizations (ESMO, EAPC, ASCO, ESTRO etc.) and apply indicators for

- program development and implementation
  - Timeline: 1-2 years
- Continuous education of MDT in early integration and in team work
  - How to do: Require education for oncologists and palliative medicine specialists in patient-centred care and early integration
  - Timeline: Now

## Research

### Questions to be addressed

What are some opportunities and challenges for integrating oncology and palliative care teams to conduct research together?

What are some key research priorities related to integration of palliative care and oncology?

What are some key research priorities related to symptom assessment and treatment?

What are some key research priorities related to psychosocial support, communication and decision making?

What are some key research priorities for a broad implementation of integration of palliative care and oncology on regional, national and global level?

### Introduction

With increasing integration of oncology and palliative care, specialist palliative care is no longer only involved in the last days and weeks of life, but throughout the disease journey from the time of diagnosis of advanced cancer. Patients are often concurrently managed by both the oncology and palliative care teams, creating ample opportunities for collaborative research to improve patient care.

A systematic review in 2010 that examined the quantity, design and scope of palliative oncology publications identified significant gaps in the literature. Among 1213 articles included over two 6-month periods, 365 (30%) were reviews or systematic reviews. Over half of the studies (n=438, 52%) focused on physical symptoms among cancer patients, with few studies examining the interface between oncology and palliative care and how palliative care can be better integrated with oncology to improve care.<sup>17</sup> Patients with survival of >6 months, 4-6 months and less than 3 months to live each constituted approximately 1/3 of studies; however, patients with longer survival (>12 months) and very short survival (<1 month) were under-represented.<sup>542</sup> Only 6% of studies were randomized controlled trials, with low quality of reporting.<sup>139</sup> Thus, there remain significant opportunities to improve both the quantity and quality of palliative oncology studies.

In this section, we will focus our discussion on three major areas of research opportunities parallel to increased integration between oncology and palliative care: (1) system-oriented health services studies to examine different models of care and understand the optimal processes and outcomes of

improved integration of oncology and palliative care; and (2) patient-centred research to examine physical symptoms, psychosocial distress, communication, and decision making preferences throughout the disease trajectory; and (3) public health oriented research to examine external validity of the integration of palliative care and oncology in the whole society, e.g. a region or a country, and to develop and evaluate societal implementation strategies. Table 13 highlights some of the opportunities and challenges for Integrating palliative care and oncology to conduct research.

Opportunities	Challenges
Sharing of clinical and research expertise	Need time to communicate and build the trust and relationship between teams
Access to patients (e.g. enrolling patients from oncology clinic to assess palliative care needs)	Potential conflicts between teams because of differences in approaches
Opportunities for new areas of research and discoveries at the interface of disciplines (e.g. defining roles and responsibilities for delivery of palliative care by oncologists)	Potential competition for study leadership
Sharing of work (e.g. expertise) and resources (e.g. staffing) may reduce overall cost	More resources may be needed to allow larger research teams

**Table 13. Opportunities and Challenges for Integrating Oncology and Palliative Care Teams to Conduct Research**

**Opportunities for System-Oriented Research**

A growing number of studies have addressed potential benefits from early integration of palliative care in oncology.<sup>3,5,49-53</sup> The question is no longer whether patients would benefit from palliative care, but *how* palliative care oncology teams need to provide, *when* is the optimal timing for referral to specialist palliative care, *how* comprehensive do the palliative care teams need to be, and *what* is the minimum model for care delivery. A recent Delphi study identified 11 major criteria to refer patients with advanced cancer to outpatient palliative care.<sup>477</sup> Table 14 summarizes some of the main questions regarding system-oriented research in palliative care.

A recent systematic review highlighted 38 aspects of integration under five main domains: clinical structures, clinical processes, administration education, and research.<sup>45</sup> Although there are many ideas on how integration can take place, empirical data is lacking to demonstrate improved outcomes outside of a clinical trial setting. For instance, only few studies have examined how routine symptom screening coupled with care pathways can be used to refer patients to palliative care.<sup>383,543</sup> Moreover, there is tremendous opportunity for joint research studies between oncology and palliative care teams to investigate the process of collaboration between the oncology and palliative care teams, such as MDTs and embedded palliative care clinics.<sup>544</sup>

Because of resource limitation, it would not be possible for every cancer patient to receive specialist palliative care. A proportion of patients with lower level of distress may be managed by their oncology team. In some countries primary care also plays an important role as front line providers. One unanswered question is how much palliative care do oncology teams and primary care providers need to know,<sup>528</sup> and how much are they expected to deliver in their daily practice.<sup>475</sup> In a survey of oncologists, greater knowledge and comfort with palliative care was associated with higher levels of self-reported palliative care delivery and specialist palliative care referral.<sup>177</sup> Oncologists and palliative care teams can collaborate to examine how to better integrate palliative care

competencies in oncology and primary care, and to document the patient care outcomes associated with this integration.

Another area of development in system-oriented research is the assessment of the level of integration among cancer centres. Such metric would allow patients and clinicians to identify institutions that offer a high level of palliative care, researchers to examine progress, and administrators and policy makers to triage resources and develop quality improvement initiatives. A recent international Delphi study identified a high level of consensus for 13 indicators under four domains (clinical structure, process, outcomes and education).<sup>48</sup> Further studies are needed to validate this set of criteria.

Domains	Recommendations of Research Questions
<b>Specialist palliative care referral</b>	<ul style="list-style-type: none"> <li>• What is the optimal timing for palliative care referral (resource-rich vs. resource-poor settings, large vs. community hospitals, cancer vs. non-cancer)?</li> <li>• Should time-based criteria or need-based criteria be driving palliative care referral?</li> <li>• Can standardized referral criteria coupled with automatic referral streamline the referral process?</li> <li>• What strategies can help to overcome barriers to referral among patients and oncologists?</li> <li>• What is the effect of palliative care intervention on patients' ability to complete cancer treatments?</li> <li>• What is the role of palliative care for patients with curable cancer?</li> </ul>
<b>Palliative care programs</b>	<ul style="list-style-type: none"> <li>• What is the standard (minimum requirement) for a palliative care program in different healthcare settings?</li> <li>• What are the advantages and disadvantages of various novel models (e.g. palliative care teams involved in multidisciplinary tumour boards, embedded clinics)?</li> <li>• What should be the metrics/benchmarks measure the success of a hospital, region or nation on palliative care delivery?</li> <li>• How to develop and use clinical practice guideline on palliative care inform practice?</li> <li>• How can primary care teams integrate to provide palliative care?</li> </ul>
<b>Education</b>	<ul style="list-style-type: none"> <li>• How much palliative care do oncologists need to know to deliver effective palliative care?</li> <li>• How much oncology do palliative care specialists need to know?</li> <li>• What are the most effective strategies to educate oncologists about palliative care?</li> <li>• How to standardize the training and accreditation for specialist palliative care in different countries?</li> </ul>
<b>Public policy</b>	<ul style="list-style-type: none"> <li>• What public policies are most effective to drive palliative care?</li> <li>• What are some strategies that professional organizations can adopt to support integration?</li> <li>• How to optimize investment in palliative care programs to maximize the value of healthcare expenditure?</li> </ul>

**Table 14. Research Opportunities related to Integration of Palliative Care and Oncology**

**What are the Opportunities for Patient-Centred Research?**

**Symptom Assessment**

There is considerable evidence that patients with advanced cancer develop multiple devastating physical and psychosocial problems<sup>545-547</sup> and that there is also substantial burden on their primary caregivers.<sup>548,549</sup> Frequent monitoring of these important clinical problems will allow oncologists and palliative care specialists to identify patients who would benefit from various pharmacological and non-pharmacological interventions (see Background and Prognostication). More systematic prospective monitoring of symptoms might contribute to better prognostic models, which is warranted (see Prognostication). However, the adoption of regular monitoring of patient reported outcomes has been erratic. This is partially due to the lack of standardization or consensus on what domains require monitoring, the limited degree of validation of some instruments, the barriers to implementation of routine screening, and the need for more research to ascertain the real impact of screening on patient outcomes.<sup>550,551</sup>

Patients with chronic progressive diseases including cancer frequently receive care in multiple settings including their home, acute care hospitals, palliative care units, inpatient hospices, and long term care facilities.<sup>36</sup> The monitoring and screening of patient and caregiver reported outcomes needs to accompany the patient to those multiple settings. The Edmonton Regional Palliative Care Program conducted some pioneer research on adoption in multiple areas of care<sup>552-554</sup> which was followed by several international initiatives.<sup>555,556</sup> More research is needed to define the best ways to provide valuable information to clinicians throughout the trajectory of patient care in multiple settings and clinical circumstances. Table 15 summarizes possible research opportunities in the area of screening and monitoring of cancer patients and their caregivers.

Palliative care and oncology teams need to work together to develop and validate novel assessment tools on various patient-reported outcomes, and apply these instruments in clinical and research settings to assess health outcomes. For instance, PROMIS has developed multiple assessments based on computer adaptive testing but require further testing.<sup>557</sup> Recently, the International Consortium for Health Outcomes Measurement recommended a standard set of patient-centred outcomes for patients with colorectal and breast malignancies.<sup>558,559</sup> Assessment of personalized symptom goals may allow both oncologists and palliative care teams to determine the individual response to symptom interventions and further tailor treatments.<sup>560</sup>

Domains	Recommendations of Research Questions
<b>Symptoms and needs screening</b>	<ul style="list-style-type: none"> <li>• Which validated assessments should be used for which domains for screening at various clinical settings (oncology, palliative care vs. other specialties; inpatient vs. outpatient)?</li> <li>• What instruments/assessments should be included in a standardized comprehensive palliative care assessment?</li> <li>• How can patient function be assessed accurately?</li> <li>• How best to conduct screening for some concepts, such as patient understanding of illness, communication styles, spirituality and caregiver needs?</li> </ul>



	<ul style="list-style-type: none"> <li>• How to overcome the patient, healthcare professional and system barriers to facilitate routine screening in a busy oncology and palliative care practice?</li> <li>• How electronic data capture may be used to collect and display patient reported outcomes?</li> </ul>
<b>Assessment of treatment response</b>	<ul style="list-style-type: none"> <li>• What is the minimal clinically important difference and responsiveness to change for various scales?</li> <li>• How can personalized symptom goals be used to augment practice?</li> <li>• What are the predictors of treatment response?</li> </ul>

**Table 15. Research Opportunities Related to Symptom Assessments**

### Symptom management

There are multiple contributors to physical and psychosocial distress including cancer location and burden, toxicities of cancer treatment, and comorbidities. As cancer treatment evolves new treatments such as targeted and immune therapies have dramatically modified the risk-to-benefit ratio, adding another layer of complexity to cancer treatment decisions at the end-of-life.<sup>184,561-563</sup> Oncology teams are experts in the use of many of these new modalities and palliative care teams are experts in symptom evaluation and management.

Many symptoms, such as fatigue, pain, anorexia and dyspnea are highly prevalent throughout the disease trajectory.<sup>564,565</sup> In a meta-analysis of 52 studies, cancer pain was present in over 50% of patients, and with one third of patients reporting moderate or severe intensity.<sup>566</sup> This high prevalence calls for more research and resources to improve the detection and treatment of pain by oncologists, palliative care specialists, pain medicine specialists and other professions.

Although specialist palliative care involvement has clearly been found to improve symptom control compared to oncology care alone,<sup>64</sup> many symptoms have few effective therapies and remain under-treated even by a comprehensive palliative care team.<sup>560,567</sup> For example, anorexia-cachexia is reported in up to 60% of patients with advanced cancer. Management of cachexia should begin at the pre-cachexia phase, when patients are seen predominantly by their oncologists. Here, multimodal multidisciplinary interventions targeting nutrition, physical activity, inflammation, appetite and nutritional impact symptoms are essential.<sup>568,569</sup> Here, collaborative research between oncologists and palliative care teams to develop evidence-based palliative interventions can be fruitful (Table 16). In contrast, other issues such as delirium and signs of impending death mostly occur in the last days and weeks of life, and do not require a high degree of collaboration.<sup>262,570,571</sup>

Domains	Recommendations of Research Questions
<b>Treatment toxicities</b>	<ul style="list-style-type: none"> <li>• How to better assess adverse effects in clinical trials and daily practice?</li> <li>• What is the pathophysiology of adverse effects related to novel therapies?</li> <li>• What are novel supportive care interventions for various treatment related adverse events?</li> </ul>
<b>Cancer related symptoms</b>	<ul style="list-style-type: none"> <li>• What is the pathophysiology? And what are the potential therapeutic targets?</li> <li>• What combination of multimodal therapy has the greatest impact on symptom outcomes?</li> <li>• What validated outcomes are required for regulatory approval for symptoms such as fatigue, cachexia and dyspnea?</li> </ul>

	<ul style="list-style-type: none"> <li>• How to address chemical coping and opioid addiction in cancer patients while providing good pain control?</li> </ul>
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**Table 16. Research Opportunities related to Symptom Management**

### Psychosocial Issues and Communication

Palliative care teams can support oncology teams in the delivery of psychosocial support and excellent patient and family communication.<sup>52,312,362</sup> There is a great opportunity to conduct research on the best methods for the delivery of effective psychosocial support. There is also need for research on methods of communication with patients and their families. Randomized controlled trials can be conducted on areas such as physician posture,<sup>572,573</sup> discussions regarding resuscitation<sup>574</sup> and the impact of the content of the message.<sup>476</sup> Better prognostication and prompt sheets may also enhance communication.<sup>281,413,575,576</sup> Table 17 summarizes important areas of psychosocial support, communication, and advance care planning where palliative care teams can develop research initiatives together with oncology teams.

Domains	Recommendations of Research Questions
<b>Psychosocial, spiritual and caregiver care</b>	<ul style="list-style-type: none"> <li>• What interventions are best for adjustment disorders?</li> <li>• What are the strategies to screen for spiritual care needs in the medical setting?</li> <li>• What are the best interventions to support caregivers along the disease trajectory?</li> <li>• What are the strategies to support decision making?</li> <li>• How to support bereaved caregivers at risk of complicated grief?</li> </ul>
<b>Communication and decision making</b>	<ul style="list-style-type: none"> <li>• How to accurately predict survival in advanced diseases and use that information to support decision making?</li> <li>• What are the strategies to communicate prognosis and help patients gain a better understanding of their illnesses without jeopardizing the patient-clinician relationship?</li> <li>• How to facilitate serious illness conversations over the continuum of disease?</li> <li>• How can decision making aids and prompt sheets be standardized?</li> <li>• How can physicians tailor the decision making process to different decision making preferences among patients and families?</li> </ul>

**Table 17. Research Opportunities related to Psychosocial Support, Communication and Decision Making**

## Opportunities for Public Health Research

### Public health and implementation impact

The clinical as well as the social context of death and dying in cancer is rapidly changing. Globally, the WHO also strongly supports advocacy efforts to make the essential medicines available for palliative care. This public health policy work is grounded in the theory that palliative care programs at a country level needs to be context dependent and implementable. Place of death, place of care at the end of life, access to palliative care, circumstances of dying, and even end-of-life decisions are strongly related to the health care system, the legal context, type and models of palliative care

available within a country. Therefore, more implementation research is needed regarding integration of palliative care and oncology.

Most evidence on integration of palliative care and oncology is based on clinical or health service evaluation studies conducted in only one or few hospitals.<sup>3,5,49,52,59</sup> In most countries it is yet unknown how well integration of early palliative care and oncology has been implemented throughout the health care system. Palliative care is indeed increasingly recommended in cancer patients, but yet seldom practiced to all in need. In an observational study of 4466 deaths in four European countries it was shown that palliative care was delivered to 50% of patients in Belgium, 55% in Italy, 62% in the Netherlands and 65% in Spain.<sup>577</sup> Palliative care specialist services attended to 29% of patients in the Netherlands, 39% in Italy, 45% in Spain and 47% in Belgium. In this international study, cancer patients were two times more likely to receive palliative care as compared to patients with non-curable diseases. Furthermore, if palliative care is delivered, it is often being initiated at the very end of life for most patients, when the patient is within few weeks prior to death. A nationwide study in Belgium shows that the time of onset of palliative care is median 20 days prior to death for cancer patients, as compared to 12 days in heart failure and 10 days in COPD.<sup>578</sup>

Hence, we cannot talk of palliative care for the majority of cancer patients early in their disease trajectory. This demonstrates that there is a major difference between university hospital experience of cancer patients in which most of the palliative care trials have been conducted and the experience of a full population of cancer patients in one country, hence the impact of implementation of integrated palliative care across a country.

### **New Public Health studies**

A new research perspective is coming also from the “New public health approaches”, using evidence from the field of health promotion, health behaviour and public awareness building.<sup>579,580</sup> Cancer patients are taken care of by oncologists or physicians for only a small part of the time, it is the spouses, families and the broader community that takes care of these people 24/7. Hence, the impact of family, volunteers and the larger community is extremely important for cancer patients. They support cancer patients not just in their wellbeing, but also for expressing their care preferences, participating in shared decision making, and eventually in the decisions at the end of life.

In this perspective one should also bear in mind that the general public and the public opinion have not yet a full understanding of the potentials of integration of early palliative care in an oncology treatment trajectory. The reality in most countries is that palliative care is still very much of a taboo or a stigma because awareness and experiences of palliative care potential is limited to terminal care, hence associated with imminent death. Therefore, we need also research into the development of palliative care public awareness campaigns and into studying human behaviour in health crisis situations, and empowerment of patients and families in making the right decisions both for their cancer treatment as for their wellbeing and quality of life.

In order to increase the level of evidence concerning implementation of early palliative care in oncology and improving the involvement of patients, families and the broader community, next to clinical and health services research, also more public health oriented research is needed. Table 18 summarizes important domains, possible research methods for monitoring the implementation of integration across a country, and possible research aims for public health studies relevant to integration of palliative care and oncology.

Domains	Recommendations of Research Methods
<b>Monitoring implementation scope</b>	<ul style="list-style-type: none"> <li>• Administrative databases</li> <li>• Health care registries, e.g. nationwide sentinel networks</li> <li>• Nationwide post-mortem surveys</li> <li>• Auditing of integrated care services</li> </ul>
	Recommendations of Research Aims
<b>Evaluating the quality of integration of palliative care and oncology</b>	<ul style="list-style-type: none"> <li>• Developing of palliative care quality indicators for the evaluation of the quality of the integrated services</li> <li>• Cross-country and cross-setting (university hospital vs local hospital) validation of the indicators</li> <li>• Implementation of the quality indicators</li> <li>• Development of quality improvement interventions</li> </ul>
<b>Health promoting early palliative care in cancer</b>	<ul style="list-style-type: none"> <li>• What are the perceptions of palliative care potentials among cancer patients and their families, among health care professional, and among the general public?</li> <li>• Developing of health promotion campaigns to empower cancer patients and their families to talk to their health professionals early in their illness trajectory about palliative care needs and care preferences.</li> <li>• Developing of palliative care awareness campaigns to improve knowledge and attitudes towards early palliative care in cancer patients and in the general public.</li> </ul>

**Table 18. Research Opportunities related to Public Health and Population Health**

**What are the opportunities for collaborative research regarding cancer treatments?**

Palliative care teams are increasingly involved in the care of patients undergoing palliative therapies for advanced cancer, including systemic therapies, radiation and surgical procedures. They have a critical role in helping to maximize the quality of life of patients undergoing cancer treatments, and also facilitating the complex decision making process surrounding treatments at the end-of-life (i.e. last months before death). The advent of novel therapies such as immunotherapies creates even more opportunities for collaborative research between the oncology and palliative care teams to optimize patient outcomes.

There are exciting opportunities for joint research from the collaboration by these two groups by a better understanding of the pathophysiology of treatment-related adverse effects. The interaction between cancer burden, treatment toxicity, and comorbidities is complex and variable. As an example, a highly effective immunotherapy will reduce symptoms related to the tumour mass and

also improve the patient's and caregiver's psychological wellbeing but will add symptoms related to fatigue and immune related adverse effects such as dermatitis, colitis and hypophysitis.<sup>581</sup> Figure 7 summarizes the complex interaction between tumour mass, tumour treatment, and comorbidities in the generation of symptom and psychosocial burden. Cancer, through its direct effect on organs and tissues or its indirect effect on systemic mediators can result in multiple symptoms, decreasing patients' function and quality of life. Cancer treatments may control tumour growth, but may also lead to significant toxicities. Co-morbidities could further contribute to the overall symptom burden. Supportive and palliative care aim to alleviate symptoms and improve quality of life by modulating the afferent signals and enhancing the coping mechanisms.

Palliative care specialists not only need to collaborate with surgeons, radiation oncologists, medical oncologists and haematologists clinically, but also in research studies to identify the best ways to optimize patients' functional status and nutrition status before, during and after treatments. More research is also needed to determine the best strategies to prevent and/or treat various treatment-related adverse events.

Cancer treatments close to the death are associated with lower quality of end-of-life care.<sup>582,583</sup> Novel targeted therapies and immunotherapies are generally associated with fewer side effects than conventional chemotherapy and are being increasingly offered to patients with lower performance status.<sup>563</sup> A small proportion of these patients experience a remarkable treatment response, altering the natural history in a significant manner and adding to the prognostic uncertainty. While oncologists can offer hope through new treatment opportunities, palliative care teams can nurture hope for better quality of life throughout the disease trajectory and help patients to balance the ever shifting priorities. More collaborative research is needed to better understand patients' goals of care, illness understanding and treatment preferences, to develop better prognostication tools and decision aids to inform the complex decision making process regarding treatment continuation and discontinuation as death approaches.<sup>184,304</sup>

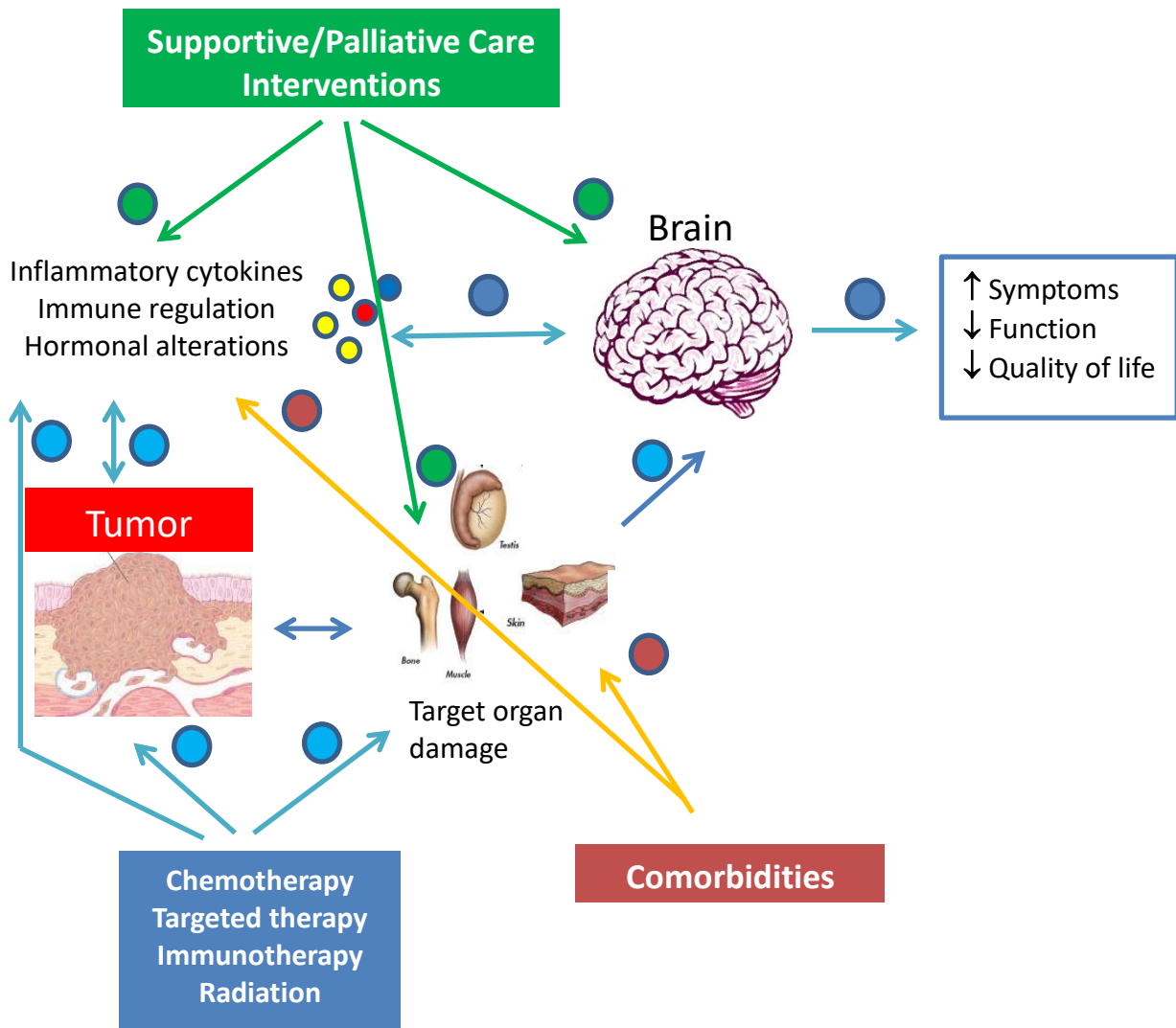
### Evolving Models to Support Collaborative Research

Compared to established medical disciplines such as oncology, palliative care focuses on personhood care instead of management of specific diseases. Thus, palliative care specialists are uniquely positioned to conduct research by drawing upon the similarities among different diseases to derive common principles of patient-centred care (e.g. management of dyspnea, serious illness conversations), while personalizing management based on the unique differences among the different disease (e.g. cancer trajectory is more predictable).

Although there is no lack of academic oncologists, palliative care researchers are in small supply. Thus, educational programs and funding opportunities are needed to train more palliative care clinicians in the principles of research and unique aspects of conducting palliative care studies. Such investments will likely result in more opportunities for research collaborations and accelerate development of innovative interventions to improve patient care.

As new therapies become available to cancer patients there are opportunities for oncology and palliative care teams to prepare proposals aimed at measuring carefully the impact of those therapies in the physical and psychosocial wellbeing of the patients and the ideal management of the symptomatic complications secondary to those therapies. These proposals will provide access to

sources of funding from industry that traditionally have been largely unavailable to palliative care research teams. At times when academic funding is becoming less available in most countries these joint efforts will provide support for logistics and career development of academic palliative care physicians and oncologists.



**Figure 7. Conceptual Model of Interaction among Cancer, Cancer Treatments, Comorbidities and Supportive and Palliative Care Interventions on Symptoms and Quality of Life.**

## Conclusion

There are many unanswered questions related to the optimal delivery of palliative care in cancer patients, with many challenges to conduct high quality research. With increased integration between oncology and palliative care, there are tremendous opportunities to identify novel research questions at the interface of disciplines, combine the resources to complete high quality research, generate new knowledge to advance symptom management and care delivery, and develop better models of integrated care towards improving patient outcomes.

## Recommendations

- Research into new public health approaches for integration of oncology and palliative care is needed
  - How to do: Establish international and national research programs to support research on content, methods and how to verify the effects
  - Timeline: 1-2 years
- Develop a minimum and maximum set of indicators for the follow up of successes in the implementation of early integration of oncology and palliative care
  - How to do: Initiate research programs internationally and nationally
  - Timeline: Now
- Initiate collaborative research programs in oncology and palliative care for symptom management (needs) and their application in SPC and in the discussion in MDTs
  - How to do: Initiate research programs internationally and nationally
  - Timeline: Now
- Top academic positions in palliative medicine/care (professors) must be present at all academic cancer centers and medical schools
  - How to: Professional awareness programs and advocacy groups needs to be initiated
  - Timeline: 1-2 years

## Summary and call for action

During the work with this commission it has become evident how heterogeneous the organizations, the content of the models and the performance in clinical practices are. The heterogeneity goes even further into the content of the education programs. That includes the presence of palliative care in oncology training, if present at all, as well as the structure, the content and (lack of) formalization of palliative medicine as a specialty in many countries. This heterogeneity with a lack of international agreements and standards of palliative care in oncology is probably one main barrier for a successful integration. *“If one of the partners in a relationship is undefined, ambiguous, the probability to build a long lasting relationship will probably be low and very challenging”.*

## Policy

Internationally, strong and clear resolutions and recommendations are given by the WHO, OECD, professional organizations (ASCO, ESMO, EAPC) and international charters (EAPC, IAHP, WPCA) on the place for palliative care as a part of the cancer care programs. The content and directions can be summarized by the statement given by the World Health Assembly (WHO) in 2014: *“Strengthening palliative care as a component of comprehensive care throughout the life course”* which states that palliative care should be covered under national universal health coverage plans. It has been shown in several high quality studies that an integration of palliative care into oncology care improves several outcomes, like symptom management, patients’ and family members’ quality of life and possibly survival for patients with short life expectancy. Systematic use of PROMS improves symptom control, reduce psychological distress and can improve survival. The need for integration is further supported by the increase in incidence and prevalence of patients living with advanced cancer.

These clear and strong recommendations given during the last couple of decades are contrasted by the findings in this commission: Lack of integration of oncology and palliative care. In most national

cancer care plans, palliative care is not formulated as an integrated approach together with oncology. If it is present, it is often an add-on to the tumour directed approaches. It seems to be a lack of willingness and capability to implement and prioritize palliative care in the cancer care plans, in care programs as well as in clinical care pathways.

The lack of true implementation may in addition to the above mentioned factors also be related to the heterogeneity of the organizational models of palliative care, the lack of systematic education in palliative medicine in medical schools and during specialization in oncology as well as lack of education of oncology during palliative medicine specialization.

One may ask if palliative care has become even more under-prioritized during the last decade. In this time period much attention has been given to the advances of new systemic tumour directed therapies and a non-anticipated attention away from patient-centred care may have occurred. The marketing of the new treatments may have created the budget winners?

In order to achieve improvements in complex systems like health care, several approaches are needed by combining top-down and bottom-up actions. It is recommended in this commission that the strong political recommendations are followed up at national and regional levels. The politicians and the health care bureaucracy together need to develop plans and implementation strategies and combine these plans with economic incentives and basic funding of the integration between oncology and palliative care. It is well documented that palliative care may reduce cost and improve patients' quality of life and the quality of life of their family members.

**Action: "True integration" must be recommended by national health care authorities, followed up with resource allocation and priorities and monitoring of successful implementations. It is a need for international valid indicators of successful integration of oncology and palliative care.**

## Cultures

Cultures in health care play important roles by serving as invisible "roadmaps" for interpersonal interactions like how a doctor communicates with a patient or how physicians with different specialties interact. Cultures also act as barriers in the process of changing and improving practice. The oncology culture can be described as a tumour directed culture with its positive implication when the treatment goal is to cure and thereby achieve tumour control and ideally total eradicate the tumour. Undoubtedly this culture has been and is essential to improve cure for many cancer diagnosis. However from a patient perspective if cure is not achievable, like in patients with advanced lung, pancreatic, colon or breast cancer, a combined tumour-directed and patient-centred approach is needed and strongly recommended in this commission. In the palliative care culture the primary focus is to improve patients' quality of life. In this commission, patient-centred care including shared decision-making with a primary focus on the patient (the host) is recommended. The palliative patient-centred culture therefore differs from the oncology culture, it has different players and has until recently in many countries been organized separate from mainstream health and oncology care. From a patient perspective being in a non-curative situation, the palliative culture need to be present and should not be considered to be in competition but rather synergetic – integrated - with the tumour directed culture.



One of several ways to understand why the patient-centred palliative care approach is not implemented into oncology clinics is the gap and antagonisms between the two cultures. When different approaches from two cultures are to be blended in cancer care programs one needs to understand the differences and the shared values, and plan the implementation according to a multicultural reality. The antagonisms held by the two maintain status-quo, i.e. we versus them, but represents in our view a substantial barrier towards integration.

**Action: Culture analysis need to be performed and the implementation of palliative care need to be conducted based upon involvements of the leaders of the oncology and palliative care programs. The unofficial leaders at all levels also need to be mapped and involved in the implementation plans.**

### Organization and competence

The overall aim of the organizational model is that patients and their families have access to the care they need, when they need it, resulting in improved health care outcomes. In the integrated oncology and palliative care model, early integration is a key concept. It clearly illustrates that the content and competence of palliative care is much more than end of life care.

The MDT approach can be used as a key component of the organizational model in the hospitals to link oncology and palliative care services. However the organizations need also to outreach to the community and home care. The models need to have a clear and robust organization but also be flexible according to the patients' needs. Several organizational models of palliative care have been developed and evaluated. This commission recommends dividing the models into three levels: primary, secondary and tertiary care and that the place, competence of oncology and palliative care need to be adjusted to the level of care and the patients' needs. At the primary health care level, the GPs need also to have the necessary competence in palliative care. Their role is central in home care.

One limitation of the organizational models identified in the literature and discussed in this commission is their heterogeneity. This hinders generalization of findings. This commission has identified a need to develop international standards for the structure and content of the organizational models as well as to further evaluate the effects in public health care research.

For a successful integration of oncology and palliative care a multidisciplinary approach is needed. The health care providers need skills in patient-centred care. Wide variations in education have been identified for oncologist and for palliative medicine specialists and also exist for education of the other participants in the multidisciplinary teams. The general lack of competence in palliative care is also a barrier for successful implementation of the integrated models.

**Action: International standards of oncology and palliative care are needed for:**

- **Integrated oncology and palliative care models are needed to evaluate the effects of these models clinically.**
- **Palliative care education in oncology and oncology education in palliative medicine.**
- **Defining the necessary competence and the content of the education at the three different layers need to be performed at a high level, preferably internationally, and not governed by tradition or local preferences**

## Patient-centred care

The concept of total pain which is central in palliative care infers a broad understanding of patients' needs during a disease trajectory. Many cancer patients undergo life-prolonging treatment for years or are cancer survivors with manifest or latent late effects of treatments. Therefore the chronic disease model is highly relevant in oncology but is seldom referred to or utilized.

The patients and his family are expecting and demanding to be actively involved in the care planning, at all stages of the disease trajectories. A central part of involvement and engagement of patients is a systematic collection of "the patients' voice". Furthermore there are expectations about information and communication to patients about treatment and care plans which often are not fulfilled when comes to patients with advanced disease and a limited life expectancy. Often they are not aware of their disease status and the expected effects of tumour-directed treatment.

The fragmented nature of the cancer care system calls for a methodology to implement the planning, coordination and to perform resource allocation according to patients' needs. Standardized care pathways (SCP) is a method to plan and implement complex health services and to assure that the right people, are at the right place, to the right time. This commission proposes to use the method of SCP as a model to develop a seamless patient flow in a customized organizational model.

Symptom assessment by systematic use of patient reported outcome measures (PROMs) performed by using validated PROMs is pivotal for patient-centred care throughout the whole cancer disease trajectories. It can be considered as a key method to engage patients into the decision making processes where PROMs are key information to customize the SCPs. PROMs were traditionally collected in paper based questionnaires. This commission recommends development of electronic tools for collection of PROMs, e-PROMs that can be integrated into the electronic patient record systems.

Shared decision making (SDM) is another central component of patient-centred care. It is highly relevant in all phases of cancer treatment, but is even more central for patients with advanced non-curable disease. SDM is an active and continuous process combining the tumour-directed and the patient-centred approach in the care planning. This commission recommends that SDM is included as a mandatory part of oncology guidelines and is visualized in the content of the SCPs.

**Actions: Patient-centred care must be actively implemented into oncology care by means of systematic use of SCPs where oncology and palliative care is fully integrated. PROMs and SDM are methods which should systematically and actively be used in all parts of cancer care.**

## Research

An early integration of oncology and palliative care gives new arenas and opportunities for collaboration in addressing new research questions. Some key questions to answer are related to health services issues and others related to patient-related issues such as assessment and treatment of physical symptoms, psychological distress, communication and decision making processes and performances.

New tumour directed treatments such as targeted and immune therapy have added another layer to the complexity to the end of life. It gives new opportunities for collaborative research in addressing the interactions between tumour burden, treatment toxicity and comorbidities. At the health service arena some examples of questions to answer are: how to optimize integration of oncology and palliative care? What are the optimal organizational models at the primary, secondary and tertiary levels of care for integrated oncology and palliative care? How to optimally utilize the human resources in the SCPs?

Research competence and funding are basic. Few resources are allocated to palliative and end of life care research. Data from several countries indicate that 0.3 to 1 % of resources allocated to cancer research goes to cancer palliative care research. Lack of research funding also minimizes the opportunities for training physicians in palliative care research and thereby qualify clinicians to be researchers and to apply for academic positions.

**Action: It is urgently needed to invest in research in palliative care in order to develop an evidence base on how to organize and how to perform palliative care in oncology practice. National earmarked grants for research programs are needed, which are sufficiently funded for 3-5 years.**

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