

Position Paper

## A new international framework for palliative care

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convened by the European School of Oncology<sup>1</sup>

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### Abstract

In spite of recent advances in anti-cancer treatments, most adult cancer patients still ultimately die from their disease. There should therefore be free access to palliative care around the clock and seven days a week, for all cancer patients, as a fundamental human right.

At present, the implementation of palliative care and patients' access to it are inconsistent across Europe and many other parts of the world. The World Health Organisation (WHO) made an important advance in 1986 by first defining palliative care and, then updating this definition in 2002. However, this definition could benefit from further refinement in order to reflect the increasing multi-professional specialisation in this subject, and to recognise the different models for delivering this type of care.

We recommend that palliative care should be defined as follows:

- *Palliative care* is the person-centred attention to symptoms, psychological, social and existential distress in patients with limited prognosis, in order to optimise the quality of life of patients and their families or close friends.

Based on this definition, we propose two further types of palliative care which reflect the reality of how palliative care is actually delivered:

- *Basic palliative care* is the standard of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their normal duties to patients with life-limiting disease.
- *Specialised palliative care* is a higher standard of palliative care provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialised members of the primary or secondary care teams. If a patient has difficult symptoms which cannot be controlled by his/her current healthcare team, he/she has a *right to be referred*, and the current healthcare provider has an *obligation to refer*, to the local palliative care team.

Important priorities to ensure the standardisation of, and uniform access to, palliative care for all cancer patients include:

- Integration of palliative care services with the primary care and oncology teams.
- Establishment of a specialised palliative care service in each major cancer centre.
- Establishment of educational programmes covering palliative care for undergraduates, oncologists, primary care team members and specialists training in palliative care.
- Support for research using appropriate methodologies to underpin the scientific basis of palliative care.
- Establishment of quality assurance programmes.
- Recognition of palliative medicine as a medical specialty.

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- Establishment of academic centres of excellence with chairs of palliative medicine and palliative care nursing.
  - Removal of unnecessary restrictions on all drugs which are proven to be of benefit in symptom control, especially improving access to strong opioids.
  - Improved information for patients and family carers to allow them to make choices and exercise autonomy.
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## 1. Introduction

Statistics of cancer incidence and mortality in Europe show that this disease is steadily increasing in significance, both in terms of mortality and morbidity, in keeping with the growing proportion of older people. In the developing world, it is expected that there will be an enormous increase in cancer incidence, mortality and morbidity [1]. In spite of recent advances in anti-cancer treatments, most adult cancer patients will still ultimately die from their disease, or from side-effects of and complications arising from its treatments.

Healthcare professionals are increasingly aware of the need to change the aim of anti-cancer treatment in selected patients from ‘curative’ to ‘life-prolonging’ or ‘palliative’ [2]. However, so-called ‘palliative’ anti-cancer treatments given by cancer specialists in cancer units may still not cover all of the symptom control, psychosocial and spiritual needs of cancer patients and their families [3].

In most European and other developed countries, healthcare professionals and also the public are becoming more aware of the options for palliative and supportive care in advanced cancer [4,5]. However, in both developed and developing parts of the world, existing healthcare services, from primary to tertiary care, may not be currently equipped (both in terms of knowledge and resources) to respond to this growing need of patients and their families, [1].

Against this background of change and the public’s rising expectations of greater autonomy and choices, the availability of palliative care, of uniformly high quality, has to be made more equitable and accessible, in both developed and developing countries.

## 2. What do we mean by ‘palliative care’ for cancer?

Palliative care was originally defined by the World Health Organisation (WHO) in 1986 as:

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anti-cancer treatment.” [6]

This definition has been extremely important and influential in raising the awareness of palliative care across the world. However, it came to be regarded as somewhat limited and ambiguous, as it rests on the interpretation of responsiveness to ‘curative’ anti-cancer treatment. The WHO itself recognised this later: “*The earlier WHO definition of palliative care stressed its relevance to patients not responsive to curative therapy. This statement might be interpreted as relegating palliative care to the last stages of care.*” [7] With improvements in anti-cancer treatments, including less toxic chemotherapy regimens and new methods of biological control, patients are living longer with cancer and especially for older people who have other significant co-morbidity, the exact definition of ‘cure’ is becoming less relevant. Furthermore, in recent years, specialists working in palliative care in some developed countries have moved away from restricting palliative care to incurable disease. The WHO therefore introduced an updated definition in 2002, which attempts to address this shift in emphasis:

‘Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’ [7]

This new WHO definition was welcomed as it highlights the need to start palliative care earlier in the disease process. However, in developed countries where there was already many years of experience of delivering palliative care alongside anti-cancer treatments and where specialised teams and services to deliver palliative care have been developed, the more pressing issue has become – how to ensure that patients receive the benefits of palliative care at all of the appropriate stages and acknowledging the different skills of healthcare professionals who care for them?

## 3. European school of oncology international working group

To address this issue the European School of Oncology (ESO) convened an international working group in Milan late 2000. The working group consisted of palliative care, oncology and pain experts from a wide

range of European countries. They represented both medical and nursing disciplines. The working group discussed the issues and elected a writing committee to summarise the conclusions.

An early decision of the working group was that there needed to be new definitions, not only of what palliative care itself consists, but of the different levels at which it is practised. The latter reflects the increasing sophistication of palliative care specialisation in many European countries, as well as other parts of the world, such as Australia/New Zealand and North America. In a few countries, notably Great Britain, Poland and Australia, palliative medicine is now recognised by the training colleges as a distinct specialty or subspecialty of internal medicine. In many other countries where this degree of official specialisation does not yet exist, there are nevertheless many highly developed services and teams based in primary or secondary care, which are delivering high quality palliative care. Some of these services have originated from hospices, others from oncology or pain teams.

#### 4. European School of Oncology's proposed definitions of palliative care

The ESO international working group now proposes the following new definitions (together with accompanying explanations), which we believe more accurately reflects the 'state of the art' of current practice in Europe and other developed regions. The first definition is of palliative care itself and the second and third are refinements which reflect the levels at which palliative care can be delivered.

*Palliative care* is the person-centred attention to physical symptoms and to psychological, social and existential distress and cultural needs in patients with limited prognosis, in order to optimise the quality of life of patients and their families or friends.

*Basic palliative care* is the level of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their duties to patients with life-limiting disease.

All healthcare professionals who work with cancer patients should have a minimum standard of education and training to offer basic palliative care to all their patients and clients for new or simple problems, and should be able to recognise when to refer them to a specialised palliative care team for persisting or more complex problems. Although basic palliative care was originally aimed at patients with advanced, progressive cancer, its principles and benefits should also be made available to patients who have early disease or who are undergoing curative or life-prolonging therapy, but have a limited prognosis or special physical, psychological, social or existential or culturally determined needs.

*Specialised palliative care* is the standard of palliative care provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialist members of the primary or secondary care teams.

We have used the term 'specialised' here, because we recognise that the designation of a true specialty and hence 'specialist' level for a professional working in a palliative care service currently varies between countries. However, there should be an agreed minimum level of training and weekly commitment to palliative care teamwork. The specialised palliative care team itself must be aware of its own abilities and limitations, and should be able to consult and refer patients to pain clinics, surgical and medical teams for specific interventions, and other secondary care services, according to the patient's and family's needs.

Specialised palliative care services should also contain, or be linked to, a centre for research and education in palliative care developments.

The level of persistence, severity or complexity of problems which should activate a referral from generic healthcare professionals to those who can offer specialised palliative care needs to be further elucidated, through international collaboration and prospective clinical trials. For a guide, it should be accepted that patients (or family carers) who have problems which persist for more than two weeks in spite of the best available basic palliative care should be discussed with, or referred to a specialised service.

With respect to the severity or complexity of problems, the level which triggers a need for discussion or actual referral to specialised palliative care will depend on the specific type of problem. Using pain as an example, patients should be thus referred to a specialised service if pain reaches a level of 60 on 0–100 mm scale (or is rated as 'severe' on a verbal scale covering none–mild–moderate–severe); or if the pain has a major neuropathic component; or if the patient is intolerant of standard medication provided at the level of basic palliative care. It is important that these triggers are based on realistic criteria which reflect the capability of specialised teams to pick up referrals and their ability to provide different and more effective therapeutic interventions which are evidence-based.

We believe the broadening of the definition of palliative care, by both the WHO and the ESO international working group, to include patients at earlier stages of cancer illness is helpful, but it should not detract from the special kind of care which is required when patients are approaching the end of life. We therefore propose a further definition to highlight this part of palliative care:

End of life care <sup>2</sup> is the specific application of palliative care interventions and services in the last hours, days or weeks of life.

The phase of end of life care is entered not so much after any change in the patient's medical status (which may be difficult to discern in a chronic gradual deterioration), but rather by a conscious decision by the healthcare team – following appropriate discussion with the patient and family – that curative or life-prolonging treatments should no longer be pursued. This may indeed come after medical deterioration, but it may also follow a change in the mental attitude of the patient towards the illness. The passage into end of life care should mean that comfort measures should be of the highest priority, and it may be appropriate to withdraw previously useful life-maintaining measures, such as blood transfusions, parenteral feeding or intravenous hydration.

As with palliative care itself, *basic end of life care* should be part of the general knowledge and skills of any healthcare professional, while *specialised end of life care* is provided by the multi-professional palliative care team for patients who are dying in difficult or complex situations.

## 5. European School of Oncology recommendations on how palliative care should be delivered

The following recommendations and statements from the ESO international working group are meant to provide supplementary explanation and guidance of how palliative care is best deployed.

Palliative care or end of life care at both levels offers rational medical and nursing and other healthcare interventions which should be evidence-based wherever possible, which are consistent with the patient's current anti-cancer treatment.

Palliative care provides psychological, social and spiritual support to help patients and families to cope with the disease, its treatments and – if incurable – with the adjustment to cancer progression and dying. It facilitates proven therapies from other members of the general healthcare team, including validated complementary therapies which are consistent with other conventional treatments that the patient is receiving.

Palliative care places patients at the centre of decision-making.

It empowers them and helps them to make more informed treatment choices to optimise their own quality of life, based on an understanding of the benefits of treatment balanced fairly against the side-effects and other costs. A pre-requisite for this is open and honest

communication regarding the nature and stage of disease, and the likely prognosis.

Palliative care enables patients and families to face death from cancer.

Open communication and appropriate information help to prepare patients and families for advancing disease. Because of this, palliative care has traditionally made its greatest contribution towards the end of life. Hospice services, in particular, have been particularly important in this aspect. However, patients and families may also benefit from access to palliative care in the early stages of cancer, when treatments with curative or life-prolonging intention are being applied, but uncertainty about outcome may be adding to their anxieties.

Palliative care also extends to providing bereavement support for families and friends after the death of patients.

This can be provided for simple cases of grieving by any healthcare professional, but abnormal grieving should be referred to trained individuals in a specialised palliative care team, or to a special bereavement service.

Palliative care can be delivered wherever the patient is, or prefers to be.

Palliative care should be available, at both basic and specialised levels, in patients' own homes, by educating, supporting and, at the specialised level, working alongside the primary care team. It should also be available in the oncology centres, in follow-up or outreach clinics and in general medical and surgical hospital units where cancer patients are admitted.

A *palliative care unit* is a specially configured healthcare unit, ideally with inpatient beds, ambulatory out-patient or day-care facilities and home care outreach services, which provides high quality specialised palliative care.

Such units can exist in hospitals, or can be based in the community. They are staffed by highly trained professionals covering a range of disciplines which contribute to specialised palliative care. They are usually funded by the health service, and often have academic links with universities and may have partial funding from charitable sources.

A *hospice* is the term used in many countries for a type of specialised palliative care unit, which concentrates on end of life care.

Hospices also care for patients with advanced and terminally ill non-malignant diseases. They are often funded by charities, in some countries with significant contributions from the state, and frequently have volunteers who contribute time and skills to fund-raising and other support services. Regardless of the source of funding, they should always be integrated into the local and regional strategic plans for providing comprehensive palliative and supportive care.

<sup>2</sup> In this document 'end of life care' is used synonymously with, and in preference to, the older phrase 'terminal care'. It should be noted that in some European countries both 'end of life care' and 'terminal care' have negative connotations and therefore the appropriate translation will vary.

## 6. Why is palliative care especially relevant for cancer?

The diagnosis of cancer is still associated, in the twenty first century, in the public's mind with suffering and the certainty of a painful death. Patients anticipate losses and suffering, even during cancer treatments intended to cure. Even diseases commonly associated with a terminal outcome, such as human immunodeficiency virus/acquired immuno-deficient syndrome (HIV/AIDS) or motor neurone disease (ALS), do not receive the same public attention to pain and suffering as cancer does. (It is recognised that this situation is changing globally because of greater public awareness and epidemiological trends, and so we recommend that a later working group should address the special needs surrounding palliative care for non-cancer populations).

On the other hand, in many countries it should be acknowledged that, at present, the diagnosis of cancer makes the access to palliative care – where it exists – much easier. (The corollary of this is the relegation of non-cancer patients with life-threatening disease and unrelieved distress to a 'second class' position with respect to accessing palliative care services; this inequity needs to be addressed by a later working group). The problem arises when patients' and families' expectations for palliative care are raised by a diagnosis of cancer, and the actual services are not available locally to respond to their needs.

In cancer treatment, oncologists may feel it is appropriate to withdraw when they think the disease is not curable. This often leads to a sudden transition in the locus of care from secondary/tertiary care to the primary care team. The shift away from the protective hospital environment emphasises the need for good dialogue and coordination between the oncology and primary care teams, and for palliative care services to strengthen their involvement with the patient and family at this point, so that they do not need to feel abandoned.

Patients with cancer may be younger than those with most other chronic life-threatening diseases. This has special consequences for their families, which may include partners trying to remain at work and dependent children; and for the professional carers, who are confronted with their own mortality by identification with patients of their own age.

Prognostication in cancer is always uncertain, which can lead to increased anxieties and difficulties in planning, even when the patient is apparently in remission, and especially when the disease relapses with metastases [8]. Furthermore, patients may die from cancer from a variety of causes (local progression, metastases, non-metastatic complications, iatrogenic illness, etc.) – thus the clinical pathways are more varied and unpredictable than with other non-malignant progressive diseases. This underlines the need for continuing surveillance and psychosocial support, which palliative care can provide if it is available to all cancer patients by right.

## 7. Minimum requirements for palliative care

The ESO international working group proposes that in order to ensure an equitable provision of palliative care throughout European countries, certain minimum requirements need to be met. We have attempted to show, where possible, how these requirements may be met through clinical and organisational protocols.

### 7.1. Fundamental principles

- (a) Palliative care should be recognised immediately in all developed countries, and as a high priority in developing countries, as an essential facet of healthcare for patients with cancer, and for their families and close friends.
- (b) Palliative care should be available around the clock, seven days a week, at a basic level through the general healthcare services and at an expert level through specialised palliative care teams.
- (c) All major cancer centres should include a specialised palliative care service.
- (d) Palliative care should aim to optimise the control of pain and other distressing symptoms.
- (e) Palliative care should offer psychological, social, existential and culturally sensitive support for patients and their families and other informal carers.
- (f) Palliative care should be part of each country's national, regional and local plans for comprehensive supportive care of cancer patients.
- (g) The advancement of palliative care for cancer patients should be integrated with corresponding developments covering palliative care for patients with progressive and life-limiting non-malignant diseases.

### 7.2. Clinical issues

- (a) *The objectives of palliative care services include –*
  - (i) The optimisation of quality of life and of dignity in illness and in dying.
  - (ii) Recognising the patient's choice and autonomy.
  - (iii) Recognising the patient's needs, in any care setting.
  - (iv) Recognising the needs of family members during the illness and, if required, for bereavement support.
- (b) *How to achieve these –*
  - (i) When a patient has difficult symptoms which cannot be controlled by his/her current healthcare team, he/she has a *right to be referred*, and the current healthcare provider has an *obligation to refer*, to the local specialised palliative care team.
  - (ii) Care should be provided preferably in the patient's home, if that is his/her choice and it is

feasible, by a home care service working in liaison with the primary care team.

- (iii) If care cannot be provided in the patient's home, the palliative care team should be able to access and support the patient in any appropriate outpatient, day-care or in-patient setting.
- (iv) Unnecessary restrictions on prescribing those drugs known to be helpful for symptom control, hinder the relief of pain and other forms of distress; therefore there should be full and equal access to all proven drugs, especially the potent opioids.
- (v) The palliative care service should demonstrate multi-professional and interdisciplinary team-working.
- (vi) The palliative care team should support the primary care team and oncology team in their own care of the patient, by sharing of knowledge, skills and resources.
- (vii) The palliative care team may take the lead in the care of the patient, if appropriate, at the request of the primary care or oncology team.
- (viii) The palliative care team should demonstrate the application of recognised quality assurance programmes.
- (ix) Socially isolated patients should be identified in order to have their needs recognised and met.
- (x) Patients and families from ethnic minority groups should have their special cultural and religious needs recognised and met.
- (xi) Children and young people with cancer should have their special physical and psychological needs recognised and met, in conjunction with appropriate paediatric or adolescent services.

### 7.3. Educational needs

#### (a) *The objectives of educational programmes in palliative care include –*

- (i) Education, training and continuing professional development (CPD) should be available for all disciplines working in palliative care.
- (ii) Palliative care education, training and CPD should be aimed at improving knowledge, skills and attitudes.
- (iii) Patients, their families and the public should have access to information and education on cancer and palliative care.
- (iv) Healthcare policy-makers and politicians in all countries should be kept informed about palliative care priorities.

#### (b) *How to achieve these –*

- (i) Palliative care education should preferably be delivered in multi-professional programmes

which emphasise the integrative approach to supporting patients.

- (ii) Palliative care should be taught at the undergraduate level in all disciplines.
- (iii) Postgraduate training for any professions which have contact with cancer patients, and, in particular, for primary care staff and oncologists, should include a programme covering advanced levels of palliative care.
- (iv) CPD of all specialties and of the primary care team should include palliative care issues.
- (v) CPD should teach professionals to be aware of their own limitations, to know where to access more information, and how to refer the patient to a local palliative care team.
- (vi) Professional attitudes towards palliative care needs of patients and family carers may be enhanced through greater emphasis on communication skills teaching in all disciplines.
- (vii) Education programmes for professionals in primary care and oncology should be jointly developed by their own disciplines and specialists in palliative care.
- (viii) Professionals who work in a palliative care team should have a structured training programme, which should emphasise competence in delivering palliative care in a multi-professional team, as well as working effectively as an advisor to other professionals.
- (ix) At present, it is *not* recommended that specialists in palliative care should take examinations in this subject.
- (x) All countries should recognise the specialty of palliative medicine, which should have an agreed training programme (and within Europe, preferably harmonised across countries).
- (xi) There should be at least one academic centre for palliative care, with a chair of palliative medicine, in each country, to take the lead on medical education.
- (xii) There should be at least one chair of palliative care nursing in each country to take the lead on nursing education.
- (xiii) Professional educational material relating to palliative care should be available in all regionally relevant languages.
- (xiv) Information and educational programmes aimed at the public should be available in all relevant languages, including the ethnic minority groups in Westernised countries. Within Europe, the European Union (EU) has an obligation to make all these translations available.
- (xv) Within Europe, the EU should facilitate the possibilities of exchange of current educational programmes in palliative care developed in

some Member States, to be used in other European countries, in the countries of the former Soviet Union, and in other developing countries.

#### 7.4. Research issues

##### (a) Objectives of research in palliative care –

- (i) There should be more research on subjective outcomes, especially measuring quality of life, for patients with advanced and terminal cancer.
- (ii) Research on palliative care aspects should be undertaken at the same high levels of quality and ethics as other types of cancer research.
- (iii) All healthcare professionals should have access to and be able to interpret the palliative care research which applies to their patients.

##### (b) How to achieve these –

- (i) Palliative care research should be designed in sympathy with the needs of the patients in mind, and the methods may vary with different research questions and at different stages of the disease.
- (ii) Methodologies for evaluating palliative care interventions and services need to be further developed and tested.
- (iii) More research is needed on the basic mechanisms of symptoms and treatments, on suitable outcome measures including quality of life scales, and on appropriate methodologies such as qualitative studies.
- (iv) Within Europe, standardised instruments for palliative care research should be translated and validated in all EU languages, to facilitate international collaboration and comparisons.
- (v) High quality research methodologists should be encouraged to become involved in the design of palliative care studies.
- (vi) There should be more high quality palliative care studies being published in high-impact, peer-reviewed international journals.
- (vii) The chairs of palliative medicine should take the lead on medical research.
- (viii) The chairs of palliative care nursing should take the lead on nursing research.
- (ix) Education for all specialists in palliative care should include research methods training.
- (x) Palliative care researchers should collaborate with senior researchers in other disciplines, to undertake better studies.
- (xi) Healthcare professionals should be shown and should understand the benefits to patients and families from participating in palliative care research.

- (xii) In Europe, the EU and national funding bodies should be required to fund more palliative care research, e.g. by ‘ring-fencing’ funds.
- (xiii) European countries should set up research fellowships in palliative care studies, which should be available also to prospective researchers from the countries of the former Soviet Union and from developing countries.
- (xiv) There should be more European and international research-based conferences which cover all relevant disciplines and methodologies for palliative care studies.

#### 8. What is the ‘gold standard’ for palliative care?

The ESO international working group wished to describe a ‘gold standard’ for palliative care in all European countries. It realises that this is an idealistic position, but one that nevertheless can be used as a target to be aimed at by healthcare professionals and health services alike.

Ideally, all the features of basic and specialised palliative care described above, should be available immediately in all developed countries, for all eligible patients. It should be emphasised that promoting palliative care is not about defining a new patient group or new treatment modalities *per se*, but rather the rational application of resources to optimise quality of life for seriously ill people. However, it is recognised that current limitations of finance and other resources (staffing, specifically designed units, beds, equipment, etc.) are lacking at different levels within Europe and also to a greater extent between Westernised and developing countries.

Details of what should constitute this ‘gold standard’ service can be found on the ESO website [9].

#### 9. What is meant by ‘multi-professional teamwork’?

Many times in this document, we have referred to multi-professional teamwork. It is important to clarify this, and to propose minimum requirements for palliative care at both the basic and specialised levels.

1. Multi-professional teamwork implies that a network exists of trained professionals in different branches of health and social care.
2. This network should, for some ‘core’ members of the team, be founded on regular meetings or other forms of consultations where individual patients are discussed.

3. The core members of a multi-professional team in palliative care depends on the level –
  - (i) For *basic palliative care*, the multi-professional team should include at least the general practitioner and a community-based nurse, who have good access to one of the members of the oncology team (e.g. a specialised nurse or social worker).
  - (ii) For *specialised palliative care*, the multi-professional team should ideally include –
    - (a) One or more doctors trained to a higher level in palliative medicine.
    - (b) One or more nurses trained to a higher level in palliative care.
    - (c) Input from named and permanent professionals from the following disciplines, who are trained to a higher level in their own branch of health or social care –
      - (a) Social work.
      - (b) Psychology or psychiatry.
      - (c) Nutritional support.
      - (d) Physical therapy.
      - (e) Occupational therapy.
      - (f) Religious (pastoral) care – this may have to cover representatives from several religions, depending on the location and cultural mix).
      - (g) Pharmacy.
      - (h) Validated complementary therapies.

Further details of the working group's recommendations on multi-professional teamworking can be found on the ESO website [9].

## 10. What are the next steps in the implementation of this framework?

The ESO international working group was convened on an *ad hoc* basis, with representatives from several, but not all, European countries. It is important that wide coverage of the issues and proposed solutions is sought throughout the enlarged EU, especially with the many new countries which have joined in 2004. It would be appropriate to hold a series of meetings based on the original international group, but including more countries and also more disciplines.

In order to further the aims and penetration of palliative care into all areas of cancer management, there needs to be collaboration between the main professional bodies. This should include the ESO, possibly as the coordinator and organisations such as the WHO, European Organisation for Research and Treatment of Cancer (EORTC), European Society of Medical Oncology (ESMO), Federation of European Cancer Societies (FECS), Multinational Association for Supportive Care

in Cancer (MASCC), European Association for Palliative Care (EAPC), International Association for Study of Pain (IASP) and International Union against Cancer (UICC). In many European countries, there already exist strong uni- and multi-professional organisations aimed at advancing palliative care. These should be consulted and included in the discussions, and they should be encouraged to share what they have individually learned and developed. Organisations which could practically assist this multilateral collaboration are the International Observatory on End of Life Care [10] and the EAPC Centre for Palliative Care in Eastern Europe [11].

There is a move in Great Britain and other parts of the world to think in terms of 'supportive care' for cancer and other life-limiting diseases. Just as there has been uncertainty and ambiguity about the meaning and scope of palliative care, so supportive care is accompanied by some confusion. The guidance from the UK National Institute for Clinical Excellence proposes that supportive care is the comprehensive care of patients and their families from the time of diagnosis, or even pre-diagnosis, throughout both curative and palliative treatments [12]. Palliative care, according to the ESO definition given above, thus represents a crucial part of supportive care which is aimed at those in whom the prognosis is limited. We would welcome further dialogue between those involved in palliative care and in supportive care to clarify the boundaries and overlaps.

Finally, it is imperative that in order to offer truly patient-directed care, there has to be much more engagement by professionals and those involved in running palliative care services, with patients, their carers and their representatives [13]. This must be done in a way that gathers users' views of the problems they encounter, the barriers they meet and the experiences they have of receiving palliative care.

## Conflict of interest statement

None.

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