



The Scottish Parliament
Pàrlamaid na h-Alba

Published 15th September 2015

SP Paper 784

9th Report, 2015 (Session 4)

Web

Health and Sport Committee

A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us?



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Health and Sport Committee

To consider and report on health policy, the NHS in Scotland, sport and other matters falling within the responsibility of the Cabinet Secretary for Health, Wellbeing and Sport, and measures against child poverty.



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Note: The membership of the Committee changed during the period covered by this report, as follows:

Malcolm Chisholm replaced Richard Simpson on 2 September 2015.

Introduction to the Report

1. At its meeting on 23 June 2015 the Health and Sport Committee agreed to commission research on international comparisons of measurement of data used in palliative and end of life care. The research aimed to explore which indicators were used to measure the access to and the quality of palliative and end of life care in other countries. It also considered which indicators have proven effective and why, based on international experiences and research. The research was to focus on recommendations made in published research and literature.
2. The research for the Committee was produced by Professor David Clark, Wellcome Trust Investigator, School of Interdisciplinary Studies, University of Glasgow.
3. The views expressed are those of the author of the report.

Executive Summary

4. Palliative care aims to prevent and alleviate suffering associated with life limiting illness, and it is particularly associated with care at the end of life. Its principles are holistic and multi-disciplinary, focussing on physical, social, psychological and spiritual concerns in the context of serious illness. To these ends it engages the skills of medicine, nursing, social work, psychology, allied health professions, family members, and often volunteers and wider communities. It has developed specific expertise in the understanding and management of pain associated with advanced disease and it provides expertise in relation to other, often complex, symptoms that may occur across the trajectory of illness.
5. The purpose of this report is to: identify, discuss and compare effective international data measurement indicators which provide accurate information about access to and the quality of palliative and end of life care. These indicators should be translatable into the palliative care framework within Scotland. Indicators identified should cover the typical variety of settings which are common in Scotland namely: acute facilities, hospice, community care and home care.
6. Palliative care is still a relatively new field and one which is developing rapidly and gaining a significant measure of wider professional, policy and public interest. Its origins lie in the hospice movement of the late 1960s, when its early activities were mainly in the charitable and voluntary sector. Most of those it served at that time had a diagnosis of cancer and 'terminal care' was often delivered for a very short period of time before death. Today the need for palliative care is changing. There is a growing desire to make palliative care available to all who can benefit from it, regardless of diagnosis, social circumstances, geography or care setting. There is an interest in earlier intervention to deliver the benefits of palliative care

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over longer periods. To this end palliative care becomes not just the business of specialists, but of professionals and carers of many kinds who encounter people with serious and life-limiting illness. Meanwhile, ageing populations, the likelihood of experiencing several significant health problems at the end of life and a growing emphasis on person-centred care and individual choice, all create new demands in the delivery of palliative care.

7. Palliative care is both a public health and a human rights issue. The first perspective assumes the insertion of palliative care into the public health system, thereby positioning it in the world of policy making, government priorities, need, supply, and resource allocation. The second perspective derives from the assumption that the development of palliative care can gain benefit from a rights-based approach.
8. The two are inter-connected and together they have the potential to secure the right and fair access to palliative care as legal and policy imperatives, with binding consequences when they are not met. Currently most countries are still some way off this position. But in 2014 the World Health Assembly passed a resolution requiring all governments to recognise palliative care and make provision for it in national health policies. This is resulting in heightened attention to the state of palliative care in specific jurisdictions – the extent to which it is recognised, resourced and delivered as well as the quality of provision and the educational and research programmes that can support it.
9. This report looks at three sets of palliative care indicators:
 1. Indicators of **specific resources** (or inputs) that support the delivery of palliative care – services, beds, staff, drug availability, training, policies, research infrastructure, guidelines, funding mechanisms, professional accreditation
 2. Indicators of **need** or **process** that tell us something about the requirement for palliative care or the ways in which it is being organized and delivered
 3. Indicators of **quality** (or outcomes) that tell us something about how well palliative care is being delivered – audits, evaluation studies, quality markers, service user feedback and results from randomised trials.
10. Only 20 countries in the world have achieved a significant degree of palliative care development as demonstrated by levels of service provision, education, drug availability, research, financing and policy recognition. Palliative medicine is recognised as a specialist field of activity in only 26 countries worldwide, the first of which was the United Kingdom in 1987.
11. Globally, good access to pain management is the exception not the rule: 5.5 billion people (83% of the world's population) live in countries with low to non-existent access to pain relief, 250 million (4%) have moderate access, and only 460 million people (7%) have adequate access. Insufficient data are available for 430 million (7%).

12. All of the key studies of palliative care development around the world rank the United Kingdom at the top of the scale with regard to the organisation and delivery of palliative care. Some of the measures used to do this require further refinement, but results across studies and methodologies are fairly consistent. Within these studies however it is not possible to characterise the Scottish context, since palliative care in Scotland is only a constituent part of the data for the UK as a whole.

Need and process

13. Reliable studies estimating the need for palliative care at a population level have been produced in Australia, Spain and England. These give an upper estimate that in rich countries around 82% of all people who die would benefit from palliative care. This would equate to c40, 000 in Scotland. In England, slightly less robust estimates have been produced which indicate the numbers that might currently be receiving palliative care. These have been used to form estimates of those who might benefit from but are currently not receiving palliative care - giving an estimate for Scotland of 10,600 people who die each year without receiving palliative care.
14. Part of the problem is one of identification of those who might benefit. An important study has demonstrated that in Scotland on a given day, 28-9% of the hospital population (in 2010 and in 2013) were in the last year of life and that 8-9% of the hospital population on any given day will die before they leave. This seems to present a good opportunity for identification and planning.
15. The Supportive and Palliative Care Indicators Tool (SPICT) has been in development since 2010 as a collaborative project between NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group (see Appendix 1). Now widely known, with international collaborators in Australia, North and South America and Europe, it is a guide to identifying people with one or more advanced conditions, who have deteriorating health and a risk of dying – and who might benefit from the palliative care approach. It has significant potential for use across care settings and has the ability to combine with other measures – such as palliative care registers and Key Information Summaries. But all of these approaches are untested in rigorous comparative studies and need further development. The lesson of the Liverpool Care Pathway must be one of caution about introducing untested procedures into the palliative care system without foresight and consideration about the unintended consequences.

Outcomes

16. The presence of high scores for resources and inputs, along with evidence of the use of measures of need and process is not a guarantee of good outcomes for palliative care. The United Kingdom scores high on the international palliative care rankings, but these are overwhelmingly based on measures of resource or input, and not outcome. As a result the UK has not been shielded from significant public

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criticism about its end of life care provision, much of it based on quality inspections as well as on negative public opinion. This has been far less marked in the Scottish context however.

17. Researchers increasingly favour patient reported outcome measures in palliative care and there is some evidence that these can rapidly feedback into service delivery and practice, where they are used locally. There is now a well-recognised clutch of measures which have been well validated and are in use internationally. Within these the items that appear most useful to practitioners relate to pain, symptoms, emotional needs and family concerns. An empirical study would be required to ascertain to what extent these measures are in use in Scotland. Meanwhile, population based indicators of palliative care, with appropriate numerators and denominators are still not well developed. In Scotland, efforts have been made to introduce a small number of these, but with one exception (time spent in the place of usual residence in the last six months of life) these have not yet been a success.
18. Despite the emphasis on patient views, some proxy measures bear continued consideration. Chief among these is Views of Informal Carers – Evaluation of Services (VOICES) which has been used locally in Scotland (though not recently). It has been adopted in England as the instrument for annual monitoring of satisfaction with care, as seen by the carer or relative of someone who has died recently and forms the core of the National Survey of Bereaved People.

Key findings and recommendations

19. Around the world there is evidence of growing activity relating to the development and testing of both outcome measures and indicators of palliative care quality. But most of this appears to be conducted within specialist centres and is yet to find its way into the mainstream of health and social care delivery.
20. There is little evidence of nationally adopted palliative care indicators that are in use. Whilst guidelines and standards for palliative care delivery proliferate, along with measures of outcome, there is no consensus on the appropriate indicators of palliative care quality that should be endorsed by governments. Some sets of indicators in the literature look far too detailed and cumbersome to achieve widespread adoption.
21. Attention is needed to the adoption of a small number of palliative care indicators that are robust and workable across settings in Scotland and which are endorsed by the key organisations and groups.
22. Further consideration should be given to the piloting of VOICES and to its wider adoption (or a localised and shorter version thereof) as a national quality indicator.

23. A systematic review is needed of published research on palliative care that has been conducted in Scotland. Discussions about the creation of a palliative care research network for Scotland are to be encouraged, with a focus on indicators and outcome measures.
24. A serious information deficit needs to be filled on data relating to the provision of palliative care in Scotland – starting with inputs and resources, but also including needs analysis, access, quality and outcome.

Introduction to the research

25. This work is intended to inform and guide the Health and Sport Committee's Inquiry into Palliative Care, in particular by contextualising current provision in Scotland against wider international norms and in relation to known trends in the development of palliative care in cognate countries. It focuses on the specific matter of palliative care indicators, mainly in relation to specialist palliative care, but also in the context of wider services. The author is also working with the Scottish Government as Consulting Editor to the Strategic Framework for Action on Palliative and End of Life Care, due to be published in late 2015.
26. The brief for this report was to: identify, discuss and compare effective international data measurement indicators which provide accurate information about access to and the quality of palliative and end of life care. These indicators should be translatable into the palliative care framework within Scotland. Indicators identified should cover the typical variety of settings which are common in Scotland namely: acute facilities, hospice, community care and home care.
27. The relevant palliative care indicators are assessed in three categories:

Category 1: Indicators of specific resources (or inputs) that support the delivery of palliative care – services, beds, staff, drug availability, training, policies, research infrastructure, guidelines, funding mechanisms, professional accreditation.

Category 2: Indicators of need or process that tell us something about the requirement for palliative care or the ways in which it is being organised and delivered

Category 3: Indicators of quality (or outcomes) that tell us something about how well palliative care is being delivered – audits, evaluation studies, quality markers, service user feedback and results from randomised trials.
28. The report assesses what is known about these internationally, particularly among the 20 countries of the world that are most advanced in their hospice-palliative care development. These 20 countries, with the population given for those closest to that of Scotland, are: Australia, Austria (8.47m), Belgium, Canada, France,

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Germany, Hong Kong (7.18m), Iceland (0.32m), Ireland (4.59m), Italy, Japan, Norway (5.08m), Poland, Romania, Singapore (5.39m), Sweden (9.59m), Switzerland (8.08m), Uganda, United Kingdom and the United States of America.

29. In taking this approach it is important to note that in all of the international mapping studies to date, the particular characteristics of Scotland are not available, since they appear within the United Kingdom as the unit of analysis. This paper addresses the issue of how this might be overcome in future.
30. In relation to international indicators, the Committee is particularly interested in the following nine questions.
1. What indicators are commonly used? What indicators have been used consistently over time? What is the scope of these indicators?
 2. How are indicators determined to be successful or not? Are indicators used generally at a national level or local level? Are these indicators part of a legislative framework or voluntary agreements or other approaches?
 3. What legislative requirements are there to accessing and receiving palliative and end of life care?
 4. Are indicators reviewed and re-evaluated regularly? How are these indicators used to influence service provision and funding?
 5. What safeguards are in place to ensure that data collected from the indicators are accurate and consistent across providers?
 6. What data is collected, how often and what type of analysis takes place? Who collates, holds and analyses this information? How is the data used and reviewed? Is the data published? How long has the particular country been gathering data?
 7. How successful are the indicators in capturing both access to and quality of palliative and end of life care in different care settings? Do indicators differentiate between cancer and other life-limiting illnesses and adult and paediatric care?
 8. Are there any other mechanisms in place in countries with successful palliative and end of life care systems, such as peer review and awareness-raising, which would be helpful to put into place in Scotland to achieve the objectives of equitable access to high-quality palliative and end of life care?
 9. How does the provision of palliative care in Scotland compare to other countries globally?
31. The main sections of this report offer a wide ranging discussion of the issues; this is followed by some comments on their relevance to the Scottish context, along with certain recommendations that could be considered; answers to each of these nine questions are then presented.

Context: history of palliative care development

32. Palliative care in its modern guise first emerged during the 1960s and 1970s, though its roots and antecedents are much older. Palliative medicine was first recognised as a specialty in the United Kingdom in 1987 and this recognition now exists in some 25 other countries.¹ Palliative care can therefore still be regarded as an emerging field of health and social care intervention, which continues to seek ways to integrate with wider systems and policy frameworks.
33. Palliative care aims to prevent and alleviate suffering associated with life limiting illness, and it is particularly associated with care at the end of life. Its principles are holistic and multi-disciplinary, focussing on physical, social, psychological and spiritual concerns in the context of serious illness. To these ends it engages the skills of medicine, nursing, social work, psychology, allied health professions, family members, and often volunteers and wider communities. It has developed specific expertise in the understanding and management of pain associated with advanced disease and it provides expertise in relation to other, often complex, symptoms that may occur across the trajectory of illness. Within the organisation, delivery and practice of palliative care, ethical and moral concerns also feature significantly.
34. In some ways palliative care has the attributes of a single issue social movement, since it has engaged the interests and commitments of those well beyond the world of healthcare delivery and it is focussed around a specific aspect of care. But it is also a multi-faceted field of specialisation, with associated academic endeavours in teaching and research and a growing recognition among professional societies, scientific funders, universities and training establishments. It has been drawn to a public health paradigm when considering levels of need, appropriate policies and services for delivery, together with suitable quality assurance and evaluation. It also makes an expanding claim for recognition as a human right. Increasingly, the reach of palliative care extends to health policy makers, politicians and global health organisations and discourses.
35. Palliative care has a close but sometimes complex relationship with hospice care, and this differs across countries of the world. Many varieties of hospice and palliative care delivery can now be observed in a wide number of settings. Whilst few of these are supported by proven evidence of success, they do testify to the rich field of activity and the imaginative and diverse approaches that have been developed in different resource, cultural and healthcare contexts. Palliative care is also seeking to develop an appropriate relationship with other areas of the health care system, in particular those primarily focussed on curative treatments, rehabilitation or the management of long-term conditions. It faces specific challenges in the face of changing demographics, epidemiology and patterns of symptomatology. As palliative care develops its scope, aims and boundaries are

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continuing to be re-defined. At the same time it is responding to changes in the clinical, demographic and epidemiological landscape. The need for palliative care now is significantly different to when hospice founders first began to define it 50 years ago.

36. A significant breakthrough in the development of palliative care in the global context came in 2014. First, the World Health Organisation published the first ever Global Atlas of Palliative Care at the End of Life,² which was endorsed by the WHO executive board.³ A few months later, the World Health Assembly, the governing body of WHO which is made up of the health ministers of member countries, passed a resolution requiring all governments to recognise palliative care and make provision for it in national health policies.⁴ Work is now underway to ensure the implementation of the resolution, particularly in Low and Middle Income Countries, but its imperatives are important for all countries – and to this end they are being addressed in the drafting of the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care, due for publication by the end of 2015. Very recently WHO has published an excellent 'fact sheet' (see Appendix 2) on palliative care.⁵ These are important times therefore in the development of palliative care and provide a wonderful opportunity to move thinking and practice about it right to the heart of the health and social care system.

Conceptual clarification/definition

37. There has been significant debate about the various definitions and models of palliative, end of life and hospice care that now exist. The World Health Organisation has produced two definitions, in 1990 and in 2002 but many more are reported in the literature.
38. The main debate currently in the definition of palliative care is the extent to which 'end of life issues' and death itself form a salient part of the focus of care. It was in 1974 that the Montreal surgeon, Professor Balfour Mount, inspired by the modern hospice ideal that was beginning to develop at that time, opted for the term 'palliative care' as one that might have better application in the health care system. Quite quickly there was an interest on the part of those in the field to bring the benefits of the palliative care approach to patients and families to an earlier stage of the disease progression. Earlier palliative care intervention has increasingly been seen as a good thing. But over time policy makers in particular have adopted the term 'end of life care' – and this is generally seen to be focussed on the last year of life. In the public mind understanding of these issues appears fairly sketchy, though it is also under-researched.
39. A 2001 United Kingdom survey conducted by the charity Help the Hospices found that 92% of respondents were aware of the term hospice, compared to 68% who were unaware of palliative care.⁶ A 2003 Scottish survey however found that the majority of respondents had some knowledge of palliative care, though one third

reported no knowledge at all. The most knowledgeable were health care workers, those working in palliative care and women.⁷

40. A study conducted in Northern Ireland in 2011 showed that whilst the majority of respondents (83%) had heard of the term 'palliative care' over half claimed to have low knowledge about it, whilst a fifth stated they had no understanding of the term at all. Again women and those working in the health care system reported the higher levels of knowledge. The majority defined palliative care as pain relief for people with terminal illness at the end of life with the aim of achieving a peaceful death. Although participants were not asked to specify conditions, many associated palliative care with cancer and care of older people. When respondents were asked to reflect on the aims of palliative care, the majority cited delivery of comfort (82%), pain relief (81.3%), and dignity (76.3%) as priorities.⁸
41. The two approaches to palliative care can be summarised in the words 'concurrent' and 'transition'. Should the model of palliative care be one that sees it being offered concurrently with the trajectory of illness, from an early stage and in some cases even from the point of diagnosis of a serious illness? Or should there be a 'transitioning' to palliative care when other interventions have proved ineffective?
42. Today, for example in America, a central feature of palliative care development is the goal of developing palliative care concurrently with interventions focussed on cure and rehabilitation. Some important studies have supported this and are well represented in the literature.⁹ Part of the dilemma here is that these – mainly hospital based – services are not well recognised in the US reimbursement framework and so are often reliant on philanthropic subventions of various forms. Palliative care activists are therefore seeking ways to demonstrate their cost-benefits alongside the work of the existing medical services.
43. By contrast there is the more widely understood notion of transitioning to palliative care when the potential for cure or rehabilitation has been exhausted and when the focus shifts to 'comfort care' and the maintenance of quality of life. This model has been enshrined in the hospice Medicare funding scheme in the US since the 1980s and has fuelled a massive growth in American hospices, the majority of which are now for-profit organisations. Until now, receipt of hospice Medicare funding has required patients to forgo further curative treatment and has been restricted to those deemed to have a prognosis of six months or less. In 2016 however, pilot schemes will be introduced into 40 US states across 141 hospices, which will allow patients to receive hospice and curative care at the same time. The goal of the scheme is to encourage more patients to opt for hospice and thereby reduce healthcare costs. At present, nearly 30% of Medicare's \$600 billion annual budget is spent on treatment in the last six months of life, much of it on expensive interventions with limited benefits. Also from 2016 Medicare will for the first time reimburse doctors and other health professionals for talking to patients with advanced-stage diseases about their goals and wishes and the likely results of their remaining options for treatment.

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44. Hospice use itself can be an indicator of good quality end of life care. A very recent study¹⁰ shows that in 2011, 47.1% of those who died in America used hospice in the last 6 months of life. This is a very high figure that has increased steadily in recent years. It is also a statistic that cannot be provided for Scotland or any country of the UK and is made possible in America only because of the existence of, and ability to track, Medicare benefits for hospice provision. But the study also shows that American hospice use varied across states from 20.3% in Alaska to 60.8% in Utah. Patterns of hospice use also varied by state. The percentage of hospice users who had very short hospice enrollment ranging from 23.0% in the District of Columbia to 39.9% in Connecticut. The percentage of very long hospice use varied from 5.7% in Connecticut to 15.9% in Delaware. The percentage of hospice disenrollment ranged from 6.2% in Hawaii to 19.0% in the District of Columbia. Nationally, state-level hospice use among people who died was positively correlated with the percentage of potentially concerning patterns (including very short hospice enrollment, very long hospice enrollment, and hospice disenrollment) among hospice users. Oregon was the only state in the highest quartile of hospice use and the lowest quartiles of both very short and very long hospice enrollment.

Public health, equity, human rights, and palliative care

45. In the past decade it has become common to talk about the twin ideas that palliative care is both a public health and a human rights issue. The first assumes the insertion of palliative care into the public health system, thereby positioning it within a discourse of need, supply, and resource allocation. The second assumes that the development of palliative care can gain traction and attention from a rights-based approach.

Public Health

46. In 2015, at the European Association for Palliative Care world congress in Copenhagen, the Belgian sociologist Professor Luc Deliens gave a plenary lecture that underlined the need for palliative care to engage with the model of public health. This is an often repeated statement, but what is the link between palliative care and public health? First, there is concern that palliative care is still not well understood, it requires integration within health-care systems, and it needs measurable outcomes. This version of 'public health' articulates closely with that of the World Health Organisation and is the stuff of the World Health Assembly resolution of 2014. In palliative care terms, it has four components—the so-called WHO foundation measures: drug availability, education, policies, and (added later)¹¹ implementation. Against these measures, there is still much progress to be made in establishing palliative care provision and making it fully available at the population level through the health-care systems of individual countries.
47. Second, there is a view that palliative care has a different starting place. This begins with communities and capacity, rather than services and deficits. It recognises that in the last year of life for most people, 90% of time is spent in the

place of usual residence and that most of the care is delivered by family members and informal carers. This perspective has been widely articulated by Professor Allan Kellehear, another sociologist, but his notion of public health is rather different. Kellehear begins from the perspective that for much of our lives, including at the end of them, most of us are not face to face with health-care professionals and services. Rather, we encounter illness, loss, and mortality as social experiences that are shaped primarily by culture, by geography, by beliefs, by communities and relationships. Within this, medicine and medical care can be quite small elements. When he calls for a public health model of palliative care, he is therefore talking about something rather different. He points to the significance of community and ideas about prevention, harm-reduction, and early intervention strategies to address the social epidemiology of death, dying, bereavement, and long-term caregiving. This outlook has a health-promoting dimension, sees the main source of end of life care as families and communities (not specialists and services), and argues for a societal reappraisal of death, dying, and bereavement.¹²⁻¹³ The goal in this version is to achieve a greater measure of compassion and dignity in all aspects of dying and death, in whichever aspect of society they are manifested, and certainly not within the healthcare system alone.

48. The need for palliative care has been heavily defined by the disease status of patients and their particular associated needs. But as the field matured, a new front of exploration opened up associated not with the diagnosis, organ of the body, or disease severity, but with the particular places, settings, and social groups that might benefit from palliative care. From the 1990s on, specialist interest began to develop in palliative care for prisoners, for homeless people, and for those identifying as lesbian, gay, bisexual or transgender. From this perspective, palliative care availability and access are increasingly framed as matters of equity and also of human rights.
49. In autumn of 2011 two separate declarations emphasized the importance of palliative and end of life care. The United Nations (2011) made reference to the need for palliative care provision in its statement about the care and treatment of people with non-communicable disease. Then, the World Medical Association (2011) made its case for improvement in end of life care, stating that receiving appropriate end of life medical care must not be considered a privilege but a true right, independent of age or any other associated factors.
50. The palliative care community itself has also been active in producing exhortatory charters and declarations, usually promoted at specialist international conferences.¹⁴ These call on governments to develop health policies that address the needs of patients with life-limiting or terminal illnesses and to promote the integration of palliative care alongside other health services. They promote the need for access to essential medicines, including controlled medications, for all who need them, and they focus on the identification and elimination of restrictive barriers that impede access to strong opioids for legitimate medical use. These pronouncements also emphasise the importance of the supply line for such drugs, along with appropriate rules and laws governing their distribution and prescription,

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by properly trained practitioners. Such calls underline the need for appropriate initial and undergraduate education programmes for healthcare providers to ensure that basic knowledge about palliative care is widely disseminated and can be applied wherever there is the need in the healthcare system. They also highlight the need for postgraduate and specialty palliative care programmes so that patients with complex problems can receive appropriate care. Key to all this - and at the heart of the 'traditional' public health orientation - is the requirement that palliative care is properly integrated into wider healthcare systems with cost-effective services designed in relation to need and demand.

Human rights

51. Recognition of palliative care as a human right¹⁵ has been developing for some time, and access to palliative medication has been incorporated into a resolution of the United Nations Commission on Human Rights.¹⁶ The claim that palliative care is a human right seems however to be but partially founded.¹⁷ The United Nations Committee on Economic, Social and Cultural Rights has stated that it is critical to provide attention and care for chronically and terminally ill persons, sparing them avoidable pain, and enabling them to die with dignity. Also, under article 12 of the International Covenant on Economic, Social, and Cultural Rights, and article 7 of the International Covenant on Civil and Political Rights, countries are obliged to take steps to ensure that patients have access to palliative care and pain treatment.
52. Likewise, according to the United Nations Committee on Economic, Social, and Cultural Rights, states are under the obligation to respect the right to health by refraining from denying or limiting equal access for all persons to preventive, curative and palliative health services. Access to palliative care is a legal obligation, as acknowledged by UN conventions, and has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health. In cases where patients face severe pain, government failure to provide palliative care can also constitute cruel, inhuman, or degrading treatment. There are problems however with framing palliative care as a human rights issue from a western perspective and thereby setting standards which low and middle income countries will find hard to attain. It is also difficult to see how individuals might be compensated if their 'human right' to palliative care is denied in some way.
53. Nevertheless, there have been legitimate interests in palliative care from organisations like Human Rights Watch, and these seem set to continue.¹⁸ The most recent example (June 2015) is a declaration by the Organisation of American States, on Protecting the Human Rights of Older Persons. It requires states to offer older persons access without discrimination, to comprehensive care, including palliative care; to avoid isolation; to appropriately manage problems related to the fear of death and of pain; and to prevent unnecessary suffering and futile and useless procedures, in accordance with the right of older persons to express their informed consent.¹⁹

Changing trajectories of illness and dying

54. As the clinical practice of palliative care developed through the last quarter of the twentieth century, other issues began to challenge its orientation. Defined from the outset as a multidisciplinary endeavour, nevertheless the role of medicine has appeared to be the 'first among equals'. There has been a tendency for medical perspectives, medical assumptions and cultural practices, and medical solutions to frame the debate about how palliative care should develop. This is often because palliative physicians are looking over their shoulders at other specialities and seeking to keep pace with developments in cognate fields—oncology, geriatrics, cardiology, and respiratory medicine. It has led some external commentators to argue that a process of 'medicalisation' is at work within palliative care and that this could quickly dissipate its early more holistic intentions. There are also detractors from within, who caution against palliative medicine becoming 'just another specialty' and for whom an over emphasis on pain and symptom management seems to be at the expense of attending to the whole person, including not only a person's physical problems, but also social issues, spiritual, religious, or existential matters, as well as the needs of family caregivers, and matters of psychological and mental health. For some this raises concerns that the specialty of palliative medicine might make progress, but at the expense of the early goals of palliative care.
55. Palliative care began with an unequivocal focus on patients and families affected by cancer. It seemed that the widespread stigma associated with the disease, the poor prognosis that existed in many instances, the fairly predictable progression, and the possibility of severe pain and other debilitating symptoms all combined to make a perfect testing ground for the palliative care ethos. This came to be known as the 'rapid decline' trajectory, and it appeared to fit well with the perspective of hospice care, primarily focussed on the final months and weeks of life. Palliative medicine at first locked onto this paradigm and gave particular focus to alleviating the challenging problems associated with specific pain syndromes, as well as breathlessness, anorexia and cachexia, anxiety, and depression - all of which came to be seen as key determinants of quality of life in patients with advanced cancer.
56. Over time there were calls to extend the perceived benefits of palliative care, beyond patients with cancer to those dying from - and living with - other conditions. Patients started to be seen for whom the medical context was less familiar. Initially, this involved people with neurological conditions, such as multiple sclerosis and motor neurone disease, but in time it was extended to those with heart failure, stroke patients, people with dementias, as well as those affected by HIV/AIDS. Services for children also developed.
57. The distinction between cancer and non-cancer palliative care was in evidence for a period starting in the 1990s, but has become less common more recently. This was driven by the growing recognition of multiple morbidities and symptom burdens that occurred in medicine, which seemed particularly relevant to palliative

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care. At the same time, cancer was in many western countries making the transition into a treatable disease, associated with the new phenomenon of cancer survivorship and of cancer as a chronic and/or 'social care' issue. Palliative care, therefore, had to focus on patients with complex multiple problems, which might endure for potentially long periods. Attempts were made to characterise these into specific trajectories of dying, but if these seemed to make sense conceptually, they were found difficult to map onto any empirical reality. In the West at least, the epidemiology of many cancers has migrated into that of a chronic disease and, at the same time, the concept of multiple morbidities has become increasingly recognised clinically, meaning that the care of patients is more complex and protracted in a setting where patterns of decline associated with frailty, dementia, and impoverishment are more prevalent.

58. This shift is also associated with population ageing. The baby boomers draw attention to the growing reservoir of care needs in later life that resulted from the heightened birth rate in the two decades before the mid-1960s. And at the same time these people are set to live longer lives, as the twentieth century increased life expectancy due to improved health care and public health measures. This in turn became a global issue. Around 58 million deaths occur in the world every year and the number may rise to 90 - 100 million by mid-century and beyond. The increase in the number of deaths will be caused by population growth and population ageing, in combination. The likely demand this will place on caregivers and services suggests a humanitarian issue - if not crisis - of enormous scale and complexity.
59. If modern palliative care began in the 1960s and 1970s with the certainties of cancer as a terminal disease of predictable course, by the second decade of the twenty-first century, it is located in far less predictable settings, sitting alongside curative interventions, closely tied in with the needs of older people, but also subspecialised in paediatrics as well as in other medical specialties. When accreditation for hospice and palliative medicine was achieved in the United States, for example, it was formalised as a subspecialty of no less than eleven fields of specialist care. In each case, new knowledge would be required to build a palliative care orientation matched to a specialist field of medical intervention and also to the social dimensions of the underlying disease type or the complexities of multiple morbidity. In short the medical landscape in which palliative care is required to operate has become much more complex and nuanced in 2015 than it was fifty years earlier, when the early pioneers of the field began their work.

Indicators of specific resources (or inputs)

60. The global distribution and availability of palliative care is known to be highly inequitable:

- Only 20 countries have achieved a significant degree of palliative care development as demonstrated by levels of service provision, education, drug availability, research, financing and policy recognition.
 - Palliative medicine is recognised as a specialist field of activity in only 25 countries worldwide, the first of these was the United Kingdom in 1987.
 - Globally, good access to pain management is the exception not the rule: 5.5 billion people (83% of the world's population) live in countries with low to non-existent access, 250 million (4%) have moderate access, and only 460 million people (7%) have adequate access. Insufficient data are available for 430 million (7%)²⁰
61. From the mid-1990s, research studies have been conducted which map the differential development of palliative care in specific regions of the world and also globally. Understanding has grown about the common elements that unite the palliative care ethos, but also of the differences within it, the variations in local practice, cultures and assumptions, and the specific challenges and barriers that are encountered as it seeks to develop.

Key studies in international palliative care development

62. The first research study to explore the development of palliative care in a comparative manner across jurisdictions, conducted in the late 1990s, focused on seven western European countries.^{21–22} It showed two key variations in the delivery of palliative care.²³ First, palliative care services were found in a variety of settings: domiciliary, quasi-domiciliary, and institutional. Second, service types were not prioritised equally in every country. Allowing for population differences, there were great variations in the numbers of palliative care services across nations, and the number of specialist palliative care beds per head of population varied from 1:c18,000 persons in the UK to 1:c1.9m persons in Italy.
63. This work led directly to another study that successfully mapped the development of palliative care across twenty-eight former communist countries in Eastern Europe and Central Asia.²⁴ Only Poland and Russia had more than fifty palliative care services, and five countries had none. Home care was the form of service most commonly found, followed by inpatient provision. There was a great absence of hospital palliative care support teams, as well as services in nursing homes and day-care provision. Only forty-eight paediatric palliative care services were identified, covering just nine of the twenty-eight countries.
64. In the period 2003–2009, the International Observatory on End of Life Care based at Lancaster University, became the key source of palliative care mapping studies around the world, constructing national reports for over sixty countries.²⁵ In particular, it carried out major reviews of palliative care development in Africa (twenty-six countries),²⁶ the Middle East (six countries),²⁷ and South East Asia (three countries),²⁸ as well as a study covering the whole of India.²⁹ These reviews

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had several features in common. They established the number and character of palliative care services existing in a given country, funding arrangements, the level of policy support, and the specific context of opioid availability.

Global comparison of palliative care development

65. Emerging from this series of studies was an ambitious project in 2006 to measure and classify palliative care development in every country in the world. This involved the development of a four-part typology depicting levels of hospice and palliative care development across the globe, an idea which had first been developed in a review of services in Africa.

Group 1: Countries with no known hospice/palliative care activity -

- Best efforts have been unable to identify any palliative care activity in this group of countries

Group 2: Countries with capacity-building activity

- There is evidence of wide-ranging initiatives designed to create the organizational, workforce and policy capacity for hospice-palliative care services to develop. Activities include: attendance at, or organization of, key conferences; personnel undertaking external training in palliative care; lobbying of policy-makers and health ministries; and an incipient service development, usually building on existing home care programs

Group 3: Countries with localized hospice and palliative care provision

- The development of a critical mass of activists is found in one or more locations; there is evidence of local support, sourcing of funding, availability of morphine, the establishment of one or more hospice-palliative care services; and the provision of training by the relevant organization

Group 4: Countries where hospice and palliative care services were reaching a measure of integration with the mainstream healthcare system

- There is a critical mass of activists; multiple providers and service types; an awareness of palliative care on the part of health professionals and local communities; the availability of strong, pain-relieving drugs; an impact of palliative care upon policy; the development of recognised education centres; academic links forged with universities; and a national association in existence.

66. By presenting a world map of hospice and palliative care development – using these four criteria - the study sought to contribute to debate about the growth and recognition of palliative care services.³⁰ The typology differentiated levels of palliative care development in both hemispheres and in rich and poor settings. It showed that only half the world's countries (115/ 234) had some form of

designated palliative care service. The numbers of countries in each category were: 1. no identified activity 78 (33%); 2. capacity building 41 (18%); 3. localized provision 80 (34%) 4. approaching integration 35 (15%). The ratio of services to population among Group 4 countries ranges from 1: 43,000 (in the UK) to 1: 4.28 million (in Kenya); among Group 3 countries it ranges from 1: 14,000 (in Gibraltar) to 1: 158 million (in Pakistan).

67. In 2011, the analysis was updated with a refined six-point typology.³¹ Two categories were sub-divided to give greater definition.

Group 3 countries:

3a) Isolated palliative care provision. Countries characterized by: the development of palliative care activism that is patchy in scope and not well-supported; sourcing of funding that is often heavily donor-dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and limited in relation to the size of the population.

3b) Generalized palliative care provision. Countries characterized by: the development of palliative care activism in a number of locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; a number of hospice-palliative care services from a community of providers that are independent of the healthcare system; and the provision of some training and education initiatives by the hospice organizations.

Group 4 countries:

4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision. This group of countries is characterized by: the development of a critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health professionals and local communities; the availability of morphine and some other strong pain-relieving drugs; limited impact of palliative care upon policy; the provision of a substantial number of training and education initiatives by a range of organizations; and existence of (or at least an interest in the concept of) a national palliative care association.

4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. This group of countries is characterized by: the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities and society in general; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of palliative care upon policy, in particular upon public health

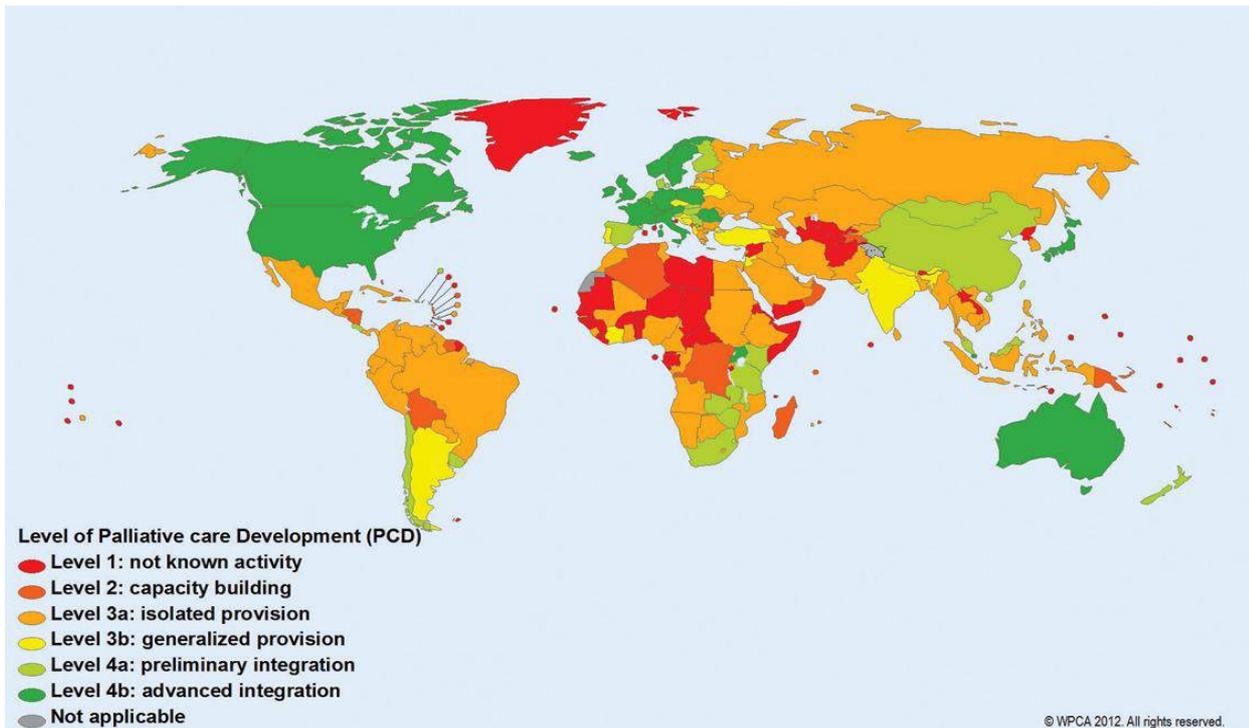
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policy; the development of recognized education centres; academic links forged with universities; and the existence of a national palliative care association.

68. Now, as shown in Figure 1, 136 of the world's 234 countries (58%) had one or more hospice/palliative care services established - an increase of 21 countries (+9%) from 2006. But by 2011, although there were indications of growing interest in palliative care on the part of national governments and policymakers, *advanced* integration of palliative care with wider health services (the highest category in the typology) had been achieved in only twenty countries globally (8.5%). Total countries in each category were: 1. 75 (32%), 2. 23 (10%), 3a. 74 (31.6%), 3b. 17 (7.3%), 4a. 25 (10.7%), 4b. 20 (8.5%). The ratio of services to population among Group 4a/4b countries ranged from 1: 34,000 (in Austria) to 1: 8.5 million (in China); among Group 3a/3b countries it ranged from 1: 1,000 (in Niue) to 1: 90 million (in Pakistan).

Figure 1 World Map of Palliative Care Development 2011



Global Quality of Death Index

69. Building on this approach, a study commissioned by the Lien Foundation in Singapore and carried out by the Economist Intelligence Unit was published in 2010.³² This attempted a linear ranking (rather than one based on defined categories) of palliative care development in forty countries, with a more complex set of indicators. The Quality of Death Index scored on twenty-four indicators in four categories, each with a separate weighting, as follows:

(1) basic end-of-life health-care environment (20%);

- (2) availability of end-of-life care (25%);
- (3) cost of end-of-life care (15%);
- (4) quality of end-of-life (40%).

70. Eleven of the Index's 24 indicators are based on quantitative data - for example, life expectancy and healthcare spending as % of GDP. Ten of the indicators are qualitative assessments of countries' end-of-life care standards, for example "Public awareness of end-of-life care", which is assessed on a scale of 1-5 where 1=little or no awareness and 5=high awareness. Three of the indicators describe whether something is or is not the case, for example, "Existence of a government-led national palliative care strategy", for which the available answers are Yes, No or In Progress.
71. The study ranked the UK first, with the best quality of death, owing to its advanced hospice care network and a history of state involvement in end of life care. It has been pointed out that in one subcategory of the ranking relating to the basic end of life healthcare environment the UK actually comes 28th.³³ The reason for its overall high ranking relates to the quality of provision of hospice care, some statutory sector involvement and the existence of a national end of life care strategy, all of which have more weighting than other categories. Some advanced nations rank poorly - for instance, Finland at 28 and South Korea at 32. The report noted the high position of Hungary (11) and Poland (15). The United States, however, with the largest spending on health care in the world, ranked just 9 in the index, principally due to limited public funding for end of life care, the costs to the patient, and the restriction of government-funded reimbursements through Medicare available only for patients who give up curative treatments.
72. The report noted that across the world, public health-care funding often prioritizes conventional treatment and provides only partial support for end of life care services, meaning such care must rely on philanthropy and community help. It took the view that a widespread cultural belief in affluent countries that governments should provide and pay for healthcare services has hampered private sector provision of end of life care services. At the other end of the scale were developing countries, such as China and India, where state funding levels for end of life care were very low, and provision patchy and localised, with private payment being the norm.
73. An updated Global Quality of Death Index is expected to be published in early autumn, 2015.

European development

74. A 2015 study shows³⁴ palliative care development data from a total of 46/53 (87%) countries across the WHO European Region, compared at two time points – 2005 and 2012. The analysis is based on data collected for two editions of the European Atlas of Palliative Care. It is broken down by Home Care Teams (HCT),

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Inpatients Units/Hospices (IPCS), and Hospital Support Teams (HST). In 2012, there were more than 5000 specialized palliative care services in Europe (2063 HCT, 1879 IPCS and 1088 HST) - an increase of 1449 since the same survey in 2005. The increases were statistically significant in Western Europe but not for Central and Eastern Europe.

75. This study is important in that it developed a measure of coverage for these specialist services – defined as the relationship between the known level of provision and the actual level of need – as set out in guidelines produced by the European Association for Palliative Care (EAPC)³⁵.
76. The EAPC defines ‘specialist’ services as those where the main activity is the provision of palliative care. These services generally care for patients with complex and difficult clinical problems. Specialist palliative care therefore requires a high level of education, appropriate staff and other resources. The study analysed data relating to three main types of specialist PC services: home care teams (HCT) consisting of 4 – 5 full-time professionals; hospital support teams (HST) (providing specialist advice and consultation with at least one physician and a nurse) and inpatient services (IPCS) – palliative care units or hospices with at least 8 beds.
77. According to the EAPC guidelines the required number of home care teams is one team per 100,000 inhabitants; the required number of both hospital support teams and inpatients palliative care services is one team per 200,000 inhabitants. Coverage – expressed as a percentage – is the measure of ‘fit’ between provision and need where 100% is ‘ideal’, figures below demonstrate under-performance against the guideline and figures above demonstrate over-performance.
78. Figure 2, taken from the 2015 paper, shows that for Western Europe as a whole in 2012 coverage was as follows: IPCS (62%), HCT (52%), and HST (31%). For Central and Eastern Europe coverage was: IPCS (20%), HCT (14%), and HST (3%). The levels of all three services are dramatically lower in Eastern Europe than in Western Europe and the trajectory of improvement between 2001 and 2012 is much flatter in Eastern Europe.

Figure 2 Changes in palliative care coverage 2005-12, Western and Eastern Europe

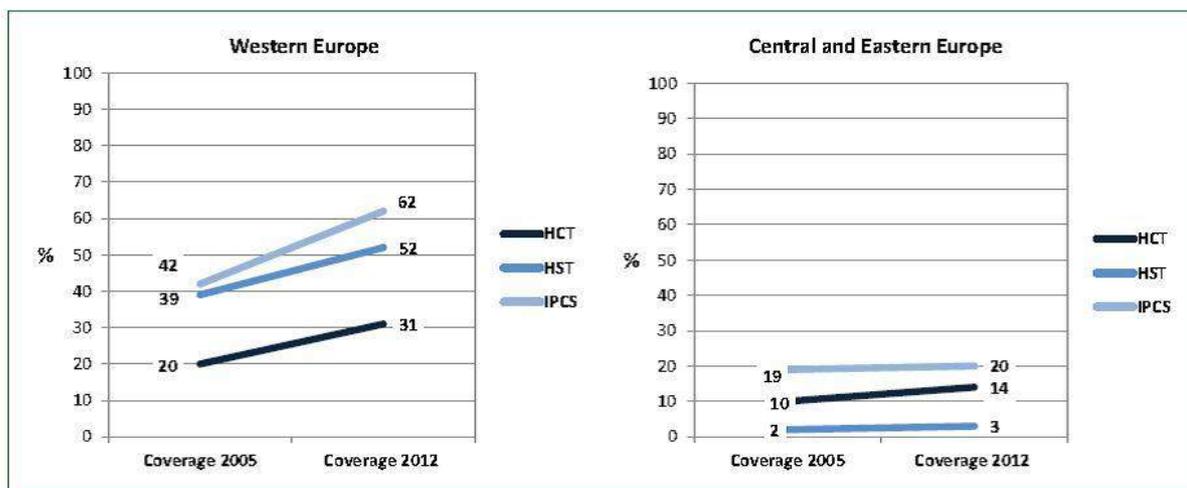


Figure 1. Changes in coverage in 46 European countries per type of PC service: home care teams (HCTs), hospital support teams (HSTs) and inpatient PC services (IPCSs).

79. In some instances however, countries striving to improve palliative care services more than doubled their absolute number of services over the period. These included Portugal (from 8 to 54 services, +575%), Denmark (from 18 to 54, +200%) and Germany (from 331 to 690, +108%), Slovenia (from 8 to 24 services [300%]), Romania (from 21 to 42 [200%]), Georgia (from 2 to 16 services [800%]) and Latvia (from 5 to 13 [260%]).
80. Provision of IPCS is greater than any other kind of palliative care service. Nineteen countries have almost 50% coverage in this type of service. Coverage higher than 80% was found in Luxembourg, Iceland, Austria, Sweden and Macedonia. Complete (100%) coverage for IPCS was found in Belgium, Denmark, Netherlands and Germany. The best HCT coverage was found in Iceland (122%), Sweden (113%), Estonia (112%), Poland (84%) and Ireland (76%). Impressive development of HST coverage was found in Belgium, Ireland, UK, Luxemburg, Andorra and France with around 100% coverage.
81. For the purposes of this report it is important to note that the United Kingdom and Iceland are the countries with the most balanced average coverage across the three types of palliative care service, with higher than 60% coverage across all three. In fact the United Kingdom overall coverage score for all three types of service is 82.3%.

EU ranking of palliative care development

82. Some work is in progress in ranking palliative care development in the countries of the European Union. There are both benefits and disadvantages to such ranking systems. They can provide some absolute measure of development as well as change over time; they can be used within specific jurisdictions to advocate for change and improvement. But they remain only partial measures of achievement;

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they can be based on unreliable data or unverified data; and they can be demotivating in jurisdictions that persistently rank low in the tables.

83. In this work³⁶ palliative care development is defined as a combination of existing palliative care provision in a country ('resources') alongside the capacity to develop further resource in the future ('vitality'). 'Resources' comprise indicators of specific palliative care services measured against population (specifically inpatient units, hospital support teams and home care teams). The calculation in the 'resource' domain is obtained as a ratio, per million inhabitants. Points are assigned to the relative position of the country with respect to the other 27 countries. The maximum number of points is 27 (28 in 2013 when a new country had joined the EU) for each of the three types of service, reflecting highest development and the minimum is one point, reflecting lowest development. This makes up a 'resource index'. The ranking position is then aggregated through computing all three indicators - resulting in a maximum of 81 (3 x 27) points across the two periods.
84. 'Vitality' is estimated through the existence of a national association, a directory of palliative care services, physician accreditation, number of researchers to population attending palliative care congresses, and publications on palliative care development.
85. The leading country (by raw score) is considered as the reference point against which all other countries are measured. Different weightings are then applied for each country to 'resources' (75%) and 'vitality' (25%). The result (Table 1) is a palliative care development ranking of the countries of the EU for 2007, in which the first five places are occupied by : UK, Ireland, Sweden, Netherland, Poland and the bottom five countries are: Malta, Greece, Portugal. Slovakia, Estonia. Data for 2013 (28 member countries) is currently being analysed.

Table 1 EU Ranking of palliative care ‘resources’ and vitality, 2007³⁷

COUNTRY	RESOURCES INDEX	Resources in relation with UK	VITALITY INDEX	Vitality in relation with UK	EAPC INDEX
	total points (max 135)	max 75%	total points (max 10)	max 25%	(75% resources + 25% vitality)
UNITED KINGDOM	124	75	10	25	100
IRELAND	111	67	7	18	85
SWEDEN	114	69	6	15	84
NETHERLANDS	105	64	7	18	81
POLAND	102	62	6	15	77
FRANCE	93	56	7	18	74
SPAIN	97	59	6	15	74
GERMANY	74	45	10	25	70
BELGIUM	93	56	5	13	69
LUXEMBURG	100	60	3	8	68
AUSTRIA	99	60	3	8	67
ITALY	90	55	5	13	67
DENMARK	72	44	5	13	56
FINLAND	73	44	4	10	54
LATVIA	74	45	3	8	52
LITHUANIA	67	41	2	5	46
HUNGARY	65	39	2	5	44
BULGARIA	65	39	2	5	44
CZECH REPUBLIC	56	34	4	10	44
SLOVENIA	59	36	3	8	43
CYPRUS	60	36	2	5	41
ROMANIA	41	25	6	15	40
MALTA	42	25	5	13	38
GREECE	45	27	4	10	37
PORTUGAL	37	22	3	8	30
SLOVAKIA	32	19	3	8	27
ESTONIA	10	6	1	3	8

RESOURCES INDEX: is an index of specific palliative care resources for adults: inpatient units, hospital support hospital teams, home care teams, beds, palliative care physicians) per population. 27 to the highest indicator score and 1 is the lowest. As there are 5 indicators in total the maximum score is 135.

VITALITY INDEX: is an index of comparison of the level of vitality of the palliative care movement in each country as follow: we mean "vitality" is the sum of the 5 indicators previously defined: existence of a directory of services, existence of a national society, existence of certification for PC physicians, articles published, attendance at EAPC congresses (see Table Vitality): the maximum level of vitality possible is 10. For the EAPC ratio vitality is 25% of the total.

EAPC INDEX: is an index of the total palliative care development: the development that is already achieved plus the possibility of develop PC in the next future. We have assumed 75% for resources that already exist and 25% for the vitality of PC.

Indicators of need or process

It has been estimated that only about 14% of those who might benefit from palliative care currently have access to it worldwide.³⁸

86. Understanding the need for palliative care is essential in planning services. But with a form of service like palliative care, with its varying definitions and approaches, need may be difficult to conceptualize and to estimate. How many people could benefit from palliative care – and does that mean ‘generalist’ or ‘specialist’ palliative care?

Need

87. For the United Kingdom in 1997, Higginson used cause of death and pain prevalence (based on the reports of relatives) and estimated that 60.20% - 60.36% of all deaths are preceded by a need for palliative care.³⁹ For Australia in 2005, Rosenwax used the International Statistical Classification of Diseases and Related Health Problems - 10th Revision (ICD-10) causes of death/hospital-use data, and produced an estimate of estimate of 37.01% - 96.61%⁴⁰. For Spain in 2012, Gómez-Batiste used percentage of deaths plus chronic disease data, and arrived at an estimate of 75%.⁴¹
88. A 2014 paper refines these methods of estimating population-based need for palliative care based on the views of an expert panel, and the application in a sample dataset for all deaths in England, January 2006 - December 2008, using linked mortality and hospital episode data. The expert panel highlighted several considerations: the extension of palliative care to more non-cancer conditions, changing patterns of hospital/home care and multiple, rather than single, causes of death. The study therefore estimated a minimum of 63.03% of all people who die in England need palliative care, with lower and upper mid-range estimates between 69.10% and 81.87%. It concluded: ‘In high-income countries, 69% - 82% of those who die need palliative care’.⁴²
89. The authors of the study note that specialist palliative care is provided in a variety of settings, including in dedicated inpatient palliative care beds (mainly provided in hospices but including dedicated specialist palliative care wards within hospitals), in the patient’s own home or care home (home-based care) or on an advisory basis while receiving acute hospital care from other specialities. They explain that the national survey of specialist palliative care services in England for 2010 states that 46,800 people were admitted to specialist palliative care inpatient beds, 95,600 people received home-based palliative care and 100,000 people received specialist palliative care in the hospital setting. The extent to which these groups overlap is unknown. Between 100,000 (assuming complete overlap) and 242,400 people (assuming no overlap) therefore receive specialist palliative care in England annually, the authors estimate. However this does not include those with less complex needs receiving palliative care from primary and community care

teams alone (generalist palliative care), nor those whose palliative care needs go unrecognised. These estimates, ranging from 297,985 (minimal estimate) to 326,685 - 387,067 (mid-range) per annum, are notably higher than the reported number of those receiving specialist palliative (i.e. 100,000 - 242,000). Similar service-based data for specialist palliative care in other countries or regions would enable further comparison.⁴³

90. Building on this method a study in Ireland has recently used routine mortality data (2007-2011) analysed for malignant and non-malignant conditions to identify those who die who potentially require palliative care input. During the period 2007-2011, there were 141,807 deaths in Ireland. Eighty per cent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from non-cancer conditions. The study concluded that Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease and the associated palliative care needs and noted that new models of palliative care may be required to address this.⁴⁴
91. One such model is proposed by the Palliative Care Funding Review for England which advocates for a palliative care tariff to provide: palliative care based on regular assessments of need, regardless of setting, with the support of a care co-ordinator and to include social care needs of those added to a locality end of life register. The review states that of those who die in England each year, 457,000 people need palliative care but 92,000 do not receive it. The review notes 'a stunning lack of good data surrounding costs for palliative care' but claims that the tariff approach could reduce hospital deaths by 60,000 per year. At a standard cost of £3,000 per hospital death, this would lead to a potential saving of £180m.⁴⁵
92. A 2014 paper detailed the likelihood of death within 12 months of a cohort of all hospital inpatients in Scotland on a fixed 'census' date of 31 March 2010.⁴⁶ It attracted a huge amount of media interest.⁴⁷ In the study, 10,743 inpatients were identified in 25 Scottish teaching and general hospitals on the census date (cottage and community hospitals and long-stay facilities were excluded). 28.8% of the patients died during the one-year follow-up period. Mortality rose steeply with age and was three times higher at one year for patients aged 85+, compared to those under 60. Men were more likely to die than women as were those with a 'medical' rather than a 'surgical' diagnosis. A striking finding was that almost one in 10 patients (9.3%) died during the index admission.
93. It has now been possible to repeat this analysis for a cohort of patients in hospital in Scotland on 10 April 2013. The purpose in doing this was primarily one of verification, as well as to look for trends over time. The results have been reported in a letter to the BMJ.⁴⁸ Was the original finding a 'one off', unrepresentative of the usual situation in Scottish hospitals on any given day? It would appear not. 10,595 patients were in hospital on 10 April 2013. The population characteristics of the 2010 and 2013 cohorts were similar overall. The follow up study found that 29.5%

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of the 2013 cohort had died one year later and 852 (8.0%) died on the index admission.

94. The study is now being extended to Denmark and New Zealand. It is a key work in demonstrating the potential for identification of hospital patients in the last year of life and the possibilities this offers for appropriate discussion and planning.
95. A 2013 paper summaries some key points on the identification of hospital patients who might need palliative care.⁴⁹ The number of people in the UK dying in a secondary care facility is set to rise by 20 per cent in the coming decades. This is occurring against a backdrop of global ageing, a rising prevalence of frailty and co-morbidity in chronic illness. Meeting the palliative needs of such diverse populations is challenging and is made more difficult with growing evidence that patients face significant physical and psychological burdens. The elevated prevalence of psychological and physical burdens towards the end of life has been noted in patients with cancer, chronic kidney disease, COPD and heart failure. The sources of physical symptoms are broad and have multiple aetiologies. Cancer pain can occur as a result of tumour pervasion or pharmacological toxicity. Physiological change also contributes to physical pain for patients with COPD and heart failure. Psychological burden is often triggered as a result of rumination. The root causes of anxiety at the end of life can be attributed to adverse drug effects, changes in metabolism, existential concerns in relation to death and loss as well as in response to chronic pain.
96. Other work has noted the interaction between physical, psychological and social aspects of chronic illness at the end of life and its impact upon burden. Physical and psychological burdens can be difficult to separate from one-another. The relationship between physical and psychological burden is noted within the literature on dyspnoea and the notion of 'total dyspnoea'⁵⁰ as a result of the association between physical burden, psychological, spiritual and social distress has been described. Evidence of the co-existence of pain, depression and fatigue in advanced cancer also exists. Although there is more understanding of the prevalence of palliative care needs within hospital sites, little is known about the specific burden associated with these patients across hospital populations. It is known that very few patients access specialist palliative care in hospital settings and this is unlikely to be related to the level of need among them. Of those patients with palliative care needs, little is known about which diagnostic and demographic factors might contribute to physical and psychological burden. This latter point is of particular concern to those seeking to develop palliative care services for patients suffering from non-malignant diseases. What measure might enable people with these conditions to be identified on a prospective basis?
97. Atul Gawande's Reith lecture, delivered in Edinburgh in November 2014, urged clinicians to engage actively in conversations with patients about end of life issues. He highlighted the key questions that might be asked:
 - What is your understanding of your situation?

- What are your fears and hopes if time is short?
- What are the trade-offs you are willing to make and not make?
- And what is the course of action that best serves this understanding?

98. We know that, in England at least, these conversations do not happen routinely in hospital.⁵¹ In Scotland, around 45% of all people in hospital are over 75 and over one third of these are entering the last year of their lives. The hospital setting can therefore undoubtedly be an important place for such conversations to begin.

Equity

99. The existence of barriers that prevent appropriate access to palliative care has been well recognised in the literature. A chapter in the Oxford Textbook of Palliative Medicine in 2010⁵² noted the following problems:

- Global indifference to the need for palliative care
- Societal problems relating to public health, culture, education, attitudes, demography, social exclusion, religion, and social class
- Organisational factors including service configuration, access and availability, sustainability, funding and workforce capacity
- Professional concerns relating to levels of palliative care delivery, education, training and attitudes
- Individual issues including disease status, age, intellectual disability, social status and marginality

100. A 2004 systematic review found a lack of knowledge and education about palliative care among health and social care professionals and a lack of standardised referral criteria for specialist services. This could result in a failure to be referred or a lack of timely referrals particularly among those from minority ethnic communities, older people and patients with non-malignant conditions, as well as those that are socially excluded – such as prisoners or homeless people.⁵³

101. As we have seen, the Palliative Care Funding Review reported that 92,000 people in England are not being reached by existing palliative care services. Based on this a pro-rata estimate (itself based on an estimate) for Scotland has also been formulated. It claims that in Scotland, 10,600 people per year would benefit from palliative care but are currently not receiving it.⁵⁴

102. Access to palliative care varies greatly depending on a person's condition, place of residence and care setting. It also varies according to particular personal characteristics which, since 2010, have special protection under the UK Equality Act. For example, the 'oldest old' are still less likely to receive hospice care, and non-religious people are less likely to report receiving appropriate spiritual

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support. Lesbian, gay, bisexual and trans people do not universally feel confident in accessing palliative care services for fear of not being accepted, and people without a fixed address sometimes fail to be noticed altogether.

103. Lower levels of awareness of hospice and palliative care and language differences amongst minority groups may limit their use of services.⁵⁵ There is evidence to suggest that people from deprived areas are less likely to use palliative services and those who do are less likely to do so in their own home. Causes of inequality in access to palliative care include: shortages of specialist staff, increased demand for services and lack of knowledge about the needs of patients from deprived areas or BME communities. BME groups are less likely to be referred to and use hospice services. A number of studies have found that BME cancer patients and their carers were not using available palliative services because they were less likely to meet their needs. They also found that there was a need for palliative services to be provided in more culturally sensitive ways in order to meet the needs of BME patients.⁵⁶

Identification

104. Ensuring equity of access to palliative care on the basis of need is a public health issue. Identifying individual patients and families who could benefit from palliative care and whether and when they should be referred to specialist services, is an individual and clinical matter. The two are however closely related.

The United Kingdom and Spain appear to be the only two countries in Europe that have a primary-care based system for identifying patients with palliative care needs.⁵⁷ About 1% of general practice patients will die each year. There is a need to find ways of identifying these patients so that their needs and preferences can be assessed in order to plan for them and to provide the right services at the appropriate. On average, each GP has experience of 20 deaths per year: about one-quarter of whom will die from cancer. These are the patients that have generally been thought of when initially discussing palliative care; about one-third will die from organ failure, e.g. heart failure and COPD; about one-third will die from multiple organ failure, frailty or dementia; and only about one-twelfth will die suddenly with little or no warning. Palliative care registers were established in the UK in the 1990s to promote the identification of these patients. GP practices create and hold the registers voluntarily, with Quality & Outcomes Framework (QOF) points attached.

105. A paper published in 2013 looked at 684 patients in nine Scottish practices who were on the palliative care register. Around 75% of patients with cancer were formally identified for palliative care, but only in the last weeks of life. For those with non-malignant disease, only 20% were formally identified, and also only in the last weeks of life, and relatively much later in the progression of their disease compared to the cancer patients. Formal identification was closely associated with and triggered by referral to specialist palliative care.⁵⁸ Key information summaries (KIS) were introduced throughout Scotland in 2013 so that anticipatory care plans

written by GPs could be routinely shared electronically and up-dated in real time, between GPs and providers of unscheduled and secondary care.

106. A literature review published in 2015⁵⁹ found 112 relevant articles dealing with the definition of dying, determination of severity of deterioration, prediction of in-hospital death, preferred place of death and options for alternative end of life care. Among these, the authors identified 18 instruments and their variants validated in different settings. Table 2 lists these instruments for predicting death, developed over several decades. Most of these are found wanting in some way – for example, they relate only to cancer, they require extensive data not easily available in routine clinical practice, or they are costly in time and effort. The authors suggested a hybrid instrument for prediction of death, Criteria for Screening and Triaging to Appropriate aLternative care (CriSTAL) which includes age ≥ 65 ; meeting ≥ 2 deterioration criteria; an index of frailty with ≥ 2 criteria; early warning score > 4 ; presence of ≥ 1 selected comorbidities; nursing home placement; evidence of cognitive impairment; prior emergency hospitalisation or intensive care unit readmission in the past year; abnormal ECG; and proteinuria. But again this has yet to be tested in clinical practice.

107. The authors of CriSTAL note the following:

The tool is not intended to preclude access to healthcare for terminally ill elderly people, but rather to provide an objective assessment and definition of the dying patient as a starting point for honest communication with patients and families. Dignified withdrawal of intensive and inappropriate treatment and triage into alternative care in non-acute facilities is an area where there is still ample room for improvement. Standard guidelines for alternative end of life care are not yet broadly adopted in Australia, yet there is increasing evidence of alternative out-of-hospital care that includes sedation to minimise distress, pain management, spiritual support, music therapy and home-based palliative care. If proven accurate in the prediction of short-term death, a reduced version of CriSTAL could be proposed for routine use at hospital admission. Using such predictive tools may encourage more appropriate services for managing patients at the end of life.

108. A recent systematic review, conducted in Scotland, highlighted two tools for the identification of palliative care patients⁶⁰:

109. **The *RADboud indicators for Palliative Care needs*** – (RADPAC) is a screening tool that takes its inspiration from the WHO definition of palliative care, which encourages palliative care to be initiated at an early phase of illness and not restricted to terminal care. A 2012 study⁶¹ sought to systematically develop a tool for GPs with which they can identify patients with congestive heart failure (CHF), chronic obstructive pulmonary disease (COPD), and cancer respectively, who could benefit from proactive palliative care. A three-step procedure was adopted, including: a literature review, focus group interviews with input from the multidisciplinary field of palliative healthcare professionals, and a modified Rand

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Delphi process with GPs. The three-step procedure was used to develop sets of indicators for the early identification of CHF, COPD, and cancer patients who could benefit from palliative care. For CHF, seven indicators were found: for example, frequent hospital admissions. For COPD, six indicators were found: such as, Karnofsky score $\leq 50\%$. For cancer, eight indicators were found: for example, worse prognosis of the primary tumour. The RADPAC claims to be the first tool developed from a combination of scientific evidence and practice experience and designed to help GPs in the identification of patients with CHF, COPD, or cancer, in need of palliative care. Applying the RADPAC facilitates the start of proactive palliative care and aims to improve the quality of palliative care in general practice. A RADPAC Residential home palliative care tool has also been developed.

110. **Supportive and Palliative Care Indicators Tool (SPICT)** - has been developed in Scotland since 2010 as a collaborative project between NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group and become widely known, with international collaborators in Australia, North and South America and Europe.⁶² SPICT is a guide to 'identifying people with one or more advanced conditions, deteriorating health and a risk of dying'. It is premised on the notion that it is possible to identify people in a timely way that have one or more advanced conditions, deteriorating health and a risk of dying. They can then be offered assessment and care planning to review their health care and wider needs and those of their family carers. It is then possible to find out about 'what matters' to them, introduce earlier supportive and palliative care integrated with their current care, and begin planning future treatment and care with them. Individual clinicians are advised to look for the following indicators of deteriorating health in their patients and consider applying the SPICT:

- Poor or deteriorating performance status
- Increasing need for personal care
- Recurrent hospital admissions
- Poor control of symptoms despite optimal treatment of underlying condition

111. In a study in one Scottish hospital SPICT has been shown to aid clinical decision making and to prompt review of patients' unmet needs for supportive and palliative care.⁶³ It is sometimes used in combination with the 'surprise question' – would you be surprised if this patient died within 12 months? The SPICT is not designed to identify patients for specialist palliative care referral, but primarily to support improved care by those providing general supportive and palliative care for their patients.

112. The SPICT may also have value (so far little explored) in enabling health care organisations to assess the level of need for supportive and palliative care among the people they serve, or for population based estimates of need.

113. In addition to RADPAC and SPICT it is worth noting another tool, this time designed to identify those in need of referral to specialist palliative care.
114. **The Sheffield Profile for Assessment and Referral for Care** – (SPARC) is a multidimensional screening tool which gives a profile of needs to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease. Crucially, it is completed by the patient, not the professional, but it is intended to trigger referral to specialist (not generalist) palliative care. SPARC is intended for use by primary care, hospital teams or other services to improve patient management, either by current professional carers or by referral to a specialist team. The patient-rated 45 item tool reflects nine dimensions of need and as such represents a comprehensive early holistic needs assessment. At the end of the questionnaire, the patient is asked, “Are there any other concerns that you would like us to know about?” and there is space provided for three questions that the patient may ask of doctors or other professionals.
115. A 2013 publication reports on an attempt to elicit the views of a wide variety of members of consumer and self-help support groups concerned with health care on the relevance, acceptability and the overall perception of using SPARC as an early holistic needs assessment tool in supportive and palliative care.⁶⁴ The study was conducted in South Yorkshire and North Derbyshire (UK). Ninety-nine consumer and self-help groups were identified from information in the public domain. Thirty-eight groups participated. 135 questionnaires and feedback forms were returned. The majority of respondents (93%) found SPARC easy to understand and complete (94%). A minority, 12.2%, of respondents found questions on SPARC 'too sensitive'. The researcher concluded that overall, respondents considered SPARC an acceptable and relevant tool for clinical assessment of supportive and palliative-care needs. Whilst a small minority of people found SPARC difficult to understand (i.e. patients with cognitive impairments), most categories of service user found it relevant.
116. A Polish version of the SPARC, reported in a 2012 paper, suggested evidence of its face and content validity – but did not assess its screening value. Fifty eight consecutive patients with advanced cancer diagnoses, who required palliative care, were recruited from a day care centre (15), home care (18), and a palliative care unit (25) of the Department of Palliative Medicine, Poznan University of Medical Sciences, Poznan, from January to March 2011. In general, satisfactory validity and reliability of the tool were demonstrated.
117. A 2015 paper reports on the clinical efficacy of SPARC⁶⁵. It notes that at present, there is no widely used systematic evidence-based holistic approach to assessment of patients' supportive and palliative care needs. The study therefore sought to determine whether the use of a holistic needs assessment questionnaire, (SPARC) would lead to improved health care outcomes for patients referred to a palliative care service. This was an open, pragmatic, randomized controlled trial. Patients (n= 182) referred to the palliative care service were randomized to receive SPARC at baseline (n=87) or after a period of two weeks

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(waiting-list control n=95). The primary outcome measure was the difference in score between Measure Yourself Concerns and Wellbeing (MYCAW) patient-nominated Concern 1 on the patient self-scoring visual analogue scale at baseline and the two-week follow-up. Secondary outcomes included difference in scores in the MYCAW, EuroQoL (EQ-5D), and Patient Enablement Instrument (PEI) scores at Weeks 2, 4, and 6.

118. The results are surprising. There was a significant association between change in MYCAW score and whether the patients were in the intervention or control group. A higher proportion of patients in the control group had an improvement in MYCAW score from baseline to Week 2: control (34 of 70 [48.6%]) vs. intervention (19 of 66 [28.8%]). This trial result identified a potential negative effect of SPARC in specialist palliative care services, raising questions that standardized holistic needs assessment questionnaires may be counterproductive if not integrated with a clinical assessment that informs the care plan.

Indicators of key outcomes

119. The presence of high scores for resources and inputs, along with evidence of the use of measures of need and process would be expected to correlate with good outcomes for palliative care. This is true in part. The specific example of the United Kingdom is interesting. Consistently ranked highly across different studies on inputs and resources, known to have developed significant research and innovation on need and outcome analysis, as well as for its important developmental role in the history of palliative care, it nonetheless has been encountering problems in its delivery of end of life care. The USA is a similar example. It has high coverage of hospice provision and extensive development of palliative care teams in hospital, but a 2015 report from the National Institutes of Health states:

“For patients and their loved ones, no care decisions are more profound than those made near the end of life. Unfortunately, the experience of dying in the United States is often characterized by fragmented care, inadequate treatment of distressing symptoms, frequent transitions among care settings, and enormous care responsibilities for families. According to this report, the current health care system of rendering more intensive services than are necessary and desired by patients, and the lack of coordination among programs increases risks to patients and creates avoidable burdens on them and their families ... Death is not a strictly medical event. Ideally, health care for those nearing the end of life harmonizes with social, psychological, and spiritual support. All people with advanced illnesses who may be approaching the end of life are entitled to access to high-quality, compassionate, evidence-based care, consistent with their wishes”.⁶⁶

120. A consultation process is currently underway in England, led by NICE to identify best practice in the care of people at the end of life. This comes in the wake of the

controversy over the Liverpool Care Pathway (LCP) and its subsequent withdrawal from use.⁶⁷ Deficiencies in end of life care have also been highlighted by the 2015 report of the Parliamentary and Health Service Ombudsman which found that the NHS in England is failing to manage care properly at the end of life, that some doctors do not recognise when death is imminent, and that poor communication and insufficient control of symptoms are widespread.⁶⁸ Related issues have been identified in a Care Quality Commission (CQC) report of August 2015⁶⁹ on 105 CQC inspections of acute hospitals across England between November 2013 and mid-May 2015. These showed significant variation in the quality rating of end of life care services provided: 57 hospitals were rated “Good” and 4 as “Outstanding”; but 40 were rated as “Requiring Improvement” and 4 as “Inadequate”.

Table 2 – CQC Inspections – Acute Hospitals Summary CQC Ratings: End of Life Care - Acute Hospitals

Domain	Outstanding	Good	Requires improvement	Inadequate
Caring	3	95	7	0
Effective	1	66	32	6
Responsive	9	58	36	2
Safe	0	55	46	4
Well Led	5	64	32	4
Overall	4	57	40	4

Aside from such inspections of care delivery, how might it be possible to routinely measure the quality and outcomes of palliative and end of life care, across health care, community and domiciliary settings?

121. In 2013 Healthcare Improvement Scotland addressed the issue of palliative care indicators. It defined an indicator as ‘a measure of outcome which demonstrates delivery of person-centered, safe and effective healthcare, and promotes understanding, comparison and improvement of that care’.⁷⁰ Four palliative and end of life care indicators were presented. A report from Information Services Division, ISD in 2014 however, and a subsequent update to the Palliative and End of Life Care National Advisory Group (in August 2015), noted some concerns with each of these, as stated in italics below. These are the four indicators:

Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified – that is, the proportion of people with cancer who are on a palliative care register and the proportion of people with a long-term condition other than cancer who are on a palliative care register.

- Data for these indicators is not available nationally. Quality and Outcomes Framework (QOF) data provides only an aggregate count per practice of patients recorded as being on a palliative care register. Also the indicator does not give a definition of ‘long term

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condition'. The 2013 document wrongly states that the Medical Profiles Project includes this data. ISD does however publish the total number of patients registered with a practice who are on a palliative care register, broken down by Health Board and as a percentage of all registered patients. This was 11,846 patients in 2012-13, representing 0.22% of all patients. Interestingly the Gold Standards Framework suggests that 1% of all patients registered with a practice will die in a year.⁷¹ A collaboration between NSS and Scottish Government (SPIRE) is seeking to create an infrastructure and governance framework to allow the data required for this indicator to be extracted from GP practices.

Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan.

- These data are stated not to be available nationally, nor is it clear how they are accessed at a local level.

Indicator 3: Increase in the number of electronic palliative care summaries accessed. The source of this data in the 2013 report was incorrect. It should be available from the Emergency Care Summary. The electronic Palliative Care Summary will soon be subsumed within the Key Information Summary (KIS). But data for this indicator is not available nationally.

Indicator 4: Place of death. This consists of two sub-indicators: proportion of people who die in hospital; proportion of people who die in their usual place of residence.

- The first of these can be derived centrally from hospital discharge records linked to registered deaths sourced from the National Records for Scotland (NRS). In 2012-13, 29,751 people died in hospital, making 53.1% of all persons who died in that period. A related indicator is already published by ISD and measures the percentage of time in the last six months of life spent at home or in a community setting. In May 2010, the NHS Healthcare Quality Strategy was published, a direct action of which was to develop a Quality Measurement Framework supporting a number of Quality Outcome Measures. These measures cover a range of healthcare topics including; care experience, healthcare acquired infections, hospital mortality rates and end of life care. Quality Outcome Measure 10 relates to: The percentage of the last 6 months of life spent at home or in a community setting.
- ISD states: 'Ideally, the measure would relate directly to the patient's preferred place of care at the end of their life. However, there is no national and systematic data recorded on a person's preferred place of care at end of life and so this publication uses instead the following surrogate measure: "Percentage of last six

months spent in home or a community setting". Although this is not a direct measure of compliance with peoples' preferred place of death, it can serve to provide a broad indication of progress in implementation of the national action plan. It is envisaged that an increase in this measure will reflect both quality and value through more effective, person centred and efficient end of life care with people being better able to be cared for at home or closer to home with a planned approach to end of life care resulting in less time in an acute setting. ISD have been working with the Quality Measurement Framework to develop this new measure and we intend to continue publishing on an annual basis at health board and local authority level'.⁷²

122. The latest data was published on 25 August 2015.⁷³ It shows:

- Of the approximately 50,000 Scottish residents who died in 2013/14, 91% of their last 6 months of life was spent at home or in a community hospital and the remaining 9% of time was spent in an acute hospital. This is similar to the previous year.
- There is some variation between NHS Boards, with the percentage ranging from 89% to 93%, in part reflecting the provision of community hospitals in different parts of the country.
- There is little variation in percentage between those living in the most deprived areas and those living in the least deprived areas (90% compared to 91%)
- People living in the more rural areas of Scotland spent a greater percentage of their last 6 months of life at home or in the community than those living in large urban areas (94% compared to 90%)

123. Over the last 10 years, one of the key themes of public policy in palliative care has been achievement of choice in place of death. In Marie Curie Hospice Edinburgh a baseline audit conducted in 2006 showed that only a small proportion (18%) of patients referred to hospice services died at home. The audit also revealed that only 31% of those who expressed a preference to die at home were able to do so, whereas 91% of those who chose a setting other than home achieved their preference. Overall achievement of preferred place of death was 56%. However a significant number of patients (29%) did not have a recorded preference.

124. A programme of quality improvement continued over the next 7 years to improve identification, communication and achievement of preferred place of death for all patients. The mechanisms to change practice were: changes to documentation; changes to clinical systems to support use of documentation; support for clinical staff to recognise the value of discussing preferences; and support for clinical staff to develop new skills. In addition the programme was incorporated into local

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clinical strategy and this enabled gaps in service to be addressed with a new service to support early discharge of those patients who wished to die at home.

125. A follow up audit, reported in 2013, showed that all patients had a recorded preference or a documented reason why their preference was unstated. One third of patients died at home – nearly double the proportion that died at home in the baseline audit. Seventy one per cent of patients who wished to die at home actually died at home - a substantial increase from 31% at baseline. Achievement of preferred place of death for patients wishing to die in the hospice remained high at 88%. The focus on assessment of preference for place of death had led to substantial improvements in the identification and achievement of preference for patients dying under the care of the hospice. Furthermore, it was associated with an increase in the overall proportion of patients who died at home. The study has much to commend it.⁷⁴
126. The European Association for Palliative Care published a white paper in 2015 on outcome measurement.⁷⁵ It notes that outcome measurement plays an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care. But until recently, almost all assessments of the quality of palliative care have focused on care structures and processes (i.e. the two previous sections of this report) rather than on outcomes. Outcome measures are often used in palliative care research to describe patient populations or to assess the effectiveness of interventions, but they are not widely incorporated into routine clinical practice. A 2015 paper shows that in Australia, where they have been introduced routinely into practice with timely feedback loops, there is evidence of improved patient outcomes at a systems level.⁷⁶ This patient-centred approach to outcome measurement requires the systematic collection of outcome measures at 'point of care' in order to inform areas where improvements need to occur.
127. The White Paper makes the important distinction between **quality indicators** and **outcome measures**. These are often incorrectly used as interchangeable techniques, which they are not. Quality indicators measure specific aspects of care or a related outcome and are expressed on an aggregated level, such as a number or percentage of patients. Outcome measures are an essential component of quality but are measured on an individual level. Outcome measures can be used to calculate quality indicators, but unlike quality indicators they do not allow for monitoring of care quality at the service or system level. However, quality indicators should reflect and be informed by the outcomes that are relevant to patients. Quality indicators can also be effective tools for quick and efficient assessment of service performance at individual as well as institutional level.
128. Two initiatives have developed national quality registers to measure outcomes and quality of palliative care services: the Palliative Care Outcomes Collaboration (PCOC) study in Australia⁷⁷ and a similar registration project in Sweden.⁷⁸ While these projects have resulted in useful national quality monitoring systems, they do not strictly make use of quality indicators but mainly focus on outcome measures. Nor have they yet achieved a level of comprehensiveness necessary to evaluate

the various dimensions of palliative care. But they are far in advance of most other countries in their systematic approach to this issue.

129. The White Paper makes 12 recommendations on outcome measurement, covering key parameters of measures, adequate measures for the task, introduction of outcome measurement into practice, and national and international outcome comparisons and benchmarking. Several are of particular relevance in the Scottish context.

1. Use Patient Reported Outcome Measures (PROMs) that have been validated with relevant populations requiring palliative care and make sure these are sufficiently brief and straightforward and that they allow for proxy reports when the patient is unable to self-report
2. Use multidimensional measures that capture the holistic nature of palliative care
3. Use outcome measures to assess the needs of unpaid caregivers (family and others) alongside the needs of patients
4. Use measures that have sound psychometric properties
5. Use measures that are suited to the clinical task being delivered and also suited to the aims of the clinical work in question and the population to which it is addressed
6. Use valid and reliable measures in research that are relevant to the research question and consider patient burden when using measures
7. Use change management principles, facilitation and communication to embed outcome measurement into routine clinical practice and evaluate the implementation process to ensure sustained use that influences practice within the organisation
8. Relate outcome measurement to quality indicators (QIs)
9. Establish and use quality improvement systems to sustain routine practice of outcome measurement and introduce inter-operable electronic systems to ensure integration of measures across settings
10. Use measures that allow for comparisons across care settings and throughout Europe. Therefore, use measures that are culturally sensitive and have validated translations in relevant languages/countries
11. Advance the field of palliative care through establishing national and international outcome collaborations that work towards benchmarking to establish and improve care standards

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12. To improve and monitor palliative care practice, policy makers should recommend routine collection of outcome data, and then these data should be used to establish a minimum dataset of palliative care outcome measures in order to improve and advance clinical care and research

130. The following table from the EAPC journal article, lists the six most commonly used outcome measures and some of their properties: the Edmonton Symptom Assessment Scale; the Palliative Care Outcomes Scale and associated Symptom List; the Memorial Symptom Assessment Scale; the Distress Thermometer: and the EORTC-QLQC-15-PAL.

Table 2. Examples of multidimensional outcome measures in palliative care.

Name of outcome measure	Number of items	Time for completion	Additional comments
Edmonton Symptom Assessment Scale (ESAS) ²⁷	9 symptoms + 1 'other problem'	Approximately 5 min	Each symptom with NRS 0–10 developed to measure the most commonly experienced symptoms in cancer patients, available in a wide range of languages, broadly validated
Palliative care Outcome Scale (POS) ²⁶	10 items on physical symptoms, emotional, psychological and spiritual needs, provision of information and support 1 open question on main problems	Mean time 6.9 min (patients) and 5.7 min (staff); repeated assessments of patients and staff mean time <4 min	Scores from 0 (<i>no effect</i>) to 4 (<i>overwhelming</i>) Patient, staff and carer version Widely used palliative care measure
POS Symptom list (POS-S)	POS-S: 10 symptoms; 2 questions about the symptom that affected the patient the most and that has improved the most		Additional symptom versions available for other conditions (POS-S MS, POS-S renal)
Memorial Symptom Assessment Scale (MSAS)	28 physical and 4 psychological symptoms	20–60 min, short form <5 min	Measuring presence, frequency, severity and distress of symptom Short-form version available (MSAS-SF): only presence and distress of symptom Developed for cancer patients and also used in other conditions
Distress thermometer ⁹⁶	Overall distress score 20 symptoms, 5 items on practical problems, 4 on family problems, 5 on emotional problems, 2 on spiritual concerns	Median length of time 5 min, with 75% taking no more than 10 min	Distress score 0–10, other items yes/no
EORTC QLQ-C15-PAL	Pain, physical function (3 items), emotional function (2 items), fatigue (2 items) quality of life (1 item), symptoms (6 items)	<20 min	Copyrighted instrument, supplement version of the EORTC QLQ-C30 for palliative care patients

NRS: numerical rating scales; SF: Short Form.

131. A Palliative Care Outcome Measures Resource Pack can be purchased from the Cicely Saunders Institute. It contains sets of outcome measures of this sort (for inpatient and community settings), guidance booklets on how and when to implement measures, and training resources (training videos, animated PowerPoint presentations, prompt cards, etc.). These are designed to support hospices and palliative care providers across the UK in implementing outcome measures into clinical practice. Purchasing a pack also enables users to join monthly webinars and to access a telephone support line, for on-going support

and any questions. The Resource Pack has been produced by Cicely Saunders Institute and Hospice UK working together, and the outcome measures are aligned with the national UK Palliative Care Clinical Dataset and the palliative care Development Currency in England.⁷⁹

132. In 2011, NICE published a quality standard for end of life care in England.⁸⁰ It covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents. It sets out markers of high-quality care for adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups. It is not expected that each quality statement will apply to all groups. Similarly, some quality statements may need special consideration when applied to certain groups. For example, people with dementia may need to participate in advance care planning significantly earlier in the pathway than people with cancer. The standard was updated in the light of the withdrawal of the LCP (section 144) and now contains the following elements⁸¹:

Statement 1. People approaching the end of life are identified in a timely way.

Statement 2. People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

Statement 3. People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

Statement 4. People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

Statement 5. People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

Statement 6. People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

Statement 7. Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

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Statement 8. People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

Statement 9. People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

Statement 10. People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

Statement 11. People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.

Statement 12. The body of a person who has died is cared for in a culturally sensitive and dignified manner.

Statement 13. Families and carers of people who have died receive timely verification and certification of the death.

Statement 14. People closely affected by a death are communicated with in a sensitive way and are offered immediate and on-going bereavement, emotional and spiritual support appropriate to their needs and preferences.

Statement 15. Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

Statement 16. Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.

133. Expected levels of achievement for the NICE quality measures are not specified. Such standards are intended to drive up the quality of care, and so aspirational achievement levels are likely to be 100% (or 0% if the quality statement states that something should not be done). However, it is recognised that this may not always be appropriate in practice taking account of patient safety, patient choice and clinical judgement and therefore desired levels of achievement should be defined locally. The quality standard makes use of existing measures and indicators provided by the End of Life Care Quality Assessment Tool (ELCQuA).⁸² The ELCQuA tool is freely available to health and social care organisations providing end of life care services in England. This includes community services, care homes, domiciliary care, primary care, out-of-hours services, specialist palliative

care services, acute hospitals, ambulance services, local authorities and clinical commissioning groups. It includes end of life care services provided by the voluntary and private sectors. Users are expected to consider the measures in the context of each quality statement and prioritise those that are most appropriate.

134. A 2013 paper describes a set of quality indicators for palliative care for adults in Flanders (the Flemish speaking part of Belgium), applicable in all settings providing palliative care, and thereby providing an example usable by other countries interested in monitoring the quality of palliative care.⁸³ The set includes an extensive list of items, as follows, where the main categories are: pain and other physical symptoms; psychosocial wellbeing; spiritual wellbeing; the care of relatives; and aftercare. These are set out below.

Table 3: Overview of Titles of Quality Indicators for Palliative Care for Patients, in Categories (translated from Dutch)

Category	Name Indicator
A. Management of pain and other physical symptoms	A1. Percentage of patients with moderate to severe pain A2. Percentage of patients with fatigue A3. Percentage of patients with shortness of breath A4. Percentage of patients with constipation A5. Extent to which patients receive support for their physical symptoms (pain, fatigue, shortness of breath, and constipation) A6. Extent to which patients receive help with physical care
B. Care for psychosocial well-being	B1. Percentage of patients with anxiety B2. Percentage of patients who feel depressed B3. Extent to which patients receive support when they feel anxious or feel depressed B4. Extent to which patients receive attention from their caregivers B5. Extent to which patients are satisfied with the counselling aspects of “politeness” and “being taken seriously” B6. Extent to which patients experience respect for their autonomy B7. Extent to which patients experience respect for

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Category	Name Indicator
	<p>their privacy</p> <p>B8. Extent to which direct relatives considered that the patient had the opportunity to be alone</p>
<p>C. Care for spiritual well-being</p>	<p>C1. Extent to which patients indicate that caregivers respect their life stance</p> <p>C2. Extent to which patients indicate that they have access to a counsellor for spiritual problems</p> <p>C3. Extent to which relatives indicate that the patient had access to a counsellor for spiritual problems</p> <p>C4. Extent to which relatives indicate that the patient received support with preparations for saying goodbye</p> <p>C5. Extent to which patients indicate that they feel that life is worthwhile</p> <p>C6. Percentage of relatives who indicate that the patient died peacefully</p> <p>C7. Percentage of relatives who indicate that the patient had accepted her/his approaching death</p> <p>C8. Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient</p>
	<p>D1. Extent to which patients in the last month before their death were in the location of their preference</p> <p>D2. Percentage of patients who died in the location of their preference</p> <p>D3. Extent to which patients know who the contact person is for the care</p> <p>D4. Extent to which patients receive information about the expected course of the illness</p> <p>D5. Extent to which patients receive information about the advantages and disadvantages of various types of treatments</p> <p>D6. Extent to which patients indicate that they</p>

Category	Name Indicator
D. Generic aspects	<p>receive understandable explanations</p> <p>D7. Extent to which patients indicate that they receive contradictory information</p> <p>D8. Presence of documentation concerning the desired care and treatment at the end of life</p> <p>D9. Extent to which relatives indicate that the patient was asked about her/his opinions with regard to end-of-life decisions</p> <p>D10. Extent to which patients experience expertise and continuity</p> <p>D11. Percentage of patients who receive medical aid soon enough</p>
E. Care for psychosocial and spiritual well-being of relatives	<p>E1 Extent to which, according to the direct relatives, attention was paid to their own psychosocial and spiritual well-being</p> <p>E2. Extent to which the direct relatives felt that they were treated well in all respects by the caregivers</p> <p>E3. Extent to which, according to the direct relatives, their autonomy was respected</p> <p>E4. Extent to which the direct relatives had the opportunity to be alone with their relative</p>
F. Generic (in the care for relatives)	<p>F1. Extent to which direct relatives received information that was understandable and unambiguous at the time of the patient's death</p> <p>F2. Extent to which direct relatives received information about the advantages and disadvantages of various types of treatment</p> <p>F3. Extent to which direct relatives perceived the expertise of caregivers and the continuity of care</p>
G. Aftercare	<p>G1. Extent to which direct relatives felt supported by the caregivers immediately after the patient's death</p> <p>G2. Extent to which direct relatives were informed</p>

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Category	Name Indicator
	about the possibilities of aftercare G3. Extent to which a final conversation or discussion was held to evaluate the care and the treatment

135. The same study also produced an exhaustive set of indicators, just relating to organisational factors.⁸⁴
136. In this area of outcomes and indicators, two points stand out. First, patient reported outcome measures (PROMs) find most favour – against proxies from carers or professionals, for example. Second, within these, questions relating to pain, symptoms, emotional needs and family concerns are consistently considered the most useful and important.
137. Despite the importance now accorded to patients reported outcomes and to quality indicators, some of the early developments in these areas have relied (successfully) on proxy measures from relatives. A particular subset of these is the ‘mortality follow-back’ survey, where views about a deceased person’s care in the last period of life are solicited from a named person, usually a surviving relative. This has been used extensively in the USA to establish good evidence of the quality of hospice care. A 2004 paper reported on the first attempt in the country to examine the adequacy or quality of end of life care in institutional settings, compared with deaths at home. It surveyed family members or other knowledgeable informants representing 1,578 people who had died, with a two-stage probability sample used to estimate end of life care outcomes for 1.97 million deaths from chronic illness in the United States in the year 2000. Informants were asked over the telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours. Family members of patients receiving home hospice services were more satisfied with overall quality of care - 70.7 % rated care as "excellent," compared with less than 50 % of those dying in an institutional setting or with home health services. The study concluded that many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect, and that family members of decedents who received care at home with hospice services were more likely to report a favourable dying experience.⁸⁵
138. In this context – of the enduring value of proxy measures - it is important to mention one such measure that has found favour in the UK and been widely reported.
139. **VOICES** (Views of Informal Carers - Evaluation of Services) - VOICES⁸⁶ has evolved from an instrument primarily used in research studies, to a tool for annual monitoring of satisfaction with care, as seen by the carer or relative of someone

who has died recently. It forms the core of the National Survey of Bereaved People conducted by the Office for National Statistics and commissioned by NHS England.

140. The aims of the survey are to assess the quality of care delivered in the last 3 months of life for adults who died in England and to use this to assess variations in the quality of care delivered in different parts of the country and to different groups of patients. Building on earlier iterations of the method, it has been conducted at the national level in England. The survey has now been run for four years and was commissioned by the Department of Health in 2011 and 2012, and NHS England from 2013. It is administered by the Office for National Statistics (ONS). VOICES data provides information to inform policy requirements, including the End of Life Care Strategy, published by the Department of Health in July 2008. This set out a commitment to promote high quality care for all adults at the end of life and stated that outcomes of end of life care would be monitored through surveys of bereaved relatives.
141. Such an approach has not been taken in Scotland, Northern Ireland or Wales however. An Audit Scotland report did conduct a sample survey based on VOICES in 2007, covering four health board regions, and results were reported from 997 respondents.⁸⁷ In the interim there has been some modest use of VOICES at a local level in Scotland, but the year on year monitoring of the quality of end of life care that VOICES affords, is not available for the Scottish population. Discussions are underway however about piloting VOICES in specific local settings.
142. In 2014, the main VOICES findings from England were:⁸⁸
- 3 out of 4 bereaved people (75%) rated the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
 - 7 out of 10 bereaved people (69%) whose relative or friend died in a hospital, rated care as outstanding, excellent or good. This is significantly lower than outstanding, excellent or good ratings of care for those who died in a hospice (83%), care home (82%) or at home (79%).
 - Ratings of fair or poor quality of care were significantly higher for those living in the most deprived areas (30%) compared to the least deprived areas (21%).
 - 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.
 - 3 out of 4 bereaved people (75%) agreed that the patient's nutritional needs were met in the last 2 days of life, 1 out of 8 (13%) responded that the patient did not have enough support to eat or receive nutrition.

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- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) disagreed they had time to ask questions with health care professionals.
- 7 out of 10 (73%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

143. An insight into the lack of development in palliative care outcome measurement can be seen in the results of a Cochrane review of end of life care pathways for improving outcomes in caring for the dying, first published in 2010.⁸⁹ It noted that in many clinical areas, integrated care pathways are utilised as structured multidisciplinary care plans which detail essential steps in caring for patients with specific clinical problems. Care pathways for the dying aim to ensure that the most appropriate management occurs at the most appropriate time and that it is provided by the most appropriate health professional. The review premised that clinical pathways for end of life care management are used widely around the world and have been regarded as the gold standard and that there is a significant need for clinicians to be informed about the use of end of life care pathways via a systematic review. The aim of the review was to assess the effects of end of life care pathways, compared with usual care (no pathway) or with care guided by another end of life care pathway, across all healthcare settings (e.g. hospitals, residential aged care facilities, community). The Cochrane Register of controlled Trials (CENTRAL), the Pain, Palliative and Supportive Care Review group specialised register, MEDLINE, EMBASE, review articles and reference lists of relevant articles were searched in September 2009. The search covered all randomised controlled trials (RCTs), quasi-randomised trials or high quality controlled 'before and after' studies comparing use versus non-use of an end of life care pathway in caring for the dying. It identified 920 potentially relevant titles, but no studies met criteria for inclusion in the review. It concluded that without further available evidence, recommendations for the use of end of life pathways in caring for the dying could not be made and that RCTs or other well designed controlled studies were needed for evaluating the use of end of life care pathways in caring for dying people.

144. In 2013, an update of the Cochrane review was published. It noted that there had been sustained concerns about the safety of implementing end of life care pathways, particularly in the UK. This of course had led the review of the LCP by Julia Neuberger to recommend the withdrawal of its use in England⁹⁰ – a position subsequently adopted in Scotland also. The updated search, conducted in June 2013, found 2042 potentially relevant titles (including the original 920), but again no additional studies that met the criteria for inclusion in the review. The authors concluded that in light of the recently documented concerns related to the potential adverse effects associated with LCP (the most commonly used end of life care pathway), they could not recommend decision making based on indirect or low-quality evidence. All health services using end of life care pathways were

encouraged to have their use of the pathway independently audited in order that any subsequent use could be based on carefully documented evaluations. The authors asserted that large RCTs or other well-designed controlled studies are urgently required for the evaluation of the use of end of life care pathways in caring for dying people in various clinical settings and that in future studies, outcome measures should include benefits or harms in relation to patients, families, carers and health professionals.⁹¹

145. Later in 2013 (and after the recommendations of the Neuberger review had appeared) the first cluster randomised control trial of the Liverpool Care Pathway was published, conducted in Italy and involving 308 patients with cancer (and their families). It found no significant difference in the primary endpoint (on the overall quality of care toolkit scale) between patients who died on wards where the LCP was being used and those on wards where it was not. However, some secondary endpoints, such as feeling treated with dignity, kindness and respect, and attention to breathlessness, were better in the LCP group. Notably, there was no evidence of harm and no difference in survival between the groups.⁹² A clinical opinion piece in the Journal of the Royal College of Physicians of Edinburgh concluded that:

- The study by Costantini et al., published six months after the Neuberger Review, provides the first strong evidence: that the LCP does not improve overall quality of care. Why might the study have found no improvement in overall quality of care? Perhaps this was due to a poor choice of primary endpoint? Or perhaps care of the dying in Italian cancer wards is already good, meaning the LCP had less chance of improving it? Of course, it may be that the LCP simply does not improve care of the dying. Patients in this study spent an average of 31.5 hours on the LCP before they died. How much can we reasonably expect to improve within this timeframe? The study by Costantini et al. was rigorous and well designed. However, the effect sizes were small, suggesting little clinical difference irrespective of statistical significance. An important question is: how generalizable are these findings? For example, do they tell us anything about the potential of the LCP to improve care for people with diagnoses other than cancer? Or in healthcare systems outside Italy?⁹³

146. In the wake of such findings, and in a document entitled, One Chance to Get it Right⁹⁴, published in June 2014, the LCP was effectively replaced in England with five new 'Priorities for Care':

1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly by doctors and nurses.
2. Sensitive communication takes place between staff and the person who is dying and those important to them.

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3. The dying person, and those identified as important to them, are involved in decisions about treatment and care.
 4. The people important to the dying person are listened to and their needs are respected.
 5. Care is tailored to the individual and delivered with compassion – with an individual care plan in place.
147. In December 2013 the Scottish Government accepted a recommendation that the Liverpool Care Pathway (LCP) should be phased out in Scotland by December 2014. In that month it issued guidance on Caring for People in the last Days and Hours of Life⁹⁵, based on four principles:
- Principle 1:** Informative, timely and sensitive communication is an essential component of each individual person's care
- Principle 2:** Significant decisions about a person's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion
- Principle 3:** Each individual person's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible
- Principle 4:** Consideration is given to the wellbeing of relatives or carers attending the person.
148. These principles were to be addressed in the context of the fuller set of Palliative Care Guidelines, which were issued by the Scottish Government in November 2014.⁹⁶

Implications for Scotland and recommendations

What implications do these findings have for Scotland and what might be recommended as a result?

History, development and definition of palliative care

149. Definitional problems continue to inhibit clarity of thought and action in the field. It is not recommended however that Scotland should depart from the 2002 WHO definition of palliative care, as follows:
- 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.⁹⁷

150. This definition goes on to state that palliative care

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- 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.

151. There is a need however to settle on an appropriate definition of end of life care, a term which is so often linked to palliative care. Here there is no authoritative definition which can be adopted and many are surprisingly flawed. The following is used in a 2015 report from the National Institutes of Health in the USA:

- End-of-life care refers generally to the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end of life. It may include a range of medical and social services, including disease specific interventions as well as palliative and hospice care for those with advanced serious conditions who are near the end of life.⁹⁸

152. It is recommended that the Scottish Government Strategic Framework for Action should generate a suitable definition for end of life care and encourage its use across Scotland.

Palliative care resources and inputs

153. **Is Scotland a category 4a country, as measured by the World Map?** We would expect this to be the case, based on the UK entry. But we lack a great deal of data on the inputs and resources for specialist palliative care in Scotland. The author of this report is currently involved in an attempt to create a Scottish

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palliative care 'atlas entry'. But this requires primary data collection methods to ascertain some very basic details – how many specialists are working in the field, how many services with what capacity are delivering care, in what settings? A serious information deficit needs to be filled on these and several related questions about the provision of palliative care in Scotland.

154. **What level of palliative care coverage exists in Scotland for inpatient services, hospital support and home care teams?** This question cannot be answered until we have reliable data on the number and character of inpatient palliative care services/hospices (with beds), hospital support teams and home care teams that exist in Scotland, as indicated in the point above.
155. **How would Scotland perform compared to other European countries if entered into the model?** This is a very worthwhile question to ask. It can only be answered once the above data deficits have been rectified.
156. **What do we know about the vitality of palliative care research in Scotland?** Primary data collection is needed to ascertain this. A good starting point would be a systematic review, such as that produced in 2013 for the Ireland.⁹⁹ Discussions about the creation of a palliative care research network for Scotland are to be encouraged.

Palliative care need and process

157. We might conclude from recent estimates that of those who die in Scotland each year (54,000) around 80% (40,000+) would benefit from some form of palliative care.
 - Which is the best measure of whether primary care is identifying the people in need of palliative and end of life care in Scotland - the Key Information Summary or the Palliative Care Register? There can be no clear answer to this. Some studies have been completed and are underway which will shed light on the question.
 - How can we identify the 29 % of the acute hospital inpatient population in Scotland that are in the last year of life? Further investment in the SPICT (appendix 1) for this purpose seems likely to yield results, but it needs wide adoption across the hospitals of Scotland.

Palliative care outcomes

- **How much progress has been made with the identification of palliative care indicators in Scotland?** The progress is clearly very limited. The HIS report and recommended four indicators of 2013 has proved to be flawed. The only robust measure available at present is the ISD analysis of proportion of time in the last six months of life that is spent in the place of usual residence.

- **Is it significant that Scotland lacks a minimum data set for palliative care and a national bereavement survey?** These are significant deficits. Work was conducted in the early 2000s on a Scottish minimum dataset but appears not to have come to fruition.
- **Does Scotland require a National bereavement Survey?** A National Bereavement Survey would be the fastest way to gather some data on the quality of end of life care in Scotland that could be monitored over time. It would have the benefit of not being restricted to those accessing any particular kind of service. It could also be used to foster local improvement and change. The results of the 2007 VOICES survey in Scotland would form a useful baseline to any updated survey - and this is to be recommended. Ideally, such a survey should be conducted across all health boards, affording opportunities for regional comparison but also for local improvement strategies – a technique developed in England by Marie Curie and made available in an online atlas format.¹⁰⁰ It would also be one source of insight into overall change in the period before the adoption of 'Living and Dying Well' and up to the time of its replacement by the Strategic Framework for Action. The Scottish Government has already expressed interest in some local pilots of VOICES.
- **In what ways can the four principles of care at the end of life, adopted by Scottish Government in 2014, be used to measure the outcomes of individual care or as quality indicators for services?** As stated these are not readily measurable, but work could be done in order to achieve this by breaking down the component principles into measurable indicators. These should be few in number and directly meaningful to the providers and users of services.

The key questions posed

1. **What indicators are commonly used? What indicators have been used consistently over time? What is the scope of these indicators?**
 - Indicators here are divided into three categories: provision, need and outcome. None are highly developed. It must be recognised that palliative care is still an emerging (and fast growing) area of health and social care provision. In many countries it has been somewhat marginal to the mainstream healthcare system. Research investment has been low and there are relatively small numbers of centres where academic studies are being developed at a high level. The United Kingdom is often seen as the benchmark country that leads the league table in these developments. By 2014, there were thirteen chairs in British universities in palliative medicine alone. Yet a study of the research outputs from these facilities for the years 2001–2008 found that there were less than forty UK-based

academics with a sustained commitment to the field.¹⁰¹ In Scotland there are professors and senior academics at several universities who work in palliative and end of life care education and research. Their expertise and capacity, along with that of their colleagues and postgraduate students, needs to be harnessed more systematically in order to build more expertise on indicators and outcomes, along with a meaningful evidence base.

2. How are indicators determined to be successful or not? Are indicators used generally at a national or local level? Are these indicators part of a legislative framework or voluntary agreements or other approaches?

- The robustness of the palliative care indicators is clearly still in question. Where they are in use they are almost always found at the local level. In the USA Medicare funding for hospice allows indicators of service use to be monitored and research on quality to be undertaken. In England, the National Bereavement Survey provides some useful indicators of quality that can be monitored over time. There is no evidence that indicators are built into legislation, though there seems to be considerable enthusiasm for them among providers, some of whom adopt them at a local level.

3. What legislative requirements are there to accessing and receiving palliative and end of life care?

- Almost none. The countries of the world ranking highest for palliative care all have some form of national strategy, if only one that is only nested within an overall cancer strategy. They mostly have recognised palliative medicine as a medical specialty and have associated training arrangements for other professions. Some European countries have made access to palliative care a legal right. In 1997, Germany introduced a law assuring the right to palliative care and a similar law was introduced in France in 1999. A law establishing the right to palliative care in Belgium was established in 2002, the same year that Belgium also legalised euthanasia. An access to palliative care Bill is currently before the Houses of Parliament and had a first reading in the House of Lords in June 2015.¹⁰² It seeks to make 'provision for equitable access to palliative care services; for advancing education, training and research in palliative care; and for connected purposes'. A bill 'to require palliative care to be provided to persons with a life-limiting condition and to members of such persons' families; and to require reports on the provision of palliative care to be made to the Scottish Parliament' was introduced and withdrawn in 2010.¹⁰³

- But as the European Association for Palliative Care points out in its Prague Charter of 2013:

Access to palliative care is a legal obligation, as acknowledged by United Nations conventions, and has been advocated as a human right by international associations, based on the right to the highest attainable standard of physical and mental health. In cases where patients face severe pain, government

failure to provide palliative care can also constitute cruel, inhuman or degrading treatment ... Yet, the governments of many countries throughout the world have not taken adequate steps to ensure patients with incurable illnesses can realise the right to access palliative care.¹⁰⁴

4. Are indicators reviewed and re-evaluated regularly? How are these indicators used to influence service provision and funding?

- There is a small but growing body of international expertise on indicators. But even the most recently published papers suggest that work is still at a formative stage. Some highly extensive sets of indicators have been produced, but it is extremely difficult to see how these could be operationalised at scale. There is little evidence that systematically collected data is influencing provision and funding. The Liverpool Care Pathway was introduced before good evidence existed to support its roll-out. Its demise was the result of public opinion and debate. The study which demonstrated that it did not improve care was only published after the use of the LCP had been ceased.

5. What safeguards are in place to ensure that data collected from the indicators are accurate and consistent across providers?

- This question assumes a higher level of activity on the collection of indicators than that which actually exists. In most cases the development and use of indicators is still at the level of research investigation and trialling, rather than routine operation.

6. What data is collected, how often and what type of analysis takes place? Who collates, holds and analyses this information? How is the data used and reviewed? Is the data published? How long has the particular country been gathering that data?

- Examples of concerted effort outcomes measurement in palliative care have been in development for some years in Australia and Sweden, but this has not led yet to the adoption of widely-used indicators.

7. How successful are the indicators in capturing both access to and quality of palliative and end of life care in different care settings? Do indicators differentiate between cancer and other life-limiting illnesses and adult and paediatric care?

- Very partially. But they represent a start and are to be encouraged. It is still the case that primary research, often undertaken in very specific settings and localities, is our best source of knowledge on access to and the quality of palliative care. Such research has shed light on inequitable access to specialist palliative care, the continued prominence of those with a diagnosis of cancer as the main beneficiaries. Research on children's palliative care is even more limited than that on adult services.

8. Are there any other mechanisms in place in countries with successful palliative and end of life care systems, such as peer review and awareness-raising, which would be helpful to put into place in Scotland to achieve the objectives of equitable access to and high-quality palliative and end of life care?

- Interest in and awareness of palliative and end of life care appear to be rising in Scotland. This relates to some wider public debates about ageing, dying and death that are taking place – and also public discussion on assisted dying. Now is a good moment to capitalise on this. It is an excellent time for the Scottish Government Strategic Framework for Action on Palliative and End of Life Care to be in preparation. In the United States, Hungary, France and elsewhere there have been some efforts to develop a social marketing approach to palliative care and the social media have an important role in this.¹⁰⁵

9. How does the provision of palliative care in Scotland compare to other countries globally?

- We must assume, in the absence of evidence to the contrary, that the provision of palliative care in Scotland is comparable with that, as measured, for the United Kingdom as a whole. This would make it world class. But as this report shows, alongside that high ranking status, sit several major concerns about the delivery of palliative and end of life care. Unlike, England (but perhaps in common with Wales and Northern Ireland) Scotland seems to have escaped the steady flow of negative inspection reports, Ombudsman complaints and mass media criticisms of the quality of end of life care.

Appendix 1: SPICT



Supportive and Palliative Care Indicators Tool (SPICT™)



The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

<p>Cancer</p> <p>Functional ability deteriorating due to progressive metastatic cancer.</p> <p>Too frail for oncology treatment or treatment is for symptom control.</p> <p>Dementia/ frailty</p> <p>Unable to dress, walk or eat without help.</p> <p>Eating and drinking less; swallowing difficulties.</p> <p>Urinary and faecal incontinence.</p> <p>No longer able to communicate using verbal language; little social interaction.</p> <p>Fractured femur; multiple falls.</p> <p>Recurrent febrile episodes or infections; aspiration pneumonia.</p> <p>Neurological disease</p> <p>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</p> <p>Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.</p> <p>Recurrent aspiration pneumonia; breathless or respiratory failure.</p>	<p>Heart/ vascular disease</p> <p>NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:</p> <ul style="list-style-type: none"> • breathlessness or chest pain at rest or on minimal exertion. <p>Severe, inoperable peripheral vascular disease.</p> <p>Respiratory disease</p> <p>Severe chronic lung disease with:</p> <ul style="list-style-type: none"> • breathlessness at rest or on minimal exertion between exacerbations. <p>Needs long term oxygen therapy.</p> <p>Has needed ventilation for respiratory failure or ventilation is contraindicated.</p>	<p>Kidney disease</p> <p>Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.</p> <p>Kidney failure complicating other life limiting conditions or treatments.</p> <p>Stopping dialysis.</p> <p>Liver disease</p> <p>Advanced cirrhosis with one or more complications in past year:</p> <ul style="list-style-type: none"> • diuretic resistant ascites • hepatic encephalopathy • hepatorenal syndrome • bacterial peritonitis • recurrent variceal bleeds <p>Liver transplant is contraindicated.</p>
<p>Review supportive and palliative care and care planning</p> <ul style="list-style-type: none"> <input type="checkbox"/> Review current treatment and medication so the patient receives optimal care. <input type="checkbox"/> Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage. <input type="checkbox"/> Agree current and future care goals, and a care plan with the patient and family. <input type="checkbox"/> Plan ahead if the patient is at risk of loss of capacity. <input type="checkbox"/> Record, communicate and coordinate the care plan. 		

Please register on the SPICT website (www.spic.org.uk) for information and updates.

SPICT™, April 2015

Appendix 2: WHO fact sheet on palliative care

Fact sheet N°402

July 2015

Key facts

- Palliative care improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, whether physical, psychosocial or spiritual.
- Each year, an estimated 40 million people are in need of palliative care, 78% of them people live in low- and middle-income countries.
- Worldwide, only about 14% of people who need palliative care currently receive it.
- Overly restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate pain relief and palliative care.
- Lack of training and awareness of palliative care among health professionals is a major barrier to improving access.
- The global need for palliative care will continue to grow as a result of the rising burden of noncommunicable diseases and ageing populations.
- Early palliative care reduces unnecessary hospital admissions and the use of health services.

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.

Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.

Palliative care is required for a wide range of diseases. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Pain is one of the most frequent and serious symptoms experienced by patients in need of palliative care. Opioid analgesics are essential for treating the pain associated with

many advanced progressive conditions. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary disease will experience moderate to severe pain at the end of their lives.

Opioids can also alleviate other common distressing physical symptoms including breathlessness. Controlling such symptoms at an early stage is an ethical duty to relieve suffering and to respect the dignity of people.

Poor access to palliative care

Each year an estimated 40 million people are in need of palliative care, 78% of whom live in low- and middle-income countries. For children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa.

Worldwide, a number of significant barriers must be overcome to address the unmet need for palliative care:

- national health policies and systems do not often include palliative care at all
- training on palliative care for health professionals is often limited or non-existent
- population access to opioid pain relief is inadequate and fails to meet international conventions on access to essential medicines.

A 2011 studyⁱ of 234 countries, territories and areas found that palliative care services were only well integrated in 20 countries, while 42% had no palliative care services at all and a further 32% had only isolated palliative care services.

In 2010, the International Narcotics Control Board found that the levels of consumption of opioid pain relief in over 121 countries were “inadequate” or “very inadequate” to meet basic medical needs. In 2011, 83% of the world’s population lived in countries with low to non-existent access to opioid pain relief.ⁱⁱ

Other barriers to palliative care include:

- lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer patients and health systems
- cultural and social barriers, such as beliefs about death and dying
- misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life
- misconceptions that improving access to opioid analgesia will lead to increased substance abuse.

ⁱ Lynch T, Connor S, Clark D. Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management* 2013;45(6):1094-106

ⁱⁱ Seya MJ, Gelders SFAM, Achara OU, Milani B, Scholten WK. A First Comparison between the Consumption of and the Need for Opioid Analgesics at Country, Regional and Global Level. *J Pain & Palliative Care Pharmacother*, 2011; 25:6-18.

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What can countries do?

National health systems are responsible for including palliative care in the continuum of care for people with chronic and life-threatening conditions, linking it to prevention, early detection and treatment programmes. This includes, as a minimum, the following components:

- Health system policies that integrate palliative care services into the structure and financing of national health-care systems at all levels of care.
- Policies for strengthening and expanding human resources, including training of existing health professionals, embedding palliative care into the core curricula of all new health professionals, as well as educating volunteers and the public.
- A medicines policy which ensures the availability of essential medicines for managing symptoms, in particular opioid analgesics for the relief of pain and respiratory distress.

Palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services.

Palliative care needs to be provided in accordance with the principles of universal health coverage. All people, irrespective of income, disease type or age, should have access to a nationally determined set of basic health services, including palliative care. Financial and social protection systems need to take into account the human right to palliative care for poor and marginalized population groups.

Specialist palliative care is one component of palliative care service delivery. But a sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers. Providing palliative care should be considered an ethical duty for health professionals.

WHO response

Palliative care medicines, including those for pain relief, are included in WHO's list of essential medicines for adults and children. Palliative care is recognised in key global mandates and strategies on universal health coverage, noncommunicable diseases, and people-centred and integrated health services.

In 2014, the first ever global resolution on palliative care, World Health Assembly resolution WHA67.19, called upon WHO and Member States to improve access to palliative care as a core component of health systems, with an emphasis on primary health care and community/home-based care. WHO's work to strengthen palliative care will focus on the following areas:

- integrating palliative care into all relevant global disease control and health system plans
- developing guidelines and tools on integrated palliative care across disease groups and levels of care, addressing ethical issues related to the provision of comprehensive palliative care

- supporting Member States in improving access to palliative care medicines through improved national regulations and delivery systems
- promoting increased access to palliative care for children (in collaboration with UNICEF)
- monitoring global palliative care access and evaluating progress made in palliative care programmes
- encouraging adequate resources for palliative care programmes and research, especially in resource-limited countries
- building evidence of models of palliative care that are effective in low- and middle-income settings.

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Appendix 3: Existing Scales or screening tools to predict risk of death and their domains

Source: see reference 57

Year/ Author	Scale name and scoring	Components
1949 Clark and modified by Péus	Karnofsky Performance Score (KPS)	Quality of life across the spectrum of health from 0= normal to 100 = terminal
1981 Addington-Hall	1981 Addington-Hall	Five dimensions of quality of life: activity, daily living, general health, support of family and friends, and outlook
1985 Knaus 1992 McMahon 1995 DelBufalo 2006 Zimmerman 2013 Sharif	Acute Physiology and Chronic Health Evaluation APACHE II APACHE III APACHE IV APACHE-L	The point score is calculated from 11 ICU physiological measurements + age: Temperature (rectal), Mean arterial pressure, pH arterial, Heart rate, Respiratory rate, Sodium (serum) Potassium (serum), Creatinine, Haematocrit, White cell count, Glasgow Coma Scale
1987 Charlson 1988 Pompei	Charlson Comorbidity Index (CCI)	Includes 19 categories of comorbidity and each condition is assigned with a severity score of 1, 2, 3 or 6 depending on the risk of dying associated with this condition. Higher scores indicate greater comorbidity (patients with a score >5 have a 100% risk of dying at 1 year)
1993 Le Gal	SAPS II	Age, heart rate, Systolic BP, Temp, GCS, CPAP Y/N, PaO ₂ , FIO ₂ , urine Output, BUN, K, Bicarbonate, WCC, Chronic diseases, medical/surgical admission
1996 Anderson 2008 Virik and Glare	Palliative Performance Scale (PPS)	Assessment of observed ambulation, activity, evidence of disease, self-care, intake, level of physical activity and level of consciousness. Score 0=death Score 70=bed bound Score 100=full health and

Year/ Author	Scale name and scoring	Components
		ambulation
1998 Elixhauser 2009 Van Walraven 2013 Austin	Elixhauser comorbidity Index	Relies on administrative databases to retrieve diagnostic items for 30 coexisting disease groups and applies weights to severity
2001 Subbe	MEWS	Scores of 5 or more were associated with increased risk of death
2004 Glare 2012 Maltoni	Palliative Prognostic Score (PaP)	Karnofsky Performance Status plus Dyspnoea Anorexia White cell counts Clinician's weighted prediction of survival
2013 Kuo-H	Rapid Emergency Medicine Score (REMS)	Blood pressure, respiratory rate, Glasgow Coma Scale, peripheral oxygen saturation,
2005 Rockwood	CSHA Clinical Frailty Scale	Scores of 1 (very fit) to 7 (severely frail) assigned by physician on the basis of qualitative definitions incorporating physical functioning and presence of comorbidities
2006 Paterson	SEWS	Respiratory rate, oxygen saturation, temperature, blood pressure, heart rate and conscious level
2006 Kellet 2012 Kellett	Simple Clinical Score (SCS)	Weighted cores derived from 16 independent variables: age, pulse, systolic blood pressure, respiratory rate, temperature, oxygen saturation, breathless on presentation, abnormal ECG, diabetes, coma, altered mental status, new stroke, unable to stand unaided, nursing home resident, daytime bed rest prior to current illness
2008 Groarke	EWS	Pulse, systolic blood pressure, respiratory rate, oxygen saturation and neurological status. Increases in score indicate risk of complication or death

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Year/ Author	Scale name and scoring	Components
2008 Stone	Palliative Prognostic Index (PPI)	PPS + Oral intake Oedema Dyspnoea at rest Delirium
2008 Glare	Clinical Prediction of Survival (CPS)	Combines clinical experience with performance assessment
2010 Prytherch	ViEWS	Applies paper-based EWS score to a Vital Signs database and uses known relationship between deteriorated physiological measures and clinical outcomes such as in-hospital mortality with 24 h of the observations
2012 & 2013 Rothman	Rothman Index	Nurse-led assessment of whether minimum standards for each of 8 body systems, food intake, pain, risk of falls and 1 psychosocial (adequate support system) criteria are met or not met

APACHE, Acute Physiology and Chronic Disease Evaluation; CSHA, Canadian Study of Health and Aging; EWS, early warning score; ICU, intensive care unit; MEWS, modified early warning score; SAPSII, Simplified Acute Physiology Score II; SEWS, standardised early warning scoring system; ViEWS, VitalPAC™ early warning score.

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