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**Palliative care in the USA and England: a critical analysis of meaning and implementation towards a public health approach**

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**Abstract**

Delivering optimal and equitable palliative care is an international challenge. There are few cross-national comparisons examining challenges in expanding palliative care along public health lines. This paper presents a critical review of palliative care in the USA and England, which share similar challenges but have different contexts of healthcare.

Beyond some obvious differences in the organisation of palliative care, a set of underlying common issues can be identified. A key tension in both is balancing attention 'downstream' in the dying phase, as well as 'upstream' earlier in the course of serious illness. In both, the dominant models of palliative care provision have resulted in excellent care towards the end of life for some patients, but there remain major deficiencies in care for the majority. England has a National Strategy for End-of-life care; the US has no equivalent, although a number of influential agencies have published statements.

Achieving a public health approach in palliative care requires international consensus on the meaning and target population of palliative care, replacement of prognosis based understandings of entitlement to palliative care with a needs based approach, and development of an evidence base for cost effective partnerships between providers across the specialist-generalist divide.

**Key words:** Palliative care; public health, hospice, end-of-life care; USA; England; policy; international comparisons.

## 1. Introduction

While there is international consensus about the elements required to deliver optimal palliative care (PC) (World Health Organisation, 2014), PC services are organized in different ways internationally and key terms (such as 'hospice') mean different things (European Association for Palliative Care, 2009, 2010). Comparison between nations is necessary to develop better models of care to address rapid increases in PC needs and address barriers to innovation (Ferris, Gomez-Batiste, Furst, & Connor, 2007). The uncertain illness trajectories associated with multiple morbidity and frailty do not fit the classical patterns of 'terminal illness' upon which existing models of PC are predicated (Kimbell, Murray, Macpherson, & Boyd, 2016). Many people consequently fail to receive the PC they need; this is a global humanitarian and public health issue (Worldwide Palliative Care Alliance, 2014).

In this paper we examine the meaning and operationalization of PC in England and the USA to understand the extent to which each are implementing international recommendations about integrating PC within their health care systems so that more people can access support. England and the USA have highly developed health care systems with shared histories of PC, arguably making them 'ideal' candidates for comparison (Higginson, 2005). In both, PC emerged in the middle 20th century, within the same decade. Innovation was initially driven by highly charismatic individuals and cross Atlantic exchange, although key concepts and services later diverged (Clark & Centenos, 2014; Foley, 2014). Both are signatories to the 2014 WHO resolution on PC, which recommends development of public health policies for PC (World Health Organisation, 2014). While England and the USA are ranked first and ninth respectively in the widely reported Quality of Death Index reports

(Economist Intelligence Unit, 2015), the latter reports have been criticized for assuming ‘...*an unambiguous correlation*’ (Timm & Vittrup, 2013) between the numbers of specialized PC (SPC) services in any one country and the quality of PC. This is erroneous, since most people who need PC do not receive care from specialists, but rather from general staff (community nurses for example), who may or may not have additional training in PC. The latter reports also do not take sufficient consideration of differences in culture or context. Comparative studies of terminology, policy and practice are essential to the development of PC internationally (Timm & Vittrup, 2013).

## **2. Widening access: the public health approach to palliative care**

In 2002, in recognition of new needs thrown up by ageing and chronic non-communicable disease, the World Health Organization (WHO) revised its original cancer focused definition of PC referring to all ‘life threatening’ illnesses and making it clear that PC should be provided at an early stage, complementing other forms of care (Sepulveda, Marlin, Yoshida, & Ullrich, 2002; World Health Organisation, 1990) (box 1).

Box 1 about here

Since only a minority of people who could benefit come into contact with the relatively scarce numbers of dedicated or ‘specialist’ PC services, the thrust of international policy is to try to embed PC principles and skills into mainstream health and social care so that more people can benefit from what is called variously the PC ‘approach’, ‘primary’ PC or ‘generalist’ PC (Quill & Abernethy, 2013; World Health Organisation, 2014). This trend is most clearly demonstrated by the resolution

agreed at the 2014 World Health Assembly calling on member states to integrate PC more effectively into their health care systems. The resolution calls for national policies to: 1) support evidence based service development; 2) expand quality improvement initiatives; 3) widen support of family and volunteer caregivers; 4) ensure that the care workforce receive PC training. This was complemented by a report by the Worldwide Palliative Care Alliance stating that the scope of PC should include chronic, as well as life limiting or life threatening conditions and that there should be no prognostic limit on its delivery (Worldwide Palliative Care Alliance, 2014).

Integrating PC into mainstream care is often referred to as the public health approach in PC (American Public Health Association, 2013; Stjernsward, Foley, & Ferris, 2007) and has been described as a third evolutionary stage in the development of PC, following clinical development (stage one) and organizational expansion (stage two) (Singer & Bowman, 2002). However, the notion of PC as a public health issue is associated with ambivalence (Singer & Bowman, 2002), reflected in the lack of agreement about whether PC is a field of specialty practice, a philosophy of care or a system for delivering care (Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008). There is a lack of consistent definition of associated terms (Hui et al., 2013) and a disparity of views about the appropriate target groups and indicators for PC (Junger, Payne, Brearley, Ploenes, & Radbruch, 2012), all of which have material impacts on patient care, with many 'falling between the cracks' of different categories of perceived responsibility.

### **3. Origins of this paper**

This paper draws on our observations during exchange visits to England and USA in 2012 and 2014, where we compared the meaning and delivery of PC as a foundation for further comparative research about barriers and facilitators to the public health approach for PC. We build on an earlier paper (Seymour, 2013) exploring the evolution of PC in England where it was noted that there is an 'identity crisis' in this field of care as it struggles to evolve.

#### **4. Methods**

The paper is based on a narrative synthesis of information from three sources: 1) observations made during our exchange visits to England and USA in 2012 and 2014, where we each spent 4-6 months evaluating the challenges associated with developing PC along public health lines in our host country; 2) informal interviews recorded by hand written notes with key stakeholders, who included policy makers, practitioners, researchers and field leaders (n = 25 in the USA and n = 35 in England). The latter were 'off the record' and so we do not use direct quotes, but the interviews informed our interpretation and analysis; 3) a review of published articles and policy documents, sourced via expert advice from stakeholders and using our own knowledge. This was complemented by a scoping review conducted in 2014 to identify existing comparative research on the health care systems and PC in the USA and England. We shared our interpretations at major conferences during 2015, thus giving many key informants an opportunity to comment.

Our observations are presented in four sections. The first compares the health care systems and the recent health care reforms in both. The second compares differences in SPC services, while the third looks at gaps in general PC coverage

beyond the provision of SPC, focusing especially on older people, the largest group in need of PC. The last section addresses PC policy, highlighting commonalities and differences. We conclude with observations relevant to PC development internationally.

To help the reader, we provide below in Table 1 the various definitions of 'PC' and the related terms of 'hospice' and 'end-of-life care' in common use in the two countries at the time of our study.

Table 1 about here

## **5. Health care systems in England and the USA**

The US and English health care systems are often posited as polar opposites. The USA is described as having a 'market maximized entrepreneurial' system (Roe & Liberman, 2006) largely based on the purchasing of health insurance by individuals or employers and a 'fee for service' model of payment. Private, employer-sponsored insurance became widespread after World War II. Government-funded insurance programmes have been operative since the 1960s, with Medicaid (50 federal-state partnerships) covering health care services to some poor or nearly poor individuals, and Medicare (federal) providing almost universal coverage to seniors (aged 65 and over). Alongside these structures sits the Veterans' Health Administration (VHA), operated by the US Department of Veterans Affairs, constituting the only integrated, publically funded health care service in the country (Rice et al., 2013). In contrast, England is described as a 'market minimized National Health Service' model (Roe & Liberman, 2006) providing universal coverage, tax based funding and primarily national ownership and control of the health care services, including the employment



of most health care staff (although this model of funding does not apply wholly to hospices in England, to care homes or to GP services) (Boyle, 2011).

Closer examination reveals more similarity than is often appreciated. For example, Klein (2012) points out that the 'conventionally antithetical stereotypes' need to be revised, with health care services to older persons largely funded through public sources in both countries.

Both countries have undergone fundamental health care reform that may move their health care systems closer together. In the USA, the 'Patient Protection and Affordable Care Act' (PPACA) 2010 HR3590 (referred to as the ACA or 'Obamacare') introduced a range of measures to improve coverage of health care insurance and protect consumers, improve individual and population health, and contain costs (Meier, 2011). Table 2 outlines the key areas of reform. The Act is complicated and therefore any summary is necessarily selective. It has been observed that there will still not be universal health care coverage under the reforms, in spite of the intents of the Act (Reeve, Wizemann, Eckert, & Altevogt, 2014). Many gaps in coverage relate to the optional nature of Medicaid expansion for US States: a political concession made to enable passage of the Act. It remains to be seen what will happen to the Act after the presidential election of 2016.

Table 2 about here

In England, the Health and Social Care Act of 2012 has introduced far-reaching changes, summarized in Box 2, in NHS organization in terms of structure, accountabilities, funding arrangements and working relationships (Health and Social Care Act, 2012). There is related activity in England to improve the funding and

quality of social care in recognition of the links between social care coverage, quality of patients' experiences and NHS costs (Department of Health, 2012; Georghiou, 2012).

Box 2 about here

## **6. Specialist palliative care services: key differences**

There are a number of detailed descriptions available of the history of SPC services in the USA (Clark, 2013; Foley, 2014) and England (Seymour, 2013); we draw attention here to key characteristics.

### USA

In the USA, SPC was originally manifest through the hospice movement, following the establishment of the first free standing hospice in Connecticut in 1975 inspired by the UK example (Foley, 2014). Hospice care is now the most widely available form of SPC, delivered primarily as a community based nursing service (National Hospice and Palliative Care Organization, 2012). The US hospice movement has been profoundly shaped by the Medicare hospice benefit, enacted in 1982 (Aldridge & Kutner, 2014; Davis, 1988). This enables people aged 65+ to access hospice care if they have a prognosis of less than six months and agree to forego disease-focused treatments. There has been a 110-fold increase in service provision in 30 years, with around 44.6% of decedents receiving some level of hospice care in 2011 (National Hospice and Palliative Care Organization, 2012). However, access varies depending on locality (Meier, 2011). Hospice care is now delivered by a mixture of philanthropic 'not for profit' and 'for profit' providers (Aldridge & Kutner, 2014). 'For profit' hospice has been a source of controversy (Whoriskey, 2013-2014), especially

when associated with long term nursing home care, where questions have been raised about whether such clients are 'profit targets' for hospice providers (Ersek, Sefclk, & Stevenson, 2014).

Quite separate from hospice, the other way in which SPC is provided in the USA is via formal palliative medicine programmes. These developed much later than hospice, exclusively in the hospital sector. SPC of this sort has been styled through a social marketing campaign as '*...specialized medical care for people with serious illnesses.... Unlike hospice care, palliative care can be provided at the same time as curative treatments...*' (Center to Advance Palliative Care and National Palliative Care Research Center, 2015). By 2015, 90% of large hospitals with more than 300 beds had a SPC programme, although there is regional variety (Center to Advance Palliative Care and National Palliative Care Research Center, 2015). As far as we are aware, there are no data on the proportion of hospitalized patients who receive input from SPC teams; nor is not clear how many patients receiving hospital SPC go onto have hospice care. What are called 'public safety net' hospitals are least likely to have such a service (Smith & Brawley, 2014).

Two major deficiencies in SPC in the USA are, firstly, the limited scope and reach of hospital-based SPC services and, secondly, gaps in the support of patients not yet 'ready' for hospice (Kamal et al., 2013), given the requirement to forego disease-focused treatments in order to receive hospice services.

## England

Development of SPC evolved in England from an in-patient hospice model that developed in the 1960s outside of the National Health Service (Seymour, Clark & Winslow, 2005). Hospices expanded rapidly, building links with and gaining co-

funding from the NHS while maintaining some independence. The development of community services and consultative services in hospitals followed. Unlike in the USA, there is no clear divide between 'SPC' and 'hospice' care in England and patients do not need to forfeit disease-focused treatments when receiving any type of SPC, although in fact most services operate a prognosis driven access policy, with need for SPC commonly determined by assessment of whether the person is in the last year of life, alongside the nature of their problems and symptoms (Bennett, Davies, & Higginson, 2010; Kimbell et al., 2016).

Hospices now provide inpatient beds, as well as day care and 'home hospice' services, some of which reach into care homes, nationwide (Wee, 2013). There have been efforts to shift the focus of hospice care 'upstream', as demonstrated in the rhetoric of the charity, Hospice UK: '*... Hospice care can be accessed at any stage of a person's illness, not just at the end of life*' (Hospice UK, 2015). NHS funded SPC hospital and community services are also available nationwide, though with wide regional variation (The National Council for Palliative Care, 2013).

It has been estimated that some form of SPC is provided to between 160,000 and 170,000 people annually in England, with around 80% of referrals relating to patients with cancer (Dixon, King, Matosevic, Clark, & Knapp, 2015). There is in excess of a 30-fold variation in NHS expenditure on SPC services across different regions (Hughes-Hallett, Craft, & Davies, 2011).

## **7. Gaps in palliative care coverage compared**

In both countries, the dominant models of SPC provision have resulted in excellent care for some patients but there are major deficiencies in care for the majority. While

methodologies to identify patients in need of PC are poorly refined, partly because of the definitional issues (Gomez-Batiste et al., 2014; Murtagh et al., 2014), general patterns are understood. Many symptoms, problems and needs are shared across conditions (Fitzsimons et al., 2007) and people with chronic non-cancer conditions are likely to be older, to need support for longer and to experience longer term disability and frailty (Gill, Gahbauer, Han, & Allore, 2010). People with uncertain prognoses (who overlap with the latter) are less likely to access SPC and more likely to experience fragmented care during their illness and to receive a sub-optimal quality of care during dying (Kinley et al., 2014; Mitchell et al., 2009). In both countries relatives or friends are often the main providers of support but characteristically receive little help (Lowson et al., 2013).

In both countries, care homes are major providers of non-specialist PC but are isolated both from mainstream health and SPC services (Kinley et al., 2014). As in the USA, the care home sector in England has developed along largely privatized lines and residents' care is funded by a complex mixture of sources, leading to confusion about responsibilities for PC provision (Seymour, Kumar & Froggatt, 2011).

Studies in both countries reveal the relationship between the lack of 'social' support and the use of emergency hospital care (Georghiou, 2012; Lynn, 2013). In both hospital re-admissions, often to emergency units, are common in the last year of life, (Lyons & Verne, 2009; The Dartmouth Institute for Health Policy and Clinical Practice, 2015), yet quality of PC in hospitals is often poor (Walling et al., 2010; Gott et al., 2013).

Funding models and abundance of services contribute to high use of high-technology care in hospitals in the USA (Fisher & Wennberg, 2003). One in five adults use intensive care services at or shortly before death (Wunsch, Angus, Harrison, Linde-Zwirble, & Rowan, 2011), and a higher proportion of very elderly patients are admitted to the ICU in the USA (Morden et al., 2012; Wunsch et al., 2011), contributing to a '*...cascade of harm and overuse*' (Brownlee, Cassel & Saini, 2014). In contrast, questions have been raised in England about whether older people are subject to discrimination in access to life prolonging interventions (Independent Review of the Liverpool Care Pathway, 2013).

Fewer people of all ages die in hospitals in the USA than in the UK -approximately 25% vs 58% respectively (Dartmouth Institute for Health Policy and Clinical Practice, 2015; Public Health England, 2013), probably due to the widespread use of hospice in the USA. However, questions have been raised in the US about whether hospice is merely an 'add on' to a growing trend of more utilization of intensive services at the end of life (Teno et al., 2013).

## **8. Addressing deficiencies in palliative care: comparing policy directions**

An overarching difference between policy in the USA and England is that the latter has a National Strategy for End-of-life care (Department of Health, 2008). The US has no national equivalent, although a number of influential agencies have independently published statements related to PC (American Public Health Association, 2013; Economist Intelligence Unit, 2015; Institute of Medicine, 2014) and changes introduced by the Affordable Care Act have lent momentum to attempts to reach consensus on policies needed to improve care (Meier, 2011).

## England: an End-of-Life Care Strategy for all?

The English End-of-Life care Strategy (Department of Health, 2008) provides a framework: 'The End-of-Life Care Pathway' seeking to improve the quality of care for all those approaching death by enabling care planning, communication and co-ordination of care across the course of a final illness (Box 3). The Strategy was the culmination of a range of externally facing policy initiatives, which together had built a momentum to address PC needs beyond cancer (Seymour, 2013). A major theme within the Strategy, reflecting wider health care policy, is an aspiration to link health and social care and to coordinate patients' care across different care settings: both elusive goals.

Box 3 about here

In 2011, a national 'Quality Standard' for end-of-life care for adults was published by the National Institute for Clinical Excellence (National Institute for Health and Care Excellence (NICE), 2011 (modified 2013), as well as 'quality markers' for use by providers and commissioners to plan and develop services (Department of Health, 2009). Associated developments include publication of guidance on good practice in decision-making towards the end of life by General Medical Council (General Medical Council, 2010) reflecting key principles of legislation (Mental Capacity Act, 2005). A National End-of-life care Intelligence Network (Public Health England, 2013) has also been established to inform service planning (Dixon et al., 2015). Selected aspects of the national implementation of the Strategy include the use of 'anticipatory' or 'just in case' prescriptions (Wilson et al., 2015), and initiatives to try to improve coordination of care. Of the latter, the Gold Standards Framework has been particularly influential (Shaw, Clifford, Thomas, & Meehan, 2010). An equally

influential initiative to try to standardize quality of care in the last days and hours of life: the Liverpool Care Pathway for the Dying Patient, was withdrawn in 2013 following a national enquiry (Independent Review of the Liverpool Care Pathway, 2013). Clinically oriented initiatives have been paralleled by a movement called 'Dying Matters' to try to raise awareness among the public (Seymour, French & Richardson, 2010).

While the use of 'end-of-life care' within these various initiatives can be seen as an expression of intent to reach a broad range of people in need of PC, it has given rise to confusion in England on two fronts.

The first area of confusion is the balance of emphasis that should be placed 'downstream' on care of the dying or 'upstream', at an earlier point in a life-limiting illness. Latterly there has been a retrenchment to a 'downstream' emphasis on care of the dying rather than the wider 'upstream' emphasis which was the original intent of the End-of-Life care Strategy (Department of Health, 2008). This may be a temporary narrowing of emphasis resulting from the vacuum left from the withdrawal of the Liverpool Care Pathway (Independent Review of the Liverpool Care Pathway, 2013). However, it may also be related to the difficulties in seeing PC from an alternative perspective to that produced by terminal cancer care lens predominant in English SPC.

The second area of confusion is on the relationship between SPC providers and what are termed 'generalist' end-of-life care providers, Clarity is lacking about responsibilities of each or the most cost effective models of collaboration (Gardiner, Gott, & Ingleton, 2012). This lack of clarity underpins the great variability in referral patterns to SPC. Latterly, there is evidence of gathering momentum to address the



persistent inequalities in PC across the specialist-generalist spectrum (Dixon et al., 2015; National Palliative and End-of-life care Partnership, 2015).

*The USA: bridging the schism between 'hospice' and 'palliative' care*

In the USA, the emphasis of palliative medicine on its role in serious illness is in sharp contrast to the focus of hospice on the care of the dying: this means that a problematic separation has developed between the two. This is fuelled both by the financial dependency of hospice on the Medicare benefit with its tight prognostic requirements and mutual exclusivity with disease-focused care (Davis, 1988; Stevenson, 2012) and by dissociation of palliative medicine from 'dying' by field leaders seeking to consolidate a hard-won role in mainstream acute hospital care. USA policy commentators are increasingly calling for root-and-branch changes in the Medicare hospice benefit to create more flexibility in hospice eligibility criteria and avoid the artificial forced-choice between hospice and disease-focused care (Stevenson, 2012). Opportunities now opening up under the ACA 2010 reforms offer the possibility both of achieving a measure of reconciliation between hospice and SPC. For example, seriously ill children can now access hospice as well as curative / life-prolonging care in the same care episode (Meier, 2011) and there are some pilot projects evaluating this approach in adults' care, focused on 'goals of care' planning (Deremo, et al., 2014).

There have also been calls by field leaders to consider how rapprochement can be effected between 'PC' and 'hospice' care. This is demonstrated by the work of the 'National Consensus Project for Quality Palliative Care' based on alliances between five organizations (Foley, 2014). The latter has published guidelines (National Consensus Project for Quality Palliative Care, 2013) in which shared features and

domains of practice of hospice and PC are identified. The guidelines also examine the target patient population, describing this in ways that focus on the management of ongoing disease (National Consensus Project for Quality Palliative Care, 2013) <sup>p8-9</sup> rather than on the identification of entry to the dying phase or the last 12 months of life as in the parallel statements in England.

## 9. Discussion

The use of different terms such as 'hospice', 'PC, and 'end-of-life care' to describe the care provided to people with advanced illness has been described as a 'fundamental problem' reflecting a 'loose and unformulated approach' to the area (Bennett et al., 2010)<sup>p457</sup> and conspiring against building an evidence base for effective care. In this paper, we have shown that in spite of differences in use of terminology, England and the USA share common tensions in PC organisation and delivery posing barriers to the integration of PC into their wider health care systems in line with the WHO resolution of 2014 (World Health Organisation, 2014). The most marked of these tensions are the ambivalence about whether PC should focus 'downstream' on the dying phase or 'upstream' on serious illness and the lack of clarity about the relationship between 'specialists' in PC and 'generalist' providers.

In the USA, the 'downstream/ upstream' ambivalence is manifest in the schism between 'hospice' as a model of care of the dying, and the largely hospital based SPC programmes describing themselves as an 'extra layer of support for the seriously ill'. The manner in which the US funding mechanism for hospice operates has driven both the remarkably broad access to hospice, meaning that almost 50% of decedents now access such care, but also the arguably outmoded focus on a clearly definable terminal phase, given the uncertainty of onset of dying in chronic

non communicable conditions. On the other hand, PC outside of hospice is only gradually gaining acceptance in a medically driven health care system where futile treatment, often in intensive care units, features characteristically in the journey towards death of most seriously ill people.

In England, the 'downstream/ upstream' dilemma is manifest firstly, in the relative isolation of SPC providers from the wider project of advanced and chronic illness care; and secondly, in the emphasis placed on identifying whether a person is in the last year of life before a transition to PC is made, either in specialist or generalist care contexts. In England, outside of SPC provision, the term 'PC' has been largely replaced in common parlance by 'end-of life care' following the National Strategy of 2008 (Department of Health, 2008). As a result, the terms 'PC' and 'end-of-life care' are used interchangeably with little explicit debate about meaning or responsibilities for care delivery between 'generalist' and 'specialist' providers.

Achieving integrated PC involves identification and systematic assessment of needs among patients with serious, irreversible illness among whom dying is a future possibility (Murtagh et al., 2014) and study of the optimal constellation of services (whether specialist or generalist) to provide cost effective support. The longer term support of older adults with advanced frailty and multiple morbidity is the most glaring area of PC need in both countries. A growing emphasis in the international literature is on the need to embrace uncertainty in advanced illness and frailty (Kimbell et al., 2016), and to engage in patient and family centred advance care planning conversations to help individuals live with their illness and to inform shared decisions about care and treatment both during illness and at the end of life. To this extent, England can learn from the USA by moving from a focus on whether a person has entered the last year of life before commencing any attempt to provide

PC, to a focus on 'goals of care' planning during serious illness, even if the outcome or phase of illness is unclear. In turn, the USA can draw lessons from the (albeit imperfect) English attempt to 'upskill' the generalist workforce in the principles of PC. In both countries, partnership working needs to be developed by: cross fertilization of SPC expertise with that of other specialties such as dementia care (van der Steen et al., 2014), through dedicated medical and nursing training programmes (Quill & Abernethy, 2013) and the development of more sophisticated pathways of care in clinical service delivery that better clarify relationships between specialist and generalist providers of PC (Fallon & Foley, 2012).

## 10. Conclusion

Achieving a public health approach in PC requires international consensus on the meaning and target population of PC, the replacement of prognosis based understandings of entitlement to PC with a needs based approach, and development of an evidence base for cost effective partnerships between PC providers across the specialist-generalist divide. The Institute of Medicine argues eloquently in its report 'Dying in America' that:

'...the timing of death is a much less important consideration than whether the person is living with a set of conditions that are now causing distress or disability and thus needs services that address those problems, as determined in the context of need and not prognosis. The real challenge to design models of quality and affordable care that fit the variable trajectories and needs of seriously ill people who are nearing the end of life and their family caregivers' (our emphasis).

This is essence of the challenge for the future for all countries seeking to modernize and improve access to PC: in addressing it, we need much greater international debate and exchange to develop awareness of the limitations and weaknesses of our current approaches.

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### Box 1: The World Health Organization definition of palliative care (2002)

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.

Sepulveda, C., Marlin, A., Yoshida, T., & Ullrich, A. (2002). Palliative Care: the World Health Organization's global perspective. *J Pain Symptom Manage*, 24(2), 91-96. Appendix 1

**Table 1: Key terms compared**

<p><b>Hospice (England)</b></p> <p>‘Hospice care seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or <i>terminal illness...it aspires to be accessible to all who could benefit and reflect personal preferences and needs... Hospice care is provided in a wide range of settings, not just hospice buildings’</i></p> <p>(Hospice UK- see <a href="http://www.hospiceuk.org">www.hospiceuk.org</a> accessed August 10<sup>th</sup>, 2016)</p>	<p><b>Hospice (USA)</b></p> <p><i>‘...the model for quality compassionate care for people facing a life limiting illness, hospice provides expert medical care, pain management and emotional and spiritual support...in most cases, care is provided in the patient’s home’</i></p> <p>(National Hospice and Palliative Care Organization- see: <a href="http://www.nhcpc.org">www.nhcpc.org</a> accessed August, 10<sup>th</sup>, 2016)</p>
<p><b>Palliative care (England)</b></p> <p>‘Palliative care is the active, holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their <i>families’</i>.</p> <p>(Palliative Care Explained, National Council for Palliative Care: see:</p>	<p><b>Palliative care (USA)</b></p> <p>‘Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and <i>the family’</i>.</p> <p>(America’s Care of Serious Illness, Center to Advance Palliative Care and National Palliative Care Research Centre, see: <a href="http://www.reportcard.capc.org">www.reportcard.capc.org</a> accessed August 10<sup>th</sup>, 2016)</p>

<p><a href="http://www.ncpc.org">www.ncpc.org</a> accessed August 10<sup>th</sup>, 2016)</p> <p><i>'Palliative care is for people living with a terminal illness where a cure is no longer possible. It's also for people who have a complex illness and need their symptoms controlled. Palliative care includes caring for people nearing the end of life'</i></p> <p>Marie Curie, see: <a href="http://www.mariecurie.org">www.mariecurie.org</a> accessed August 10<sup>th</sup>, 2016).</p>	<p>'Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and alleviating suffering throughout the continuum of a person's illness by addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice...Palliative care can begin at any point in the disease progression.</p> <p>(National Quality Forum- see: <a href="http://www.qualityforum.org/Palliative_and_End-of-Life_Care_Project_2015-2016.aspx">http://www.qualityforum.org/Palliative_and_End-of-Life_Care_Project_2015-2016.aspx</a> accessed August 10th, 2016)</p>
<p><b>End-of-life care (England)</b></p> <p><i>'Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support ' (National Council for Palliative Care, 2006, cited in the National End-of-life care Strategy, 2008, p47</i></p> <p>.... any palliative care within the last 12 months is regarded as end-of-life care'. (National Institute for Health and Care Excellence (NICE), 2011 (modified 2013)</p>	<p><b>End-of-life care (USA)</b></p> <p><i>'End-of-life care is comprehensive care that addresses medical, emotional, spiritual, and social needs during the last stages of a person's terminal illness. Much end-of-life care is palliative in nature, when life-prolonging interventions are no longer be appropriate, effective, or desired'</i></p> <p>(National Quality Forum- see: <a href="http://www.qualityforum.org/Palliative_and_End-of-Life_Care_Project_2015-2016.aspx">http://www.qualityforum.org/Palliative_and_End-of-Life_Care_Project_2015-2016.aspx</a> accessed August 10th, 2016)</p>

**Table 2: Key provisions in the Affordable Care Act (2010)** (Sources: Obama Care Facts- <http://obamacarefacts.com/obamacare-facts/> (accessed August 10<sup>th</sup>, 2016); Reeve M et al The Impacts of the Affordable Care Act on Preparedness, Resources and Programs: Workshop Summary. National Academies Press 2014, available at: [http://www.nap.edu/catalog.php?record\\_id=18755](http://www.nap.edu/catalog.php?record_id=18755) Accessed August, 8<sup>th</sup>, 2016)

Quality, affordable health care for all Americans	<ul style="list-style-type: none"> <li>• A mandate to have insurance through a Health Benefit exchange</li> <li>• New requirements regarding duties to offer coverage to employees</li> <li>• Insurers obliged to sell policies at fixed rates</li> <li>• Insurance companies no longer allowed to refuse health insurance to people with pre-existing conditions</li> </ul>
The role of public programs	<ul style="list-style-type: none"> <li>• Medicaid expansion</li> <li>• Expansion/ preservation of the Children’s Insurance Programme</li> <li>• Improved community based care</li> </ul>
Improving the quality and efficiency of health care	<ul style="list-style-type: none"> <li>• Comparative effectiveness research, through a not for profit ‘Patient Centered Outcomes Research Institute’.</li> <li>• Development of a National Quality Improvement Strategy</li> <li>• Reformation of Medicaid: drug costs; bundled payments for episodes of care beginning 3 days prior to hospitalization and extending to 30 days following discharge</li> <li>• Independence at home demonstration programme</li> <li>• Expansion of access to primary care</li> <li>• Coordination of Medicare and Medicaid benefits</li> </ul>
Preventing chronic disease and improving public health	<ul style="list-style-type: none"> <li>• Reform Medicare and Medicaid to encourage uptake of preventive interventions</li> </ul> <p>Development of:</p> <ul style="list-style-type: none"> <li>• National Prevention, Health Promotion and Public Health Council</li> <li>• Prevention and Public Health Fund</li> <li>• Grant programme for public health</li> <li>• National Strategy for Health</li> <li>• Wellness programmes at work</li> </ul>
Community living assistance services and supports	<ul style="list-style-type: none"> <li>• Establish a national voluntary insurance programme for community living assistance (CLASS program)</li> <li>• Introduce reforms to Medicaid to encourage community based care</li> <li>• Disclosure of information to consumers about ownership, accounts and standards of long term care facilities</li> </ul>

**Box 2:** The Health and Social Care Act, England, 2012 (for further information, see ‘The coalition government’s health and social care reforms: 2010-2015 <http://www.nuffieldtrust.org.uk/node/467> , accessed August 8<sup>th</sup> 2016)

1. The relocation of Public Health Departments from health care to local authorities;
2. The disbandment of 151 Primary Care Trusts and creation of 211 clinical commissioning groups (CCGs) giving general practitioners and other professionals greater responsibility for assessing needs and managing financial budgets to ‘buy’

care on behalf of their local communities. CCGs are required to establish 'health and well-being' boards to improve co-ordination of local services and reduce local health disparities.

3. The transfer of many responsibilities previously located in the Department of Health and the Secretary of State for Health to an independent body, known as 'NHS England';
4. The introduction of a greater degree of competition for service contracts, with the organization 'Monitor' having a mandate to guard against 'anti-competitive' practices. This enables the expansion of private health care companies into NHS care provision, in some cases taking over contracts formerly held by NHS services.
5. Moving all NHS trusts to foundation trust status.

### **Box 3: The English End of Life Strategy**

The End-of-Life Care Strategy addresses 12 main areas of end-of-life care, including: raising profile, commissioning, research, education and training, service planning and delivery and support and involvement of carers. It sets out a six-step pathway:

Discussions as the end of life approaches  
 Assessment, care planning and review  
 Co-ordination of individual patient care  
 Delivery of high-quality services in different settings  
 Care in the last days of life  
 Care after death

The implementation of the Strategy was initially driven by an England wide project called the National End-of-life care Programme, which supported local level service and practice-development.

Available at:

<https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life> (Accessed August 9th, 2016)