State of the Nations Report:
Terminal Illness Care in England, Northern Ireland, Scotland and Wales

Sheffield Hallam University | Centre for Health and Social Care Research

Marie Curie
Care and support through terminal illness

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1.0 Introduction to the State of the Nations Report

Summary

- **This literature review was commissioned by Marie Curie to determine the current policies, strategies and delivery mechanisms that underpin terminal illness care across England, Northern Ireland, Scotland and Wales.**

- **A review is needed to aid understanding of the drivers for terminal illness care across the four nations of the United Kingdom (UK), and how these drivers are enacted. In particular, a review is needed to identify evidence of implementation of the policies across the four nations and whether there are differences within this process.**

- **In addition, future policy and research recommendations need to be made to explore further any identified gaps in the care of people with a terminal illness.**

1.1 Terminal Illness in the UK

In the UK many people live with, and die from, a 'life-limiting' or 'terminal illness'. These include coronary heart disease, cancer, chronic respiratory disease, Alzheimer's and dementia and stroke (Office for National Statistics, 2013). It is now widely acknowledged that those people with life-limiting illnesses, and their families, will require palliative and end of life care to manage complex symptoms and enhance quality of life at some point in their illness trajectory (Murtagh *et al*, 2014). Furthermore, almost two thirds of people who die are aged 75 and over, some of whom may be experiencing frailty, with the implication that this is likely to become an increasingly common route to death. Thus, the scope of palliative and end of life care provision is expanding. Policies, guidelines and recommendations for health and social care teams delivering palliative and end of life care, and for commissioners purchasing and planning services are provided by each of the four nations. Nevertheless, devolved government across the four nations means there are differing approaches to the commissioning, planning and delivery of palliative care for people living with a terminal illness and at end of life.

The Centre for Health and Social Care Research (CHSCR) at Sheffield Hallam University (SHU) was commissioned by Marie Curie in January 2016 to carry out a review of terminal illness care policy, strategy and delivery across the four nations of the UK; England, Northern Ireland, Scotland and Wales. This review will aid understanding of what drives care and how

and why provision may be different across the four nations of the UK. The subsequent 'State of the Nations Report' considers five key objectives.

1.2 The key task and sub-questions:

State of the Nations Report: Terminal Illness

1. What are the current policies that impact upon terminal illness in the four nations?
2. In light of the policies, what level of priority does each nation give to the care of terminally people?
3. What are the current strategies and delivery mechanisms that influence terminal care in the four nations?
4. What is the evidence of the implementation of the current strategies and delivery mechanisms?
5. In light of the evidence, what aspects of policy, strategy and delivery mechanisms work well in relation to caring for terminally ill people within and outside the UK and how could these be used across nations?

The task includes an assessment of what literature currently exists in regards to each topic, highlighting key issues and identifying areas and issues around which no existing literature covers. Implications for commissioning and future research are provided based on the published evidence available.

2.0 Methodology for the literature review.

Summary

- **A literature review was conducted which identified documents relevant to terminal illness care policy published since the 2004 NICE Guidance.**

- **Combined, the database and grey literature searches yielded 122 papers suitable for inclusion in this review.**

- **A tabular and narrative synthesis to provide information about what is and is not known about the research questions identified in section 1.3.**

The literature review process sought to locate academic review papers and grey literature exploring terminal illness care across the four nations. The literature review process and in particular, the screening process was iterative. All evidence which enabled a response to the research objectives of this review is shown in relevant tables for each nation. In addition, other academic review papers and grey literature that support a broader understanding of terminal illness care in the four nations was classified in accordance with the 'policy pyramid' shown in Figure 2. Examples are provided in Appendix 9.3.

2.1 Search Strategy

The search strategy was run on a range of information resources. The search strategy comprised three facets and used terms relating to: (1) terminal illness care or palliative care, and (2) terms relating to policy or guidelines, and (3) terms to limit to studies situated in the UK. Search filters were applied to limit to review papers only. The searches were undertaken in February and March 2016.

All search terms were looked for in the title and abstract fields and controlled vocabulary terms were used where available. In addition, the terms used in facet three were also searched for in the author address field. The Boolean operators AND and OR were used, alongside truncation, phrase searching and proximity operators. Only papers published between January 2004 and March 2016 and in the English language were sought.

2004 was chosen as the start date for the review because this was when England's NICE Guidance was published (National Institute for Health and Clinical Excellence, 2004). This was one of the foundation documents for England's 2008 End of Life Care Strategy (Department of Health, 2008) and also formed part of the evidence base for current policy documents across all four nations.

The following databases were searched: Applied Social Sciences Index and Abstracts (ProQuest), CINAHL (EBSCO), Cochrane Library (Wiley), MEDLINE (EBSCO), Social Care Online (Social Care Institute for Excellence), Web of Science (Thomson Reuters). These databases were selected as their scope matches the subject of this review or because they are multidisciplinary resources. A copy of the search strategy used in the database searches is located in Appendix 9.1.

Grey literature searches were undertaken on NICE Evidence Search (NICE) and targeted websites, such as government resources from the four nations. In addition, grey literature was identified through expert prior knowledge of key documentation. The grey literature searches used an abridged set of search terms; this was due to NICE Evidence Search and other websites allowing only a limited number of characters to be entered into a search string. The most salient search terms were identified through a scan of the literature yielded from the database searches. In the case of NICE Evidence Search, search filters were applied to limit to the literature from a particular origin, such as the NHS or .gov, and to apply date restrictions.

RefWorks, a bibliographic management tool, was used to organise the literature yielded from this review.

2.2 Screening Process

Using pre-defined inclusion/exclusion criteria (see Appendix 2) all literature was assessed for eligibility for inclusion in the review. In the first instance this took place at title and abstract level and all papers were doubled screened for relevancy by JS, RS or DH. The remaining literature yielded which related to palliative care policy in the UK was categorised as a Level 1, 2, 3 or 4 document (see section 2.6). The full text of all literature categorised as a Level 1 document was double read to check for relevancy by JS, RS or DH. All documents still determined to be Level 1 were then subjected to a structured information abstraction process.

2.3 Summary of the literature review selection process

Details of the results from the literature searches, alongside the screening process are summarised in Figure 1. Examples of the types of documents categorised at Level 2, Level 3 and Level 4 are provided in Appendix 9.3.
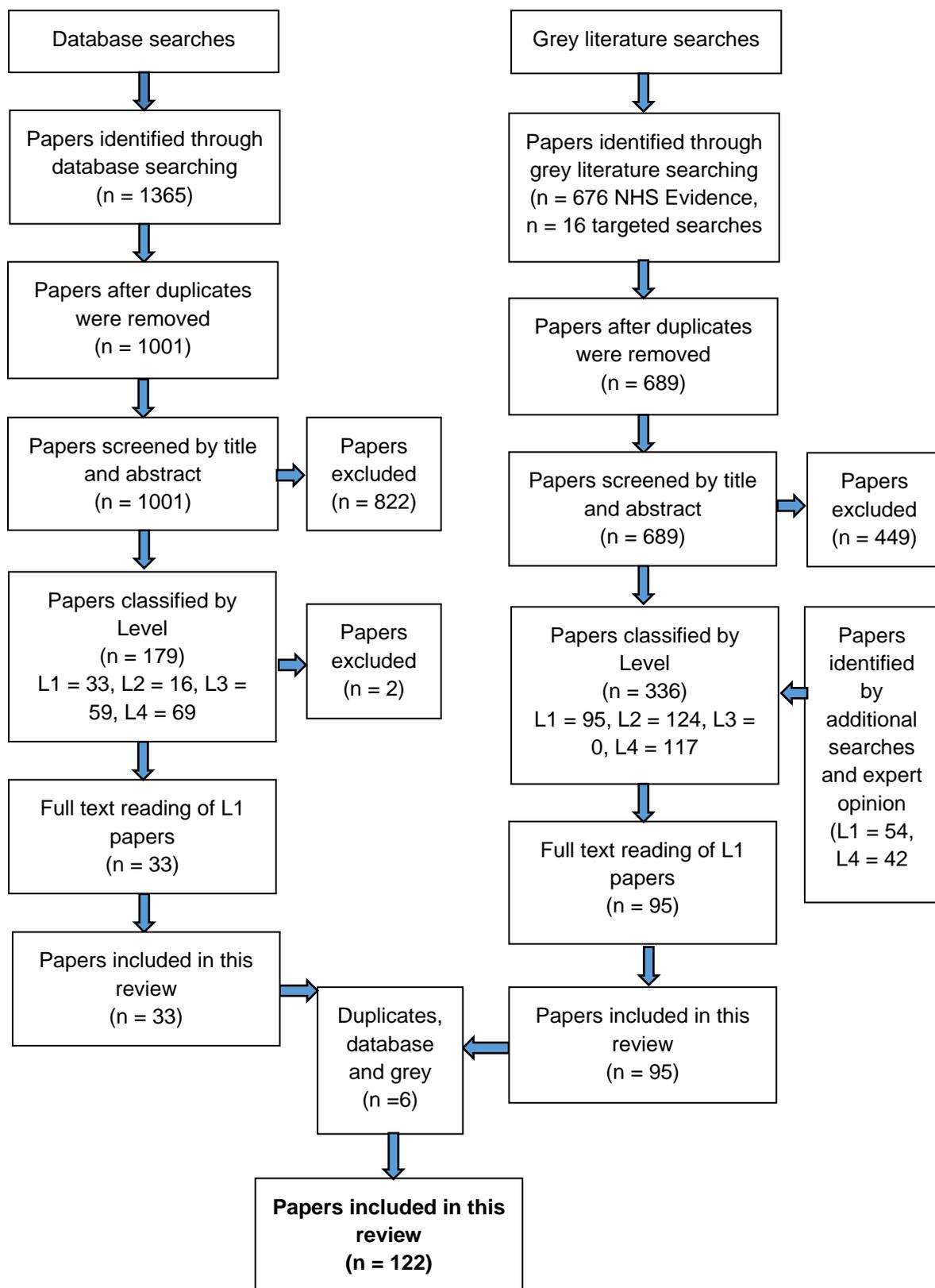
Figure 1. Search one: flow chart of the literature review selection process (adapted from Moher *et al.*,The PRISMA Group, 2009).

2.4 Data extraction

Level 1 papers were sorted by nation and then packaged into two sets for data extraction. Due to the numbers of documents included for each nation, England was treated as a set on its own, while the other three nations were packaged together. Set 1 (England) was handled by RS; Set 2 (Northern Ireland, Scotland and Wales) was handled by JS.

For each nation, documents were assigned to one of three categories:

A. Founding strategy document
B. Subsidiary document which should be read in conjunction with the founding strategy document
C. Exclude (for example if it becomes clear it is a Level 2 or Level 3 document)

Passages were extracted from the included studies and arranged into the following sections for each paper with accompanying notes where necessary:

1 Policy history
2 Key areas
4 Strategies
5 Delivery mechanisms
6 Commissioning and funding
7 Evidence of implementation

These passages of original text were used to answer the questions in Task 1.

2.5 Methodology for classification of the policy literature

Powell and colleagues (2009) provide some useful background commentary for any review of health policy:

> 'Health services are littered with half-remembered national policy documents. These respond to an identified deficit in patient services and offer a broad vision of the shape and direction of future services. Some are accompanied by additional levers in the form of dedicated funding, specific targets with associated incentives (or sanctions) and ongoing monitoring programmes; others are endorsed in successive policy reports but never attract sustained political or managerial attention. All of these visions for change are dependent on implementation in local health service organizations: complex, pluralistic organizations that are characterized by the existence of multiple objectives and diffuse power structures and overlaid by 'the vagaries of changing political ideologies, the instabilities caused by the political economy of resource allocation; the changing interfaces with local government and the voluntary sector; and the ever present difficulties of determining and evaluating ends and means in health care'. (Pettigrew *et al*, 1992 quoted in Powell *et al*, 2009).

It is vital to be clear about what is meant by policy in terminal illness. Marie Cure chose the term 'terminal illness' in preference to others because it is easily understood by patients. This review understood terminal illness policy to mean policy in terminal illness care, which is one facet of a nation's overall health policy. A definition of health policy is provided by the World Health Organisation (2016a):

> 'Health policy refers to decisions, plans, and actions that are undertaken to achieve specific health care goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people.'

If 'terminal illness care' is inserted instead of 'health', a definition of terminal illness care policy is created which appears consistent with the WHO view:

> 'Terminal illness care policy refers to decisions, plans, and actions that are undertaken to achieve terminal illness care goals. An explicit terminal illness care policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people.'

As well as terminal illness care, other phrases are often used, either as synonyms, or to refer to specific aspects of the field or stages of illness. These include palliative care, supportive care and end of life care. Palliative care is defined as:

> 'an approach that improves the quality of life of patients and their families facing the problem 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.' (World Health Organisation, 2016b).

End of life care is often defined as care in the last twelve months of life:

> 'Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions, (b) general frailty and co-existing conditions that mean they are expected to die within 12 months, (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition, (d) life-threatening acute conditions caused by sudden catastrophic events.' (General Medical Council, 2010).'

Supportive care is defined as:

'Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, palliative care, and symptom management.' (National Institutes of Health, 2016)

Although they are not strictly synonyms, in the literature the various terms which refer to the care of people with terminal illness are sometimes used interchangeably. Consequently, the search strategy aimed to capture all variants of the terminology.

Evidence suggests that the period from the exploration to full implementation phase is 2-4 years (Fixsen *et al*, 2005) and as a result policies and recommendations for services such as terminal illness care are unlikely to be embedded fully within the first three years post publication. Therefore the review considered policy documents from 2004 onwards and not just the most recent iterations or editions.

The pilot searches illustrated a variety of types of literature which could be seen as relevant or having the potential to influence this area of health policy. To attempt to understand which policy documents impact upon terminal illness across the four nations, a simple typology of relevant literature was applied to structure the analysis of the search results. Four levels of literature were identified which are illustrated in Figure 2, and described in the section as follows.

The higher a paper appears in this 'policy pyramid' the greater the implied impact on terminal illness care. For those papers further down the diagram, the impact is less certain, but they may still be relevant to the overall policy discussion.

The analysis indicated that it is those government, and government-sponsored policy papers, directly concerning the strategy for providing terminal illness care (or its synonyms, such as end of life care / supportive and palliative care) which are likely to have the most impact on that care in each nation.

Level 1
Governmental documents which constitute a nation's terminal illness care policy

Level 2
Governmental documents containing material relevant to a nation's terminal illness care policy

Level 3
Non-governmental documents containing material relevant to a nation's terminal illness care policy

Level 4
Other evidence relevant to a nation's terminal illness care policy
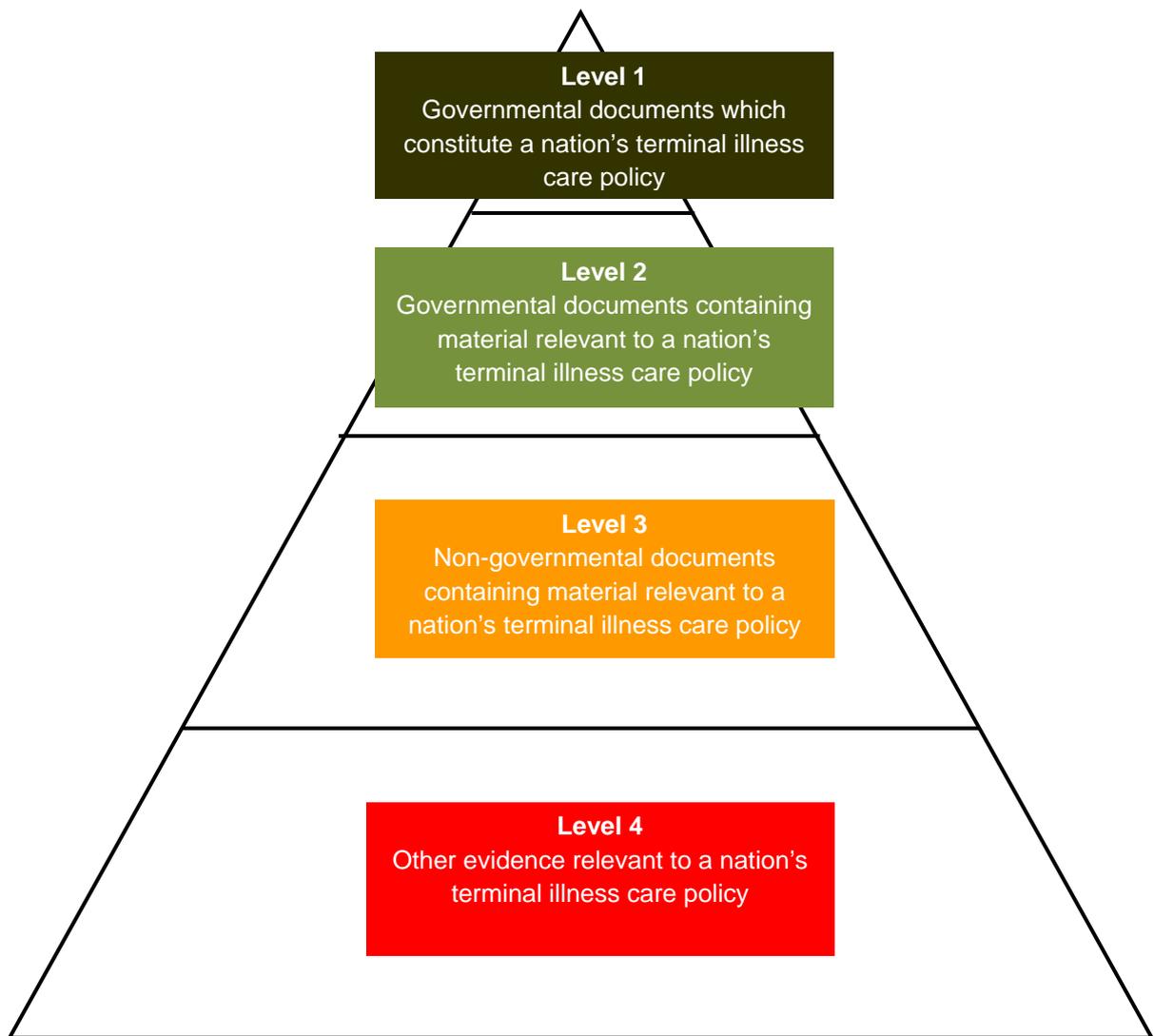
Figure 2: Diagram illustrating the typology of literature in terminal illness care policy for each nation

2.6 Typology of literature in terminal illness care policy

The relevant literature in the discussions around terminal illness care policy can be assigned to one of four levels:

<u>Level 1</u>

Governmental documents which constitute a nation's terminal illness care policy.

This simply means governmental documents which clearly and specifically concern terminal illness care or its synonyms. In practice this is typically the main strategy document(s) plus annual reports and a clutch of other key documents, which together comprise 'terminal illness care policy'.

'Governmental' in this context means any government or government-sponsored organisation, agency or network at regional or national level.

<u>Level 2</u>

Those governmental documents containing material relevant to a nation's terminal illness care policy, but which may not be specifically labelled as such.

For example, policy documents on 'long-term conditions', specific life-limiting conditions (e.g. COPD, Dementia, MND, Cancer, Parkinson's), relevant care settings (e.g. primary care, acute care, care homes, prisons), specific populations (e.g. children, elderly, transitional care), legal frameworks (e.g. on mental capacity), relevant interventions and technologies and so on. This Level contains general or overall ('macro') evidence rather than the 'micro' detail of specific interventions and treatments (which is Level 4).

'Governmental' in this context means any government or government-sponsored organisation, agency or network at regional or national level.

<u>Level 3</u>

Non-governmental documents containing material relevant to a nation's terminal illness care policy.

This includes:

(a) policy documents which clearly and specifically concern terminal illness care (or palliative care or End of Life Care or supportive care or hospice care);

And

(b) policy documents on for example 'long-term conditions', specific life-limiting conditions (e.g. COPD, Dementia, MND, Cancer, Parkinson's), relevant care settings (e.g. primary care, acute care, care homes, prisons), specific populations (e.g. elderly,

transitional care), legal frameworks (e.g. on mental capacity), relevant interventions and technologies and so on.

'Non-governmental organisations' includes for example, royal colleges, health and social care workers' professional associations and academic networks, voluntary sector organisations, interest groups, independent 'think tanks' and so on.

Level 4

The best scientific evidence relevant to a nation's terminal illness care policy. This can be drawn from any publication type not already included in levels 1-3. For example, systematic reviews, Health Technology Assessments (HTAs), Randomised Controlled Trials (RCTs), case studies, expert commentaries, conference proceedings, meetings, books, blogs, websites and so on. This Level contains evidence from the 'micro' detail of specific interventions and treatments rather than the overall 'macro' evidence (which is Level 2).

This includes:

(a) Documents which clearly and specifically concern terminal illness care (or palliative care or End of Life Care or supportive care or hospice care);

And

(b) Documents on for example 'long-term conditions', specific life-limiting conditions (e.g. COPD, Dementia, MND, Cancer, Parkinson's), relevant care settings (e.g. primary care, acute care, care homes, prisons), specific populations (e.g. elderly, transitional care), legal frameworks (e.g. on mental capacity), relevant interventions and technologies and so on.

2.7 Policy development in terminal illness care

Although Figure 2 identifies a simple and static typology of policy literature across the four nations, it should not be read as also suggesting a simple and linear 'bottom-up' model of policy development. Rather, it is suggested that policy discussion is fluid and takes place in various settings, often simultaneously, its results are published in a range of sources and it can influence policy at different levels. Although an ideal scenario would perhaps view the health policy of governments as based on good quality published scientific evidence, this may not always be the case, especially in a field where that evidence is currently sparse.

Figure 3 suggests some of these possible interactions in the policy discussions around terminal illness care between the different levels of publication.

In this study analysis was carried out in detail of the documents found by searches that were assigned to Level 1. Although there are also many relevant publications in Levels 2-4 (for lists of examples see Appendices), it is only the documents in Level 1 from which data was extracted and analysed in detail. Analysis of other levels of the literature was beyond the

scope of this review. Nevertheless, it is important to note the potential influence on policy from documents produced by non-governmental organisations; for example, the British Medical Association (BMA), National Council for Palliative Care (NCPC), the General Medical Council (GMC), Macmillan Cancer Support and Marie Curie.

It is important to point out that publications in Levels 3 and 4 can easily transfer to other levels and in practice this may happen simultaneously. For example, if a new Cochrane systematic review on pain management in end of life care is produced (in Level 4) it could immediately be referred to by governments as being part of current policy (Level 1). The January 2016 policy statements by the British Medical Association (BMA; 2016) on assisted dying are Level 3 documents, but a government may cite some or all of their contents as current official policy (Level 1). Level 3 and 4 documents may therefore be used to 'fill the gaps' in government policy. The typology is merely a device to aid understanding of the policy landscape.

Figure 3 aims to illustrate how policy may be developed in terminal illness. It is based on the London Underground map (Transport for London, 2016). In the diagram, each policy Level is analogous to a 'station', documents are like 'passengers' and their movements between levels resemble the routes of the different coloured underground railway 'lines' (Central, Piccadilly, Northern etc.). The four Levels are represented by black ovals, similar to the black circles for the stations on the Underground where different lines meet and passengers can change course.

Each coloured line in Figure 3 indicates how a policy document which originates in one Level may move to another. Some lines pass through intermediate Levels where a document's content may be mediated, while others miss out some levels so the document may remain the same or mediated to a lesser degree.

In a nation's map of terminal illness care policy development, a document may begin in Level 4 and pass through Levels 2 and 3 to arrive at Level 1 where it becomes regarded as part of government policy. Or it may have begun in Level 4 but so far has only travelled to Level 3 where, for example, a voluntary sector group may use it to campaign for a government policy change. There may be movements in both directions. When a policy document is reviewed it could travel back from Level 1 along the red line, or along a different route. The light blue line shows the movement from Level 3 direct to Level 1 without passing through Level 2. At any given moment of observation of policy development there may be no movement at all, a document simply remains at the Level where it was developed or where it was last edited.

RED LINE: document travels from Level 4 to Level 1 via Levels 2 and 3

DARK BLUE LINE: document travels from Level 4 to Level 2 via Level 3 or vice versa

GREEN LINE: document travels from Level 3 to Level 2 or vice versa

Level 1   Level 2   Level 3   Level 4
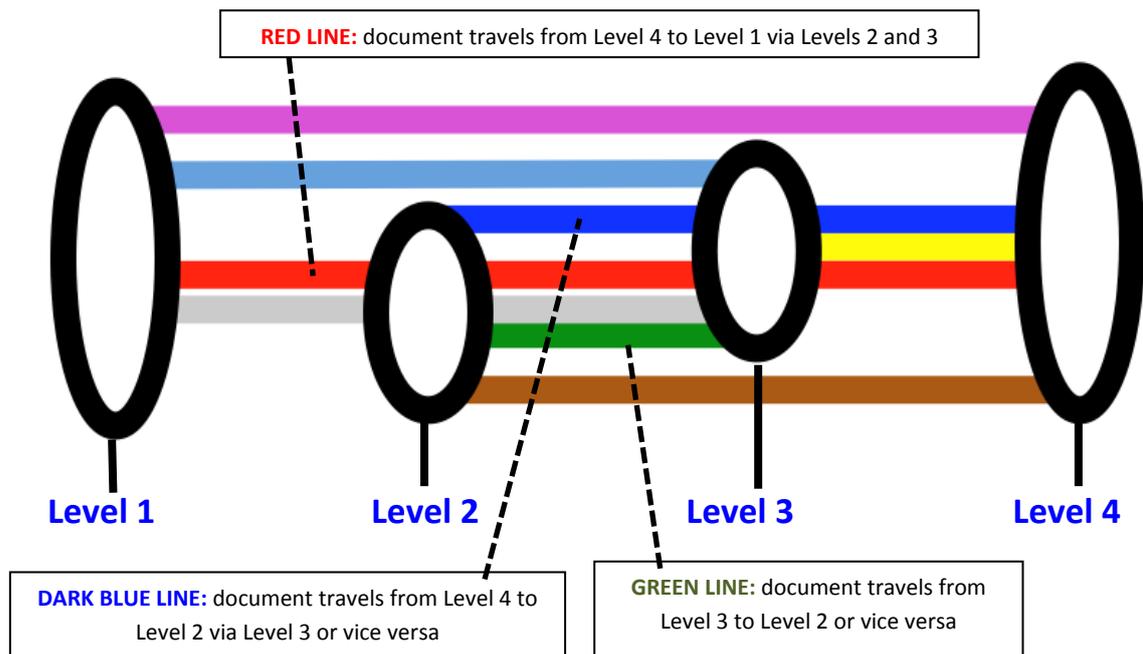
Figure 3: Model of policy development for terminal illness care in the UK's four nations

Key

Level 1

Governmental documents which constitute a nation's terminal illness care policy

Level 2

Governmental documents containing material relevant to a nation's terminal illness care policy

Level 3

Non-governmental documents containing material relevant to a nation's terminal illness care policy

Level 4

Other evidence relevant to a nation's terminal illness care policy

While regional and local policy and strategy documents exist, the focus of the current review was at a 'national' level, where nation refers to England, Northern Ireland, Scotland or Wales.

2.8 Comparing policy across the four nations

When attempting to compare health policy across the UK's four nations, there is a methodological issue to consider around the relative sizes of the four nations' populations and the respective proportion of overall UK funding each receives for that devolved governmental activity, plus any funding raised independently in each. The nations' relative population sizes are illustrated in Figure 5. Methodological questions about comparisons of health policy follow from the more general question about how the different proportions of overall UK spending are allocated to constituent nations in block grants by the controversial 'Barnett formula' (Trench, 2015).
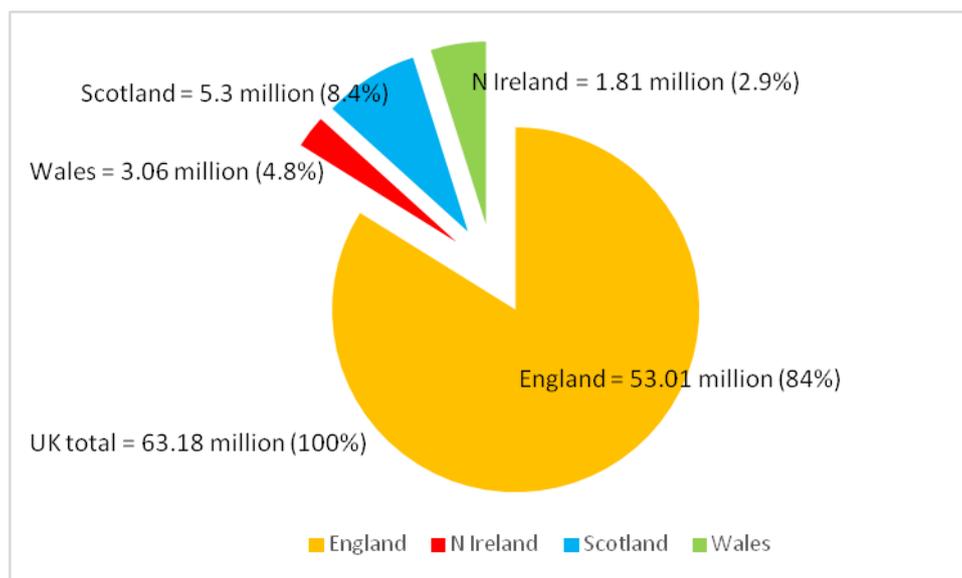
Figure 4. Breakdown of UK population by nation. Source: Office for National Statistics (2011).

In terms of health spending in each of the four nations, Dayan (2015) points out that in 2012/13:

> 'Scotland and Northern Ireland spend significantly more than England and Wales. On a simple per capita basis, England spends least. But after adjusting these figures to reflect the fact that older populations have higher health care needs and therefore higher health care costs, Wales is the UK's lowest spending country'.

Nevertheless, it could be argued that Northern Ireland, Scotland and Wales would be more accurately compared with a single region of England. For example, the North East of England

was used as a proxy for 'England' in a 2014 comparative analysis across the four nations (Nuffield Trust, 2014).

However, detailed examination of the overall methodological issue around comparison of the four nations was beyond the scope of this review.

In the review the four nations of the UK are always listed alphabetically: England, Northern Ireland, Scotland, Wales. This format is used in all sections and tables.

3.0 Results

Summary

- **The question of what constitutes a 'policy document' is contested.**

- **The review has highlighted the wide variation in the number of policy documents per nation.**

- **Although each nation has a clear strategy and delivery mechanisms, England, and to some extent Scotland, have an abundance of policy documents and this risks confusion regarding the key messages.**

- **There are similarities in the core themes that are thought to be relevant for the delivery of high quality care services.**

- **Evidence of outcome measures to support implementation of policy through delivery mechanisms varies across the nations.**

- **In relation to implementation, all nations identified the process, infrastructure and subsequent delivery mechanisms in terms of who would be responsible for that implementation, such as government, health boards, health trusts, working groups, interagency partnership, employment of lead posts etc.**

- **There is limited evidence of implementation that is independently verified.**

- **It is difficult to identify what aspects of policy work well because of the limited evidence of implementation.**

3.1 The current policies that impact upon terminal illness in the four nations

In the classification of the policy literature described in the Methodology section it was argued it is those government and government-sponsored policy papers which directly concern the strategy for providing terminal illness care (or its synonyms, such as End of Life Care or Supportive and Palliative Care) which are likely to have the most impact on that care in each nation. Nevertheless, it is important to point out that this is an assertion and that it, and the whole typology of literature on which it is based, can be questioned. What is, and

what is not 'policy' is to some extent subjective and therefore contested. But a precise definition was needed for the purposes of this study.

In each nation there are varying numbers of these 'Level 1' documents. It is this category of literature, rather than Levels 2-4, which was the focus of the review. However, it is recognised that there are policies which have an impact on terminal illness care which reside in Levels 2-4 and are thus beyond the scope of this review.

The full lists of Level 1 documents included in the review are presented as timelines for each nation in Tables 1-4.

There appears to be a significant increase in policy documents and guidelines year on year from 2008 for all four UK nations. As Figure 5 (see below) and each of the results tables (2-5) illustrate, there is an imbalance in the number of policies and strategies that influence terminal illness care across the four nations.
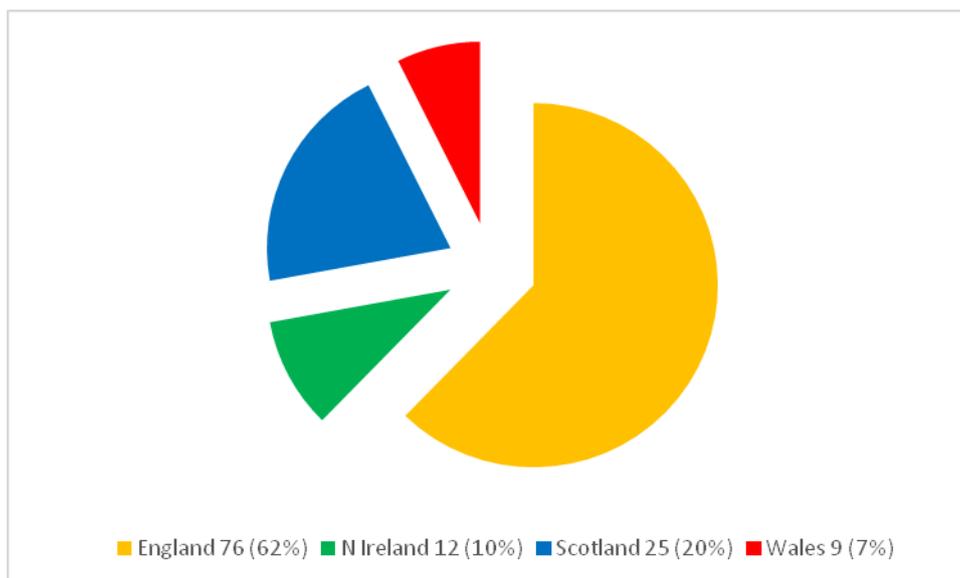
Figure 5. Comparison of total Level 1 documents by nation.

For England, n=76 documents were identified. The results identified that the 2008 'End of life care strategy' (Department of Health, 2008) was dominant across England and influenced the majority of subsequent policies and recommendations for that nation. In 2013, structural changes to the NHS such as the introduction of Clinical Commissioning Groups, had a significant impact which was reflected in the resultant policies. For full details see Table 1.

In addition to the key policy documents, England's National End of Life Care Intelligence Network (NEoOLCIN) website (Public Health England, 2016a) provides a further collection of documents. But other than those documents already included in the review, none were

assigned to Level 1, so did not influence the key findings. The NEoLCIN platform is exclusive to England; there are no comparable intelligence-gathering portals for terminal illness in the other nations.

For Northern Ireland, n=12 documents were identified and the dominant policy was found to be the 2010 'Living matters, dying matters' strategy (Department of Health, Social Services and Public Safety, 2010). This still appears to be the influential policy document. For full details see Table 2.

The review of policy papers for Scotland identified n=25 documents. The 'Living and dying well' national action plan (Scottish Government, 2008) was the foundation from which others were developed, culminating in the 2015 'strategic framework for action' for the next five years (2016-2021) (Scottish Government, 2015). For full details see Table 3.

In Wales, n=9 policy documents were identified. The 2013 strategy 'Together for health: delivering end of life care' was found to be the dominant policy although this expires at the end of 2016 (Welsh Government, 2013). For full details see Table 4.

When a comparison is made of Level 1 documents per million population, England no longer seems to have a large amount of policy papers. Instead, by this measure Northern Ireland and Scotland appear to have a larger number of documents relative to England.
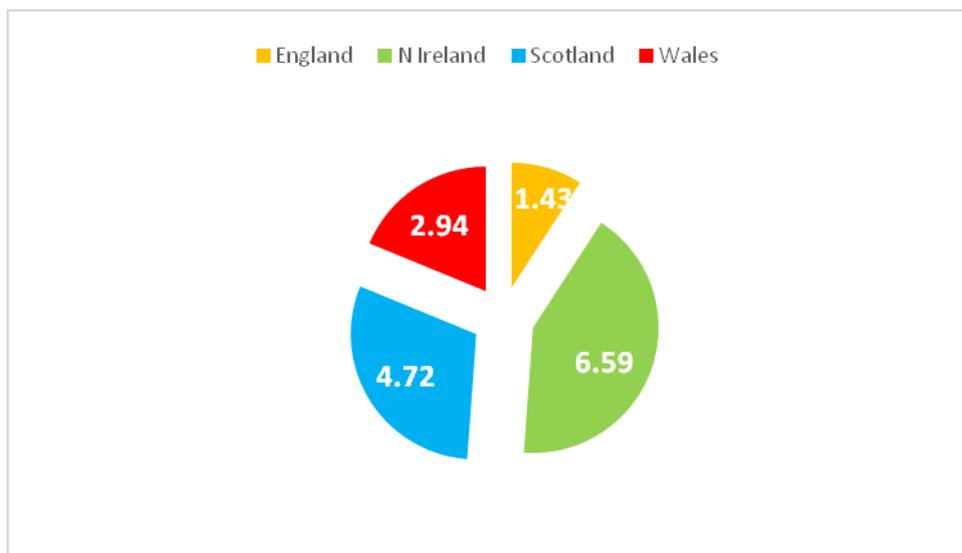
Figure 6. Comparison of terminal illness care policy documents per million population by nation

Table 1. England: Timeline of key policy documents in terminal illness care

1. 2016 Public Health England (2016) Faith at end of life: A resource for professionals, providers and commissioners working in communities. Public Health England, London.
2. 2016 NHS England (2016) Specialist level palliative care: Information for commissioners April 2016. NHS England, Leeds.
3. 2016 NHS England (2016) Commissioning person centred end of life care. A toolkit for health and social care. Updated April 2016. NHS England, Leeds.
4. 2016 Office for National Statistics (2016) Statistical bulletin: National survey of bereaved people (VOICES). Office for National Statistics, London.
5. 2015 Care Quality Commission (2015) Inequalities and variations in end of life care. Care Quality Commission, London.
6. 2015 Care Quality Commission (2015) How CQC regulates: Adult social care services: Hospice services: Provider handbook. Care Quality Commission, London.
7. 2015 How CQC regulates: Adult social care: Hospice services: Appendices to the provider handbook (2015) Care Quality Commission, London.
8. 2015 Choice in End of Life Care Programme Board (2015) What's important to me. A review of choice in end of life care. Choice in End of Life Care Programme Board, London.
9. 2015 Department of Health (2015) Government response to the House of Commons Health Committee Report on End of Life Care. Fifth Report of Session 2014-15. Stationery Office, London.
10. 2015 Gold Standards Framework (2015) Overview of the work of the National GSF Centre in End of Life care. Enabling a gold standard of care for all people in the last years of life. Gold Standards Framework, Shrewsbury. See also website: http://www.goldstandardsframework.org.uk/
11. 2015 House of Commons Health Committee (2015) End of Life Care. Fifth Report of Session 2014-15. Report, together with formal minutes relating to the report. Stationery Office, London.
12. 2015 House of Commons Public Administration and Constitutional Affairs Committee (2015) Follow-up to PHSO Report: Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. Parliamentary and Health Service Ombudsman, London.
13. 2015 National Institute for Health and Care Excellence (2015) NICE guideline: Care of dying adults in the last days of life. National Institute for Health and Care Excellence, London.
14. 2015 National Palliative and End of Life Care Partnership (2015) Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. National Palliative and End of Life Care Partnership, London.
15. 2015 NHS Clinical Services Team (2015) One chance to get it right: One year on report. An overview of progress on commitments made in One Chance to Get it Right: the system-wide response to the Independent Review of the Liverpool Care Pathway. Department of Health, London.
16. 2015 NHS England (2015) Developing a new approach to palliative care funding. NHS England, London.
17. 2015 NHS England (2015) Transforming end of life care in acute hospitals: the route to success how to guide. London, NHS England.
18. 2015 NHS Improving Quality (2015) End of life care in advanced kidney disease: A

framework for implementation. NHS Improving Quality, London.

19. 2015   Parliamentary and Health Service Ombudsman (2015) Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. Parliamentary and Health Service Ombudsman, London.

20. 2015   Public Health England (2015) Plans for a new specialist palliative care data collection in England: what this means for provider services, commissioners, clinicians, patients and the public. Public Health England, London.

21. 2015   Public Health England (2015) What we know now 2014 – new information collated by the National End of Life Care Intelligence Network. Public Health England, London.

22. 2015   National Institute for Heath and Care Excellence (2015). Clinical Knowledge Summaries: Palliative care - general issues.

23. 2014   Public Health England (2014) Patterns of end of life care in England, 2008 to 2010 Analysis of the National End of Life Care Intelligence Network local authority profiles by PHE region and centre. Public Health England, London.

24. 2014   Public Health England (2014) Electronic Palliative Care Co-ordination Systems (EPaCCS) in England Survey of clinical commissioning groups (2013) by the National End of Life Care Intelligence Network. Public Health England, London.

25. 2014   Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right Improving people's experience of care in the last few days and hours of life. Leadership Alliance for the Care of Dying People, London.

26. 2014   NHS England (2014) NHS England's Actions for End of Life Care: 2014-16. NHS England, London.

27. 2014   NHS England (2014) Developing a new approach to palliative care funding: a revised draft for discussion. Leeds, NHS England.

28. 2014   NHS Improving Quality (2014) End of life care in heart failure: A framework for implementation. NHSIQ, London.

29. 2014   Care Quality Commission (2014) Characteristics of ratings for hospice services. Care Quality Commission, London.

30. 2014   NHS Improving Quality (2014) End of life care in heart failure: A framework for implementation. NHS Improving Quality, London.

31. 2013   National Institute for Health and Care Excellence (2013) End of life care for adults. Quality standard. (Updated October 2013) London: National Institute for Health and Care Excellence.

32. 2013   Neuburger, J. (2013) More Care Less Pathway. A review of the Liverpool Care Pathway. Independent Review of the Liverpool Care Pathway. Stationery Office, London.

33. 2013   NHS National End of Life Care Programme / ADASS (2013) Sharing successful strategies for implementing 'Supporting people to live and die well: a framework for social care at the end of life.' NHS Improving Quality, London.

34. 2013   NHS England (2013) Guidance for doctors and nurses caring for people in the last days of life. Gateway number: 00264. NHS England, London.

35. 2013   Department of Health (2013) Hospices funding breakdown. Department of Health, London.

36. 2013   Public Health England (2013) What we know now 2013 – new information collated by the National End of Life Care Intelligence Network. Public Health England, London.

37. 2012   Department of Health (2012) End of life care strategy: fourth annual report.

Department of Health, London.

38. 2012   National Institute for Heath and Care Excellence (2012) Palliative care for adults: strong opioids for pain relief. National Institute for Heath and Care Excellence: London.

39. 2012   NHS National End of Life Care Programme (2012) End of life care co-ordination: implementation guidance: National Information Standard ISB 1580. London, NHS. National End of Life Care Programme.

40. 2012   NHS National End of Life Care Programme (2012) The route to success in end of life care: achieving quality for lesbian, gay, bisexual and transgender people. Leicester, National Health Service. National End of Life Care Programme.

41. 2012   Department of Health / Children and Families Policy (2012) Children's Hospice and Hospice at Home New Grant Guidance Notes and Eligibility Requirements. Department of Health, London.

42. 2012   NHS England (2012) Commissioning person centred end of life care. A toolkit for health and social care. NHS England, Leeds.

43. 2012   NHS National End of Life Care Programme (2012) Making the case for change: Electronic palliative care co-ordination systems (2012). NHS Improving Quality, London.

44. 2011   Department of Health (2011) VOICES redesign and testing to inform a national end of life care survey. Department of Health, London.

45. 2011   Department of Health (2011) End of life care strategy: Results of monitoring of funding for end of life care 2010 to 2011. Department of Health, London.

46. 2011   Department of Health (2011) End of life care strategy: third annual report. Department of Health, London.

47. 2011   Hughes-Hallett T, Craft A, Davies C, Mackay I, Nielsson T (2011) Funding the right care and support for everyone: Creating a fair and transparent funding system. Final report of the Palliative Care Funding Review. Palliative Care Funding Review, London.

48. 2011   Hunt, Katherine *et al* (2011) VOICES redesign and testing to inform a national end of life care strategy: final report for the Department of Health. Southampton, University of Southampton.

49. 2011   Ipsos MORI (2011) End of life locality registers evaluation - final report. Ipsos MORI, London.

50. 2011   National Institute for Health and Care Excellence (2011) End of life care for adults: commissioning guide. Stationery Office, London.

51. 2011   NHS National End of Life Care Programme (2011) Capacity, care planning and advance care planning in life limiting illness: A guide for health and social care staff. NHS Improving Quality (NHS IQ), London.

52. 2011   NHS National End of Life Care Programme (2011) Finding the words. Communication skills work book. National End of Life Care Programme, Leicester.

53. 2011   NHS National End of Life Care Programme and National Nurse Consultant Group (Palliative Care) (2011) Guidance for staff responsible for care after death (last offices). NHS Improving Quality, London.

54. 2011   NHS National End of Life Care Programme (2011) National End of Life Care Programme social care workstream: report from the NEOLCP social care leads to the Social Care Advisory Group 16 November 2011. London, NHS. National End of Life Care Programme.

55. 2011   NHS National End of Life Care Programme (2011) Routes to success in end of life care: achieving quality environments for care at end of life. Leicester,

National Health Service. National End of Life Care Programme.

56. 2011   NHS National End of Life Care Programme (2011) The route to success in end of life care: achieving quality in domiciliary care. Leicester, National Health Service. National End of Life Care Programme.

57. 2011   NHS National End of Life Care Programme and National Nurse Consultant Group (2011) Guidance for staff responsible for care after death (last offices). Leicester, National Health Service. National End of Life Care Programme.

58. 2011   Palliative Care Funding Review (2011) Funding the Right Care and Support for Everyone. Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review. Palliative Care Funding Review, London.

59. 2011   United Kingdom Palliative Care Funding Review Team (2011) Funding the right care and support for everyone: Creating a fair and transparent funding system. Journal of Pain and Palliative Care Pharmacotherapy, 25 (4), 362-364 3p.

60. 2011   University of Nottingham and Department of Health (2011) Bereavement care services: a synthesis of the literature. Final Report of review commissioned by DH to support implementation of the End of Life Care Strategy. Department of Health, London.

61. 2011   National Institute for Health and Clinical Excellence (2011) Implementation Programme. NICE support for commissioners and others using the quality standard for end of life care for adults. (Previously known as the cost impact and commissioning assessment). National Institute for Health and Clinical Excellence, London.

62. 2010   Department of Health (2010) End of life care strategy: second annual report. Department of Health, London.

63. 2010   National Council for Palliative Care / Neurological Alliance / NHS End of Life Care Programme (2010) End of life care in long-term neurological conditions: A framework for implementation. National Council for Palliative Care / Neurological Alliance / NHS End of Life Care Programme, London.

64. 2010   National Institute for Health and Clinical Excellence (2010) End of life care for people with dementia: commissioning guide: implementing NICE guidance. London, National Institute for Health and Clinical Excellence.

65. 2010   NHS National End of Life Care Programme (2010) End of life care - achieving quality in hostels and for homeless people: A route to success.

66.   Department of Health (2010) Further details of £30 million funding for children's palliative care in 2010/11 announced 26 June 2010. Department of Health, London.

67. 2010   NHS National End of Life Care Programme (2010) The route to success in end of life care: achieving quality in care homes. Leicester, National Health Service. National End of Life Care Programme.

68. 2009   Department of Health (2009) Transforming community services: Ambition, action, achievement. Transforming end of life care. Department of Health, London

69. 2009   Department of Health (2009) End of life care strategy: first annual report. Department of Health, London.

70. 2009   Department of Health (2009) Quality markers and measures for end of life care: response to the consultation on quality markers and measures for end of life care. Department of Health, London.

71. 2009   NHS National End of Life Care Programme (2009) Common core competencies and principles for health and social care workers working with adults at the end of life. National End of Life Care Programme, Leicester.

72. 2008   Care Quality Commission (2008) End of life care prompts: care homes:

guidance for inspectors. Care Quality Commission, London.

73.   2008   Department of Health / Partnerships for Children, Families & Maternity (2008) Better Care: Better Lives. Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions. Department of Health, London.

74.   2008   Department of Health (2008) End of life care strategy: promoting high quality care for all adults at the end of life: executive summary. Department of Health, London.

75.   2006   NHS End of Life Care Programme and National Council for Palliative Care (2006) Introductory guide to end of life care in care homes. London, Great Britain. Department of Health.

76.   2004   National Institute for Health and Care Excellence (2004) Guidance on Cancer Services Improving Supportive and Palliative Care for Adults with Cancer. Stationery Office, London.

Table 2. Northern Ireland: Timeline of key policy documents in terminal illness care

1.	2016	Regional Palliative Care Programme (2016) Palliative Care in Partnership (amalgamation of residual activity from Living Matters Dying Matters (LMDM) & Transforming Your Palliative and End Of Life Care (TYPEOLC) with Regulation and Quality Improvement Authority (RQIA) LMDM review recommendations).
2.	2016	Regulation and Quality Improvement Authority (2016) Review of the implementation of the palliative and end of life care strategy (March 2010). Belfast, Regulation and Quality Improvement Authority.
3.	2014	Department of Health, Social Services and Public Safety (2014) HSS (MD) 21/2014 - advice to health and social care professionals for the care of the dying person in the final days and hours of life – phasing out of the Liverpool care pathway in Northern Ireland by 31 October 2014.
4.	2014	HSC Public Health Agency (2014) Palliative and End of Life Care Programme. Transforming Your Palliative and End of Life Care Update June 2014. HSC Public Health Agency, Belfast.
5.	2014	HSC Public Health Agency (2014) Palliative and End of Life Care Programme. Transforming Your Palliative and End of Life Care Update May 2014. HSC Public Health Agency, Belfast.
6.	2014	HSC Public Health Agency (2014) Palliative and End of Life Care Programme. Transforming Your Palliative and End of Life Care Update Feb 2014. HSC Public Health Agency, Belfast.
7.	2013	Guidelines and Audit Implementation Network (2013) Palliative Care Guidelines. Guidelines and Audit Implementation Network (GAIN), Belfast.
8.	2013	Regulation and Quality Improvement Authority (2013) Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Care Homes. Guidelines and Audit Implementation Network, Belfast.
9.	2012	Health and Social Care Board (2012) Transforming your care: Vision to action: A consultation document 9 October 2012-15 January 2013. Health and Social Care Board, Belfast.
10.	2011	Guidelines and Audit Implementation Network (2011) General palliative care guidelines for the management of pain at the end of life in adult patients. Guidelines and Audit Implementation Network (GAIN), Belfast.
11.	2010	Department of Health, Social Services and Public Safety (2010) Living Matters Dying Matters A Palliative and End of Life Care Strategy for Adults in Northern Ireland. DHSSPS, Belfast.
12.	2009	Department of Health, Social Services and Public Safety (2009) Northern Ireland Health and Social Care Services Strategy for Bereavement Care

Table 3. Scotland: Timeline of key policy documents in terminal illness care

1.   2016   Gillies M / Scottish Public Health Network (2016)
   Palliative and end of life care in Scotland:
   The rationale for a public health approach. Scottish Public Health
   Network, Edinburgh.
2.   2015   Scottish Government (2015) Strategic framework for action on palliative
   and end of life care 2016-2021. Scottish Government, Edinburgh.
3.   2015   Scottish Government (2015) Strategic framework for action on palliative
   and end of life care 2016-2021. Supporting Evidence Summary. Scottish
   Government, Edinburgh.
4.   2015   Scottish Government (2015) Health and Sport Committee. We need to
   talk about palliative care. Scottish Government, Edinburgh.
5.   2015   Children in Scotland requiring Palliative Care: identifying numbers and
   needs (The ChiSP Study). Social Policy Research Unit, York.
6.   2014   NHS Scotland (2014) Guidance: Caring for people in the last days and
   hours of life. NHS Scotland, Edinburgh.
7.   2014   Scottish Palliative Care Guidelines – published by NHS Healthcare
   Improvement Scotland and NHS Scotland, with the Scottish Partnership
   for Palliative Care (SPPC)
8.   2014   Scottish Ambulance Service and Scottish Partnership for Palliative Care
   (2014) Palliative and end of life care policy for Scottish Ambulance Service
   staff (Revision 9.2) Approved version – 23 April 2014. Scottish Partnership
   for Palliative Care, Edinburgh.
9.   2014   Scottish partnership for Palliative Care / Marie Curie (2014) Are we living
   and dying well yet? Scottish partnership for Palliative Care / Marie Curie,
   Edinburgh.
10.   2013   Healthcare Improvement Scotland (2013) DNACPR Indicator (2013)
    Healthcare Improvement Scotland, Edinburgh
11.   2013   Healthcare Improvement Scotland (2013) Palliative and end of life care
    indicators. Health Improvement Scotland, Edinburgh.
12.   2013   Healthcare Improvement Scotland (2013) Scottish palliative care
    guidelines. Healthcare Improvement Scotland, Edinburgh.
13.   2012   Chief Executive Letter (2012) A partnership for better palliative and end of
    life care: Creating a new relationship between independent adult hospices
    and NHS Boards in Scotland (CEL 12 (2012).
14.   2012   Scottish Government (2012) Living and dying well - reflecting on progress.
    A national overview report on palliative and end of life care. Scottish
    Government, Edinburgh.
15.   2012   Scottish Government Scottish Children and Young People's Palliative Care
    Executive Group (2012) A framework for the delivery of palliative care for
    children and young people in Scotland. Scottish Government, Edinburgh.
16.   2011   Scottish Government (2011) Living and dying well: Building on progress.
    Scottish Government, Edinburgh.
17.   2010   Scottish Government (2010) A partnership for better palliative and end of
    life care: Creating a new relationship between adult hospices and NHS
    boards in Scotland. Scottish Government, Edinburgh.
18.   2010   Do Not Attempt Cardiopulmonary resuscitation - Integrated Adult Policy
    (2010) and Children and Young Persons Acute Deterioration Management

(2010).

19. 2010 Best practice statement: End of life care following acute stroke. (2010). *Healthcare Improvement Scotland,*

20. 2010 Healthcare Improvement Scotland (2010) End of life care following acute stroke. Best Practice Statement. Healthcare Improvement Scotland, Edinburgh.

21. 2009 Care Commission (2009) Better care every step of the way: report on the quality of palliative and end of life care in care homes for adults and older people. Dundee, Scottish Commission for the Regulation of Care.

22. 2008 Scottish Partnership for Palliative Care (2008) Living and dying with advanced heart failure: A palliative care approach. Scottish Partnership for Palliative Care, Edinburgh.

23. 2008 Auditor General for Scotland (2008) Review of palliative care services in Scotland. Audit Scotland, Edinburgh.

24. 2008 Scottish Government (2008) Living and dying well: a national action plan for palliative and end of life care in Scotland. Edinburgh, Scotland. Scottish Government.

25. 2007 Scottish partnership for palliative care (2007) A guide to using palliative care competence frameworks. Edinburgh, Scottish Partnership for Palliative Care.

Table 4. Wales: Timeline of key policy documents in terminal illness care

1. 2015 NHS Wales (2015) All-Wales Policy on Do Not Attempt Cardio-Pulmonary Resuscitation. NHS Wales, Cardiff.
2. 2015 Wales Palliative Care (2015) Care decisions for the last days of life. Welsh Government, Cardiff.
3. 2015 Welsh Government (2015) Together for health - end of life care delivery plan. Annual Report 2015. Welsh Government, Cardiff.
4. 2014 Welsh Government (2014) Together for health – a neurological conditions delivery plan A delivery plan up to 2017 for the NHS and its partners. Welsh Government, Cardiff.
5. 2014 Welsh Government (2014) Together for health - end of life care delivery plan. Annual Report 2014. Welsh Government, Cardiff.
6. 2013 Welsh Government (2013) Together for health - delivering end of life care. A delivery plan up to 2016 for NHS Wales and its partners. The highest standard of care for everyone at the end of life. Welsh Government, Cardiff.
7. 2012 Welsh Government (2012) Together for health – stroke delivery plan. A delivery plan for NHS Wales and its partners. Welsh Government, Cardiff.
8. 2011 Palliative Care Implementation Board (2011) Dying well matters. One Wales: 3 years on (2008-2011) Palliative Care Implementation Board, Cardiff.
9. 2008 Palliative Care Planning Group Wales (2008) Report to the Minister for Health and Social Services. All Wales Palliative Care Planning Group, Cardiff.

3.2 Level of priority given by each nation to the care of terminally ill people

A metric regarding the 'level' of priority is not available and is not published by UK nations. Nevertheless, it is clear that all nations regard terminal illness care or End of Life Care (EoLC) as a relatively high priority since all have responded with policy recommendations and directives and have produced policy documents to that end. One metric that can be used is that of spending allocated specifically to EoLC. The results of the review indicated that the level of spending allocated exclusively to EoLC appears to be subsumed across all health and social care services.

End of Life Care is a category of health service activity that is defined in policy terms but not operationalised in financial planning. Existing budgets could not be identified as distinct beyond specialist palliative care services.

3.3 Current strategies and delivery mechanisms and evidence of implementation

Tasks 1.3 and 1.4 are answered in four separate sections, one for each nation (sections 3.4 to 3.7).

- ***Task 1.3:*** *What are the current strategies and delivery mechanisms that influence terminal care in the four nations?*

- ***Task 1.4:*** *What is the evidence of the implementation of the current strategies and delivery mechanisms?*

For each of the nations a policy context is provided to help understand the history and landscape within which each exists and how this influences the delivery mechanisms and implementation.

3.4 England

3.4.1 Policy context

NHS reorganisation has been a recurrent feature of England's health policy throughout its history. A detailed discussion is beyond the scope of this review but some of the recent Level 2 documents which set out how the NHS in England will be structured in the next few years are vital to understand the environment in which any terminal illness care policies (Level 1 documents) must be put into action.

October 2014's Five Year Forward View (5YFV) (NHS England, 2014c) is a wide-ranging strategy for England's NHS. The partner associations that produced it were NHS England, Care Quality Commission, Health Education England, Monitor, Public Health England, Trust Development Authority and NICE. 5YFV is based on several themes including the importance of public health and preventing ill-health, empowering patients and communities, strengthening primary care and making the health service more efficient. A strategy for delivering 5YFV was set out in December 2015 (NHS England 2015) which 'outlined a new approach to help ensure that health and care services are built around the needs of local populations. To do this, every health and care system in England will produce a multi-year Sustainability and Transformation Plan (STP), showing how local services will evolve and become sustainable over the next five years'. The place-based planning approach set out will be led by 44 'Footprint Areas' (NHS England (2016a). Each of these areas will develop a Sustainability and Transformation Plan (NHS England, 2016b).

The background to this, according to the BMA (British Medical Association, 2015), are the fundamental challenges which face the health systems of all industrialised countries:

- Long-term health conditions now take 70 per cent of the health budget. At the same time many (but not all) people wish to be more informed and involved with their own care
- Care needs to be organised so it is genuinely coordinated around what people need and want
- It is unrealistic to think that NHS spending growth will return to the six or seven per cent increases seen in the 2000s in the short- or medium-term

The 2016 NHS Mandate (Department of Health, 2016) states that the UK Government are 'united with NHS staff across the country in a shared objective of sustaining a comprehensive service, free at the point of use, which constantly improves patient care'

Like England's wider policies on health and the NHS, terminal illness care policy has evolved in recent years. It is made up of a package of key documents published in the twelve years since the NICE Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer (National Institute for Health and Clinical Excellence, 2004). As it remains

the foundation of current policy, the 2008 End of Life Care Strategy document (Department of Health, 2008) is arguably the most important. This document set out four key aims:

Being treated as an individual, with dignity and respect

- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.

There have been many policy documents published since then which seem to represent either a re-statement or a development of the original strategy, but which do not negate or replace it. This makes it more problematic to determine what the current policies, strategies and delivery mechanisms are for England than it is for the other three nations. All government health publications since 2008 are potentially relevant to the policy discussion. The sheer weight of potentially relevant policy literature risks the clarity of the overall message. Any reader who is not a specialist in health policy (and this includes doctors, nurses and other health and social care staff) must ascertain what new information, advice or recommendations are being presented. Even though the review was restricted to an analysis of Level 1 papers there is still a list of 76 documents which impact on terminal illness in England. In addition to this list there are more general health policy documents that continue to have a major impact on terminal illness care in England, particularly in terms of the reorganisation of the NHS, commissioning and funding of services.

3.4.2 Current strategies and delivery mechanisms that influence terminal illness in England

From 2009 to 2012 there were four annual reports published which detailed progress made on meeting the 2008 EoLC Strategy's objectives. In the most recent of the four (Department of Health, 2012) key areas identified were addressed within the six chapters:

- Meeting the challenges of end of life care
- Information revolution for people approaching the end of life
- Improving outcomes for people approaching the end of life: identification and care planning
- Improving outcomes for people approaching the end of life: co-ordination and delivery
- Improving outcomes for people approaching the end of life: the last days of life and care after death
- Improving outcomes for people approaching the end of life: commissioning and levers for change

In April 2013 responsibility for the EoLC Strategy passed from the Department of Health to the NHS Commissioning Board. The National End of Life Care Programme was abolished. This was also the point that Strategic Health Authorities and primary care trusts were

replaced by clinical commissioning groups (CCGs) and it is those bodies who assumed the role of commissioning end of life care services. Clearly 'Level 2' policies, such as those reorganising the governance and provision of health care services in general, can have a large impact on terminal illness as they do for other areas of care.

The NICE Quality Standard on end of life care (National Institute for Health and Care Excellence, 2011, updated 2013) sets out 16 statements (see Table 5). It must be noted that is not mandatory to adopt NICE Quality Standards, however, they can be viewed as a strategy with specific objectives which must be achieved in order to deliver a high quality end of life care service in England:

Table 5. NICE Quality Standard's objectives for end of life care

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.
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 ongoing 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.

Since the 2012 EoLC Strategy annual report, further policy documents have been published which typically refer to 'building on' or developing the 2008 Strategy, rather than rejecting or rewriting it. For example, in 2014 NHS England commented in the 'Actions for End of Life Care' that "*the 2008 Strategy needs to be refreshed to align it with current needs of the population and the changing health and social care landscape*" (NHS England, 2014b)

Similarly, the National Palliative and End of Life Care Partnership's (2015) 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020' refers to the EoLC Strategy and the NICE Quality Standard:

"In 2008 the first national strategy for end of life care in England galvanised the health and social care system with three key insights:

- that people didn't die in their place of choice

- that we needed to prepare for larger numbers of dying people

- that not everybody received high-quality care

- Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not'. Since then other nation specific strategies and reports have followed. These have encompassed all ages, all four nations and all conditions. New care processes have been developed. New indicators of quality have been set. New systems for scrutiny have been devised. New systems for funding are under development. Investment and innovation has led to significant progress particularly in reversing the long term increase in the numbers dying in hospital. There is now a need for a relentless focus on improving

outcomes, including people's experience and quality of care, wherever the setting.

- As people, professionals and local leaders within the health and social care system and our communities, we must commit to these ambitions and to the framework that will enable their delivery. This framework is not a new strategy. It builds on the 2008 Strategy for End of Life Care and the improvements that have followed, but much more needs to be done. That Strategy was developed in a different world and a different NHS to the one that exists now.

- Today, the emphasis is on local decision-making and delivery, so this document provides a national framework for local action. Constrained resources and increasing demands put all those who use, work in, and lead local organisations under an obligation to create new ways to build more effective systems of care, putting existing resources to more creative and effective use, aligning with wider changes flowing from the NHS Five Year Forward View.

- We need a collective response. The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference. The essential challenge is to learn how to work together, collectively and differently to achieve these ambitions and the standard set out in the NICE Quality Standard for End of Life Care (2011). It is up to us. Engaging with the task, sharing good practice, using what we know and being prepared to learn what we haven't yet understood.

- We live in a world where improvement no longer comes about as a consequence of central direction. It is local leadership, in all that local leaders do, say and exemplify, that is vital to finding new ways of organising care and support for people.

- We specifically require local professionals and local leaders to act. We expect you to designate a local lead, whether this is the Health and Wellbeing Board, Clinical Commissioning Group, Local Authority or some composite of these. The job is to lead and coordinate a process for working towards these ambitions, a process that is open, transparent and effective."

Source: National Palliative and End of Life Care Partnership's (2015) 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020'

This framework document calls for a collective approach, using partnership working and sets out a framework for local action where, for example, a lead person is designated locally, rather than being imposed in a prescriptive fashion from above. The emphasis seems to be on an evolving process rather than a rigid framework.

Six ambitions are set out:

"1. Each person is seen as an individual

I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.

2. Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

3. Maximising comfort and wellbeing

My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.

4. Care is coordinated

I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.

5. All staff are prepared to care

Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.

6. Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

Source: National Palliative and End of Life Care Partnership's (2015) 'Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020'

Achievement of these ambitions is based on a conceptual model which uses a metaphor derived from the construction of buildings. This seems to echo the 'house of care' model of care which the NHS uses in the context of long term conditions (NHS England 2016b) and is also used in the 'Actions' document described above. The metaphor describes foundations and building blocks on which the ambitions rest. Once attained, these ambitions might be seen as a completed 'house of care'. There are:

- 6 Ambitions
- 8 Foundations
- A set of (up to 7) Building Blocks for each of the 6 Ambitions

There are eight Foundations:

- Personalised care planning
- Shared records
- Evidence and information
- Involving, supporting and caring for those important to the dying person
- Education and training
- 24/7 access
- Co-design
- Leadership

There are seven Building Blocks that need to be in place to deliver Ambition 1:

- Honest conversations
- Systems for person centred care
- Clear expectations
- Access to social care
- Helping people take control
- Integrated care
- Good end of life care includes bereavement

There are six Building Blocks that need to be in place to deliver Ambition 2:

- Using existing data
- Community partnerships
- Generating new data
- Unwavering commitment
- Population based needs assessment
- Person centred outcome measurement

There are six Building Blocks that need to be in place to deliver Ambition 3:

- Recognising distress whatever the cause
- Addressing all forms of distress
- Skilled assessment and symptom management
- Specialist palliative care
- Priorities for care of the dying person
- Rehabilitative palliative care

There are five Building Blocks that need to be in place to deliver Ambition 4:

- Shared records
- Clear roles and responsibilities
- A system-wide response
- Everyone matters
- Continuity in partnership

There are six Building Blocks that need to be in place to deliver Ambition 5:

- Professional ethos
- Support and resilience
- Knowledge based judgement
- Using new technology
- Awareness of legislation
- Executive governance

There are four Building Blocks that need to be in place to deliver Ambition 6:

- Compassionate and resilient communities
- Public awareness
- Practical support
- Volunteers

In the document produced by the Choice in End of Life Care Programme Board (2015), 'What's important to me. A review of choice in end of life care', progress since 2008 is recognised but argues that more needs to be done:

"End of life care has made great strides forward in recent years, in particular following the publication of the End of Life Care Strategy in 2008. Nevertheless, we know that too many people still do not receive good quality care which meets their individual needs and wishes. For example, only just over half of respondents to the National Survey of Bereaved People (VOICES-SF) felt that their relative had died in a place of their choice. At the same time the challenge of delivering consistently good experiences and outcomes for people at the end of their lives is growing. Each year, around 480,000 people die in England. This is predicted to increase to 550,000 by 2035."

Source: Choice in End of Life Care Programme Board (2015) What's important to me. A review of choice in end of life care.

To enable enhanced choice across England and ensure good quality terminal illness care for all they advise that a number of steps need to be taken:

- "each person who has consented to and wishes to specify choices and preferences in their end of life care has these recorded in their individual plan of care, with its

details held on an Electronic Palliative Care Coordination System (EPaCCS) or equivalent system; and

- each person who wishes to express their end of life care choices and preferences in advance is offered a way to do this through access to their own medical records and plans of care and the ability to add and amend information on personal choices and preferences.

- carers for people at the end of life should be formally identified as such by the relevant services, that their eligible needs for support be met in line with the provisions of the Care Act 2014, and that support be provided for carers following bereavement; and

- family members, carers and/or those important to the individual should be involved, where possible, in discussions about care preferences where the dying person has said they should be.

- every local area should establish 24/7 end of life care for people being cared for outside hospital, in line with the NICE quality standard for end of life care, which supports people's choices and preferences;

- EPaCCS or equivalent system coverage is increased to 100% of localities to enable the recording and sharing of people's choices and preferences;

- EPaCCS or equivalent systems are fully accessible to view and update for all involved in the provision of end of life care services, in particular social care organisations, and that they align with the information on care plans offered to people with long term conditions and any social care assessments;

- each person in need of end of life care has a named responsible senior clinician who would have overall responsibility for their care and their preferences; and

- each person in need of end of life care is offered a care coordinator who would be their first point of contact in relation to their care and their preferences.

- Health Education England, Local Education and Training Boards and Skills for Care ensure that staff responsible for the delivery of end of life care have training focused on the key elements of their roles which enable choice such as early identification of needs, advance care planning, communications skills, shared decision making, the use of coordination systems (e.g. EPaCCS) and working in partnership with people and other organisations to design and deliver person-centred care; and

- there be greater joint working between palliative care specialists and other clinical staff, and between secondary care and primary care staff, to identify people who may need end of life care as early as possible."

Source: Choice in End of Life Care Programme Board (2015) What's important to me. A review of choice in end

of life care.

3.4.3 Evidence of implementation of the current strategies and delivery mechanisms

In the literature it is sometimes difficult to differentiate between 'strategy' and 'delivery mechanism'. England's overall 'strategy' can be relatively easily summarised as it is still based on the 2008 EoLC Strategy document and refined or expanded in subsequent documents such as those above. But the ways in which those objectives are being achieved in practice ('delivery mechanisms') could also sometimes be referred to as 'strategy'. For example, the Electronic Palliative Care Coordination Systems (EPaCCS) can be seen as a strategy but is also, arguably, a delivery mechanism in itself.

Table 6 presents' examples of 'strategy' (from the 2008 EoLC Strategy document's 'key areas') with corresponding examples of 'delivery mechanisms' listed alongside taken from various sources.

Table 6. England: Strategies and delivery mechanisms that influence terminal care

Strategies (2008 EoLC 'Key Areas')	Examples of delivery mechanisms
Raising the profile	Dying Matters national coalition set up in 2009 by National Council for Palliative Care. (**Source:** Dying Matters (2016) www.dyingmatters.org)
Strategic commissioning	Commissioning person centred end of life care. A toolkit for health and social care. The toolkit reflects the health and care landscape as it was in October 2015, building on prior improvement from an earlier strategy, opportunities and thinking from the NHS Five Year Forward View and Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020. (**Source:** NHS England (2016) Commissioning person centred end of life care. A toolkit for health and social care. Updated April 2016. NHS England, London).
Identifying people approaching the end of life	Electronic Palliative Care Coordination Systems (EPaCCS). 'Find your 1%' mobilisation campaign led by NEoLCP. (**Source:** Dying Matters (2016) Find your 1%: Supporting GPs in delivering quality end of life care). 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. (**Source:** National Institute for Health and Care Excellence (2011) QS13 Quality Standard).
Care planning	Gold Standards Framework. (**Source:** Gold Standards Framework (2015) Overview of the work of the National GSF Centre in End of Life care. Advance Care Planning. (**Source:** NHS England (2014) Planning for your future care: a guide. NHS England). Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies. (**Source:** Freeman *et al* (2015)).
Coordination of care	Electronic Palliative Care Coordination Systems (EPaCCS).
Rapid access to care	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. (**Source:** NICE QS13 Quality Standard, 2011). A high proportion of people receiving specialist palliative care services have a diagnosis of cancer. The proportion of people with conditions other than cancer being seen by specialist palliative care services is still low but continues to increase. (**Source:** Public Health England (2015) What we know now 2014). 37% of trusts now provide 7-day 9-5 specialist palliative care. (**Source:** Royal College of Physicians (2016) End of life care audit).
Delivery of high quality services in all locations	Acute hospitals 'Transform' programme. The positive impact for individuals and carers, staff and the wider system from hospital care quality programmes is demonstrated in a suite of case studies from the NHS Improving Quality Transform Programme. (**Source:** Public Health England (2015) What we know now 2014). The GP and the primary care team occupy a central role in the delivery of end of life care in the community. GPs have a key role in initiating discussions about end of life care but this is not happening often enough at present. Patients who are well supported at home

	are more likely to be able to die at home if that is their preference. The national survey of the bereaved (VOICES) reported significantly lower level pain management for patients at home compared to other settings. (**Source:** Public Health England (2015) What we know now 2014). Electronic palliative care co-ordination systems (EPaCCS) provide the facility to assess whether people's preferences for place of care are met. Real-time reporting of people's experiences of care can be a useful way to assess the quality of care. (**Source:** Public Health England (2015) What we know now 2014). 3 out of 4 bereaved people (75%) rate 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 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%). Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%). (**Source:** Office for National Statistics (2016) National survey of bereaved people (VOICES): England, 2015)
Last days of life and care after death	NICE Guideline Care of dying adults in the last days of life. This guideline responds to a need for an evidence-based guideline for the clinical care of the dying adult throughout the NHS. It is focused on the care needed when a person is judged by the multi-professional clinical team to be within a few (2 to 3) days of death. This is different from other important NHS initiatives labelled 'end of life care' which are aimed at improving care for people in the last year or so of a chronic condition. The guideline is intended for all healthcare professionals and other care providers who might be involved in the care of a person who is nearing death in any NHS setting. It is specifically aimed at non-specialists working in primary care or in care homes, and healthcare professionals working in a wide range of clinical specialties who do not have specialist level training in end of life care. It will also provide a baseline for standards of care in settings that specialise in caring for people who are dying, such as non-NHS palliative care units and hospices. (**Source:** National Institute for Health and Care Excellence (2015) NG15. Care of

	dying adults in the last days of life.)
	Between 75% and 81% of cases, relatives agreed or strongly agreed that patients had adequate support to relieve thirst, hunger, pain and other problems. This indicates that in at least 3 out of 4 cases, people's primary physical needs are met at the end of life. Despite this, 1 in 8 respondents (13%) disagreed or strongly disagreed that the patient's need for food or nutrition was met. A similar proportion (12%) disagreed that there was adequate support for the patient to receive fluids and 12% disagreed that other problems were supported. One in 10 (10%) disagreed that pain relief was sufficient in the last 2 days of life. (**Source:** Office for National Statistics (2016) National survey of bereaved people (VOICES): England, 2015). New guidance published this year includes guidance for families whose family member's death requires referral to the coroner from the Ministry of Justice, guidance on caring well for the deceased from the Human Tissue Association and new guidance on implantable cardiac defibrillator deactivation from the British Heart Foundation. A review of child deaths in England recommended that children are offered bereavement support following the death of a parent, carer or sibling. (**Source:** Public Health England (2015) What we know now 2014). NICE QS13 Quality Standard, 2013.
Involving and supporting carers	Department of Health Carers Strategy consultation currently in progress. (**Source:** https://www.gov.uk/government/consultations/carers-strategy-call-for-evidence) HM Govt (2010) Recognised, valued and supported: next steps for the Carers Strategy. Carers, those who provide unpaid support to a family member or friend, play an essential role in end of life care. They are not always receiving the support they need to cope with the overwhelming demands of caring for someone with a terminal illness. (**Source:** Public Health England (2015) What we know now 2014). 'Every Moment Counts', the narrative for 'person-centred

	coordinated care' produced for NHS England by National Voices in 2014, in conjunction with its partners, (see Figure 1) which sets out critical outcomes and success factors in end of life care, support and treatment, from the perspective of the people who need that care, and their carers, families and those close to them. (**Source:** NHS England (2014b) 'Actions for End of Life Care').
Education and training and continuing professional development	Between 1 April 2014 and 31 March 2015 there was a formal in-house continuing education training programme on the subject of end of life care in place at 96% (136/142) of trusts. A small rise in participation rates was reported to 22% for medical staff group (i.e. doctors) and 29% for nurses. (**Source:** Royal College of Physicians (2016) End of life care audit). Inclusion of death and dying in undergraduate training could help to change the current culture that considers death to be a medical failure. (**Source:** Public Health England (2015) What we know now 2014). National surveys provide information about the specialist palliative care consultant workforce. The surveys report that much of the consultant workforce is female and work on a part time basis. The total number of consultants is continuing to increase year on year, although the rate of expansion is decreasing. (**Source:** Public Health England (2015) What we know now 2014). Current recommendations about what medical undergraduates ought to be taught about ageing are not consistently achieved. Teaching innovations might close the gap between aspiration and current practice, for example, new technologies, inter-professional education, patients' involvement in teaching and education to improve attitudes towards care of older patients. There is strong evidence to suggest that medical schools are not delivering enough teaching about ageing and geriatric medicine. This is not unique to the UK, but the UK is no better than other countries. The study, included a major poll of British medical schools, revealed that some medical undergraduates received as little as 55 hours of specialist training in the area of elderly care over their five-year courses. 'If we are to prepare our workforce for the future we need to devote more time to teaching medical students about how to manage older

	people with frailty.' Source: Rachel Oakley, Joanne Pattinson, Sarah Goldberg *et al*. New Horizons: Equipping Tomorrow's Doctors for the Patients of Today published on Monday, 23 June 2014, in Age and Ageing, the research journal of the British Geriatrics Society. www.bgs.org.uk/index.php/press/3015-new-horizons-tomorrows-doctors. (**Source:** Public Health England (2015) What we know now 2014).
Measurement and research	New guidance on measurement of quality of care in the last days of life. This includes: Factsheet 1: Sources of information for end of life care in acute hospitals Factsheet 2: Clinical audit supporting quality improvement (**Source:** NHS Improving Quality (2014) Transforming End of Life Care in Acute Hospitals Programme (Transform Programme) Considerations on assurance and quality improvement for care in the last days of life in acute hospitals.
Funding	There is limited information about costs and comparable costs of care. To date most studies have focused on the costs of hospital care and the associated costs of shifting care to community settings and the indirect costs of informal end of life care have not been fully evaluated. (**Source:** Public Health England (2015) What we know now 2014). NHS England has a dual role: • Providing leadership and support to Clinical Commissioning Groups as commissioners of secondary and community services for end of life care services, including specialist palliative care. • Direct commissioning of services which incorporate end of life care, e.g. in primary care and for people in secure and detained settings. Palliative Care Funding Review (2011): Our recommended next steps: • The current minimum data set is expanded to support the tariff and its collation made mandatory for all organisations providing NHS dedicated palliative care services. • Outcomes measures are developed which are supported by

	the dataset and the NHS outcomes framework.
	• Transition phase to the new system supported by national funding
	Palliative Care Funding Review Update (2016):
	A 'per-patient tariff', which was the original model proposed by the Palliative Care Funding Review of 2011, may not be the only, or most suitable, funding model for palliative care. "*Over the next months, we will be engaging with our stakeholders to review and consider a range of approaches to palliative care funding for children and adults, all of which will require the use of the palliative care currencies as the 'building blocks' for any funding model.*"
	(**Source:** Public Health England and NHS England (2016) Joint statement from NHS England and Public Health England: update on development of the Palliative Care Clinical Data Set and Palliative Care Currencies. Public Health England and NHS England, London.

As well as tangible examples of local implementation, in England many of the strategy documents also contain implicit evidence of implementation as they describe existing policies or practices and suggest 'more of the same' or an extension into other areas. Carrying forward these practices seems to suggest some level of implementation and acceptance. For example, it is clear there is an expectation that electronic palliative care co-ordination systems (EPaCCS) have had a positive impact across many of the Strategy's objectives.

3.4.4 Commissioning and Funding

The Palliative Care Funding Review (Hallett *et al*, 2011) said that the NHS in England would develop:

'for the first time, a per-patient funding mechanism for palliative care. No other country in the world has introduced such a system for both adults and children, so this step is bold but necessary. Britain is a world leader in palliative care and the hospice movement internationally owes its current strength to its beginnings here. There are many highly committed professionals who are doing their best to provide high quality palliative and end of life care. Yet their expertise does not reach all who need their care. Access to good services is inconsistent and the absence of sufficient provision of 24/7 community services is stark.

We know that the current system is confusing and does not help people get the care and support they need, or provide them with meaningful choice. Research consistently shows that most people would like to be cared for and die in their own

home; between 56% and 65% for adults (Higginson 2003; YouGov 2008). But the great majority of us still die in hospital and arguably at a higher economic cost.

Evidence shows us that incentivising the provision of palliative care leads to better outcomes for patients, supports choice and is the most cost effective way of using NHS resources. We need to remove the barriers within the current system to enable this to happen.'

The review's recommendations had three key aims:

- To create a fair and transparent funding system

- To deliver better outcomes for patients

- To provide better value for the NHS

These aims were to be achieved by developing:

- an NHS palliative care tariff which is based on need

- a funding system which incentivises good outcomes for patients, irrespective of both time and setting

- the commissioning of integrated care packages which stimulate community services

In the new system the NHS would fully fund:

- An assessment, on a regular basis, of the needs of a patient

- All the clinically assessed palliative care needs of a patient irrespective of setting, as in any other branch of clinical care

- A coordinator for the patient who will guide them through their journey, signposting patients and families to the full range of services including those provided by society and not funded by the state

- At the end of life, as an addition to the tariff, the social care needs of a patient after they are added to an end of life locality register

The Palliative Care Funding Review found that there is 'a stunning lack of good data surrounding costs for palliative care in England'. So plans were announced by Public Health England and NHS England (2014) for improving palliative care data. Better quality data is necessary to assess need and allocate resources more effectively:

'There is a recognition that data in the specialist palliative care sector needs to be more robust and comprehensive. There are a number of work programmes that record and use individual level palliative care data but there is currently no

mechanism for bringing this data together across sectors to provide a full picture of the care provided to patients. We therefore have significant gaps in our understanding of end of life care provision and a lack of evidence on what is 'good' end of life care.

NHS England and Public Health England are working together to explore the feasibility, options and costs of collecting individual level palliative care data nationally. In this way we can better support clinicians, service providers and commissioners in improving quality of care and achieving better outcomes for individuals and their families.'

But a recent update (NHS England and Public Health England, 2016) decided that collecting individual level palliative care data nationally would not after all take place:

'we did explore the potential for a centrally managed national data collection and the development of a national information standard, but resource constraints mean that it is not possible to pursue this option at this time. Instead, local commissioners and providers will be able to adopt the dataset locally to support local commissioning and service improvement, if they choose to do so. Over the longer term we will also be looking to see how the palliative care clinical dataset can be incorporated into the development of other national datasets.'

The 2016 update also concluded that the model for funding services in England was still under review and a consultation on possible approaches had begun:

'a 'per-patient tariff', which was the original model proposed by the Palliative Care Funding Review of 2011, may not be the only, or most suitable, funding model for palliative care. Over the next months, we will be engaging with our stakeholders to review and consider a range of approaches to palliative care funding for children and adults, all of which will require the use of the palliative care currencies as the 'building blocks' for any funding model.'

Whichever funding approach is chosen, from April 2017 a new set of 'developmental currencies' will be in place. These currencies will be used to categorise adults and children receiving palliative care according to need and to help decide how funding is allocated. Later in 2016:

'NHS England will publish a definitive set of palliative care currencies – to help categorise people receiving palliative care according to level of complexity and resource need – which will be available for use from April 2017.'

3.5 Northern Ireland

3.5.1 Background

In 2010 the Department of Health, Social Services and Public Safety (DHSSPS) published Northern Ireland's five-year strategy for palliative and end of life care for adults with an advanced non-curative illness, Living Matters Dying Matters. A range of national and international strategies and developments in palliative and end of life care had informed the development of the 2010 strategy. These included the World Health Organisation and Council of Europe; House of Commons; Department of Health England; Welsh Assembly Government; Scottish Government; Irish Hospice Association and Health Service Executive. The strategy built upon a number of existing policies and guidelines which had directly and indirectly contributed to the development of palliative and end of life services in Northern Ireland, including, Improving the Patient and Client Experience (Department of Health, Social Services and Public Safety, 2008); the Northern Ireland Health and Social Care Services Strategy for Bereavement Care (Department of Health, Social Services and Public Safety, 2009); NICE Guideline for Parkinson's Disease (National Institute for Health and Clinical Excellence, 2006) and Dementia (National Institute for Health and Clinical Excellence, 2006).

The vision for the five-year strategy emphasised the importance of:

- Understanding palliative and end of life care
- Best and appropriate care supported by responsive and competent staff
- Recognising and talking about what matters
- Timely information and choice
- Coordinated care, support and continuity

The vision of the strategy was presented within four themes:

1) Developing Quality Palliative and End of Life Care
2) Commissioning Quality Palliative and End of Life Care
3) Delivering Quality Palliative and End of Life Care
4) A Model for Quality Palliative and End of Life Care

Twenty-five recommendations emanated from the vision and identified themes, and these were built into an Action Plan. Each recommendation included the following level of detail: an identified organisation who is responsible for planning and delivery; a time frame; identified outcomes; how the outcomes should be measured. The identified organisations included: Health and Social Care Boards (HSCBs); National Screening Committee Trusts (NSC); Local Commissioning Groups (LCGs); Voluntary Sector; higher education institutions (HEIs); Patient and Client Council; Education Consortia; Public Health Agency; Primary Care; Research Consortia.

3.5.2 Current strategies and delivery mechanisms that influence terminal illness in Northern Ireland

Table 7 details the current strategies and delivery mechanisms that influence terminal illness care in Northern Ireland.

Table 7. Northern Ireland: Strategies and delivery mechanisms that influence terminal illness care

Policy documents	Key Areas of Strategy	Delivery mechanisms
Department of Health, Social Services and Public Safety (2009, 2010, 2016) Guidelines and Audit Implementation Network, (2011, 2013) Regulation and Quality Improvement Authority (2013, 2016)	Developing quality palliative and end of life care through raising public and health and social care staff awareness of palliative and end of life care.	Delivery of educational resources and training programmes by statutory and voluntary providers to the public and health and social care staff, including specialist palliative care and end of life education and training.
		Inclusion of palliative and end of life care in undergraduate medical and nursing programmes.
		Establishment of a Palliative Care Research Forum.
		Implementation of NICaN Multidisciplinary Competency Framework for Adult Palliative and End of Life Care.
		The implementation of the Transforming Your Palliative and End of Life Care Programme (TYEOLC). The impact of this programme will support all the current strategies, for example, improved identification of those in need; improved service co-ordination.
	Commissioning quality palliative and end of life care.	Appointment of a lead commissioner for palliative and end of life care at regional level and within all Local Commissioning Groups. Completion of health needs assessment by the Public Health Agency, including a focus on patients with a non-cancer diagnosis.
		Personal and public involvement
		The adoption of the Model of Palliative Care across regions
		The development and implementation of the generic palliative care standards, integrated care pathways and regional clinical

		guidelines.
		Funding through commissioning process for additional posts and expansion of specific services
		Voluntary sector organisation funding
	Delivering quality general and specialist palliative and end of life care	A mixed economy of care provision with public, independent, community and voluntary sector organisations working together in partnership.
		Adoption of a case management approach - each patient identified as having end of life care needs should have a key worker.
		Care pathway approach for transitional care for young people
		Implementing a Managed Clinical Network.
		Implementation of the Bereavement Strategy and DHPHSS (2009) and GAIN Guidelines for Palliative and End of Life Care in Nursing Homes and Residential Care Homes.
		Regional guidance for the development for the management of symptoms for adults in the last days of life
		Regional guidance for Breaking Bad News
	A model for quality palliative and end of life care	Discussion and identification of palliative and end of life care. Palliative care registers to be extended to include patients with non-cancer needs. Needs based coding, as per Gold Standards Framework, to enable a whole systems approach to enhance palliative care registers.
		Holistic assessment, and review, of patient and carer need,

		supported through the use of assessment tools such as NISAT and NICaN Holistic Palliative Care Assessment tool.
		Planning palliative and end of life care across care settings and conditions, including Preferred Priorities for Care and DNACPR
		Co-ordinating and delivering palliative and end of life care across care settings, including, palliative care nurse liaison, patient passport, out of hours care, use of GSF
		Providing care at the end of life using best practice guidelines
		Implementing the NI Health and Social Care Services Strategy for Bereavement Care

3.5.3 Evidence of the implementation of the current strategies and delivery mechanisms

In 2016 the Regulation and Quality Improvement Authority (RQIA) published a review of the implementation of the Palliative and End of Life Care Strategy, Living Matters, Dying Matters (Regulation and Quality Improvement Authority, 2016). The main aspects of the review involved the following:

- Background review of key strategic work undertaken, including examination of relevant documentation.
- Completion of questionnaire pro forma by HSC trusts, HSC board and Independent sector providers to assess progress of the implementation of the regional strategy against the 25 recommendations in the action plan.
- Review meetings with a variety of key stakeholders, including team members of the Transforming Your Palliative and End of Life Care programme, developed to support the implementation of the recommendations in the regional strategy.
- Reviewing data from the Let's Talk About survey (All Ireland Institute of Hospice and Palliative Care)

The review document provided amalgamated evidence of how the 25 recommendations had been addressed and/or implemented across Northern Ireland. Within the review document progress against the 25 recommendations are noted as strengths. Challenges to the implementation of the recommendations are also detailed. Following the review, the RQIA stated that the strategic vision is still valid and that there is no requirement for a new strategic direction. Nevertheless, a priority within the review was to develop a three-year action plan 2016-2019 to address the challenges noted, for implementation in partnership with key stakeholders. The top priority recommendations from RQIA review for Northern Ireland are:

1. A new three-year action plan to take forward the next programme of work on Palliative and End of Life Care (P&EoLC)
2. Raising public and professional awareness of P&EoLC
3. Needs assessment for specification of future services
4. Review of coordination of services, a lack of which has resulted in inconsistency in provision of 24-hour care across NI

The eight specific recommendations from the RQIA review are as follows:

1. DHSSPS, in partnership with stakeholders should develop a new Living Matters Dying Matters Action Plan for a three-year period for 2016 to 2019 building on the work which has been completed since the strategy was developed in 2010. The action plan should include defined timescales, organisational responsibilities and monitoring arrangements.

2. Raising public and professional awareness of palliative and end of life care should be a core component of the new action plan.
3. The Public Health Agency should lead on the development of a new needs assessment exercise to assess the impact of projected demographic, epidemiological and service changes on the delivery of palliative and end of life care and to inform the future specification of services.
4. DHSSPS and HSC organisations should evaluate the roles of key workers for palliative and end of life care to determine if regional guidelines for this function should be modified in the light of experience.
5. The HSC Board, in partnership with stakeholders, should review the regional coordination arrangements for developing palliative and end of life care, to ensure clarity about the roles of different partnerships and groups. This review should inform a decision whether to establish a managed clinical network for palliative and end of life care, or determine if this approach is no longer appropriate.
6. HSC Board should develop a service specification for out of hour's provision for palliative and end of life care in both hospital and community settings to increase standardisation of the availability of services across Northern Ireland.
7. HSC Board in conjunction with HSC trusts should review the arrangements for holding multi-professional palliative care meetings at practice level to identify and address any constraints to establishing these as routine practice in all areas.
8. Raising public and professional awareness of the Breaking Bad News Guidance, once revised, should be a core component of the new action plan.

Table 8 details some reported examples of what has been achieved against the 2010 PE P&EoLC strategy.

Table 8. Examples of reported current strategies and achievements by theme - Northern Ireland

Current Strategies	Strength	Challenge
RQIA: Recommendation 2 Raising public and health and social care staff awareness of palliative and end of life care	Medical students at Queen's University undergraduate programme visit local hospices during their fourth year. Wide range of training programmes delivered by statutory and voluntary organisations. Research priorities identified through the Transforming Your Palliative and End of Life Care (TYPEOLC) programme and the All Ireland Institute of Hospice and Palliative Care (AIIHPC).	Challenging for organisations to ensure staff accessed the training most appropriate for their needs. The term palliative and other terms, such as Advance Care Planning, are not always understood creating difficulties in communication between patients and clinicians.
RQIA Recommendation 3	Lead officers for palliative and end of life care appointed by HSC board and	For commissioners and providers to ensure there is a comprehensive, integrated model

Commissioning quality palliative and end of life care	PHA. Health needs assessment completed by PHA.	of service delivery for a particular geographic area. Present commissioning arrangements did not facilitate Trust input to discussions on the future directions of services, or on priorities for service development
RQIA Recommendation 4;5 Delivering quality palliative and end of life care	Regional guidelines were agreed, setting out of the function of key workers and the skills and competencies they require. HSC trusts have taken forward the regional guidance in the development of specific guidelines within their respective areas (Belfast Trust record keyworker on PARIS) Local initiatives are being developed in relation to transition planning	To identify the key worker an agreed source of information is required one that keeps the details up to date and is easily accessible by all relevant staff. Models of key worker implementation need evaluating. Less clear how it works in the hospital setting. The evidence for establishing a Managed Clinical Network was not clear, and therefore there is uncertainty as to whether this approach should be taken forward or not.
RQIA Recommendation 6;7;8 A model for palliative and end of life care	A regional approach has been developed to support practitioners and organisations in implementing the model of care set out in LMDM (the End of Life Operational System (ELCOS). This has been shared across Northern Ireland. The HSC trusts have introduced ELCOS on PARIS. Development of the electronic care record (ECR) in relation to palliative and end of life care. A project is being taken forward to deliver a Key Information Summary (KIS) (completed by GPs) through the ECR relating to palliative and end of life care.	Differences in the availability of palliative and end of life care services and advice out-of-hours across Northern Ireland. There has been an increased demand for inpatient provision by hospices, with many patients having increased levels of complex needs. This has impacted on their ability to respond to request for respite care on an inpatient basis.

The RQIA review of Living Matters Dying Matters has attempted to detail self-reported evidence of activity within each Trust, against the 25 recommendations. There is limited reference to research, project or pilot work as evidence of implementation of the strategy. A limited amount of work has been completed around the public's perceptions of palliative care (Patient and Client Council, 2013) and the Let's Talk About survey sought service user experience of palliative care service. One trust has been testing a model where information is taken from GP registers to a stand-alone palliative and end of life care register, known as the Peninsula Project. There is some evidence of the reporting of palliative and end of life care services and delivery in some of the HSC Trusts annual reports.

Here are further reported examples of activities that are considered to be strengths in the implementation of the recommendations put forward in Living Matters, Dying Matters (LMDM).

- Electronic palliative and end of life coordination system, such as PARIS.
- The use of the ELCOS model to assist practitioners in the development of an individual care plan
- Testing of a model where information is taken from GP registers to inform a stand-alone palliative and end of life care register (Peninsula project)
- Development of an electronic care record (ECR)
- Utilisation of the regional e-NISAT (Northern Ireland Single Assessment Tool)
- Your Life and Your Choices: Plan Ahead, Northern Ireland. Jointly produced by PHA and Cancer Macmillan Support, includes information about ACP
- NIAS Palliative and End of Life Care guidelines; NIAS Palliative and End of Life Care booking form
- NIAS out-of-hours palliative care referral pathway
- Pilot study in Western Trust to provide a Marie Curie unscheduled out of hours service 7 days a week (10pm - 8am). 24 hour Marie Curie rapid response on bank holidays and weekends.
- 'Let's Talk about Survey' and 'Exploring public awareness of palliative care' study identifies public perceptions of palliative and end of life care.
- 8-week distance learning programme run by Princess Alice Hospice - leads to Certificate in Essential Palliative Care.
- Palliative Care Link Nurse Programme
- Information pathways for people with advanced disease - website
- Nurse liaison project to assist with complex palliative discharges from hospital.
- Primary care led palliative care beds located in residential facilities for older people
- Out of hours toolkit
- Community pharmacist post
- The Transforming Your Palliative and End of Life Care Programme (2013-2015) is an initiative developed by Marie Curie and supported by the HSC Board and PHA, based on the delivering choice approach. There are a number of current initiatives: Pharmacy Service Improvement; Supporting discharge; Ambulance; Training for nursing homes (ECHO - Extension for Community Healthcare Outcomes).
- Programme which amalgamates residual actions under LMDM with TYPEOLC activity. Also incorporates recommendations from RQIA review under the auspices of 'Regional Palliative Care Programme - Palliative Care in Partnership' (steered by PHA/HSCB and partner organisations, including Marie Curie).

3.5.4 Commissioning and Funding

It was recommended that a lead commissioner be identified for P&EoLC at regional level and within all Local Commissioning Groups (LCGs). Systems that capture populations were required to relate to P&EoLC. Effective commissioning of quality palliative and end of life care depended on the development of robust service specifications which identify the short and long term objectives of the service to be delivered, define performance and quality standards and specify how they will be measured. The following elements were stated as important in commissioning P&EoLC: IT systems; Patient and Public Involvement (PPI); Development and adoption of care pathways across conditions; common guidelines for symptom and situation management (NICaN; Generic Palliative Care Standards; adoption of a community facing model for P&EoLC; performance objectives, including Priorities for Action targets. The Priorities for Action (PfA) target for 2009-2011 provided a key vehicle to guide commissioners in the planning of palliative and end of life care services and service providers in how these services should be designed and implemented. The PfA target stated that "by March 2011, Trusts were to establish multi-disciplinary palliative care teams, and supporting service improvement programmes, to provide appropriate palliative care in the community to adult patients requiring such services".

Existing funding mechanisms supported the delivery of the strategy. Funding was provided through the commissioning process for specific developments in some trust areas, such as, extra posts and expansion of out of hours services. Significant funding was provided from voluntary sector organisations, including, Macmillan Cancer Support; Marie Curie; Hospices; All Ireland Institute for Palliative and End of Life Care used funding from Atlantic Philanthropies. The RQIA document reported that great progress had been made in achieving the aims identified in LMDM in spite of constrained resources. It is important to note here that the commissioning of health and social care services in general is being restructured under current HSC reforms by the Health Minister. The resulting removal of the commissioner/provider split, with subsequent restructuring HSCBs and LCGs, could have repercussions for the commissioning of terminal illness care in the future. For example, it is unclear where commissioning for terminal care will sit within this new structure; also there may be implications for future contract partnerships, for example, voluntary sector contracts may be at risk of shrinking.

3.6 Scotland

3.6.1 Background

Scotland's terminal illness care policy is made up of a raft policy documents published in the eight years since the launch of the first strategy Living and Dying Well (Scottish Government, 2008). These policy documents have been the driving force for terminal illness care in Scotland, and therefore it is important to report these in order to understand the current context.

In 2008 the Scottish Government published '*Living and Dying Well: A national action plan for palliative and end of life care in Scotland*', to ensure that effective palliative-, and end of life care was available for all patients and families who need it. This strategy built on the '*Better health, Better Care action plan*' (Scottish Government 2007), the '*Review of Palliative Care Services in Scotland*' (Auditor General for Scotland, 2008) and the report '*Palliative and End of Life care in Scotland: The case for a cohesive approach*' (Scottish Partnership for Palliative Care 2007). The key components of the action plan were:

- Assessment and Review of Palliative and End of Life Care Needs
- Planning and Delivery of Care for Patients with Palliative and End of Life Care Needs
- Communication and Co-ordination
- Education, Training and Workforce Development

Within each of these themes action points were identified, outlining the responsibility of how organisations, such as the Scottish Government, NHS Boards, the Care Inspectorate, were to achieve them.

In 2015 the Scottish Government published the '*Strategic Framework for Action on Palliative and End of Life Care*'; this is the new driving force for P&EoLC in Scotland. Publication of the Strategic Framework was in part a response to the World Health Assembly, which required all governments to recognise and make provision for palliative care. It clearly builds on the work of '*Living and Dying Well*' (Scottish Government, 2008) as well as other actions and policies including:

- The '*2020 Vision for Health and Social Care*' that describes a health system focused on prevention, anticipation and supported self-management.
- The commitment to quality as outlined in the '*Healthcare Quality Strategy*', the '*National Performance Framework and the National Health and Wellbeing Outcomes*'.
- The Scottish Parliaments Health and Sport Committee Inquiry report 'We need to talk about Palliative Care

The vision of the current strategy is to ensure that those in need of palliative care will have access to it by 2021, with the following palliative and end of life care objectives:

- Improved identification of people who may benefit from palliative and end of life care
- An enhanced contribution of a wider range of health and care staff in providing palliative care
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed
- A greater openness about death, dying and bereavement in Scotland
- Recognition of the wider sources of support within communities that enable people to live and die well
- Greater emphasis in strategic plans, research activities, quality of care reviews and improvement support programmes on enhanced access to high quality palliative and end of life care.

The Strategic Framework for Action on Palliative and End of Life Care identifies 10 commitments that will focus action and implementation, including: Strengthening and co-ordinating research and knowledge transfer across regions, institutions and disciplines by taking further action to support the establishment of a Scottish Research Forum for P&EoLC; improving ways that information is recorded and shared by ensuring that the requirement for future e-health care systems support effective sharing of individual end of life preferences/ACP conversations.

3.6.2 Current strategies and delivery mechanisms that influence terminal care in Scotland

Table 9 details the current strategies and delivery mechanisms that influence terminal care in Scotland.

Table 9. Scotland: Strategies and delivery mechanisms that influence terminal illness care

Policy documents	Key Areas of Strategy	Delivery Mechanism
Scottish Government, (2010; 2012; 2014; 2015) NHS Scotland (2014) Scottish Partnership for Palliative Care and Marie Curie (2014) Healthcare Improvement Scotland (2013) Scottish Public Health Network (2016)	Developing openness about death, dying and bereavement	• Launch of Good Life, Good Death, Good Grief • Integration of Shaping Bereavement Care recommendations • Support Around Death NHS Education Scotland • NHS Inform Palliative Care Zone
	Assessment and review of palliative and end of life care needs	• Palliative care register for patients with cancer and other long term conditions, including Palliative Care Directed Enhanced Service (DES) in Scotland • Application of the Palliative and End of Life Care Indicators and the prognostic indicators in primary care as introduced by the Gold Standards Framework (GSF) (Scottish Palliative Care Guidelines 2014) • Application of currently available and appropriate tools to holistically assess needs, such as, GSF-PIG, FASTAD; HADS; ESAS, Palliative Care Performance Scale, SPICT etc. • Recommended criteria for referral to specialist palliative care • e-Health Leads per NHS Health Board • Framework for Palliative Care for Children and Young People • Clinical lead for Children and Young People's Acute Deterioration Management Policy (CYPADM)
	Planning and delivery of care for patients with palliative and end of life care needs	• Extension of the GSF to all patients who have been assessed as having palliative care needs • Implementation of Advance Care Planning (ACP) documentation and practices • Audit of anticipatory care plans that include ePCS, SBAR and KIS • Application of the End of Life Care Plan during patient transfer • Application of NHS Scotland Do Not Attempt Cardiopulmonary Resuscitation guidelines • Implementation of the end of life care pathway • Provision of care over 24 hours, including referral to Specialist Palliative care. • Key Performance Indicators for Out of Hours Palliative Care • NHS boards to develop and make available guidelines for 30 core topic areas to inform practice • Implementation of an Acute Hospital Palliative Care Service

		• Service reconfiguration to meet patient need, for example, adolescents and young adults • Increasing the capacity of care homes to deliver good quality palliative care • Implementation of the NHS Scotland Shaping Bereavement Care document
	Communication and coordination	• National roll out of the electronic Palliative Care Summary (ePCS) system to communicate appropriate information between care settings through • Patient and family feedback via better Together and complaints procedures
	Education, training and workforce development	• National education plan for generalist staff developed by NHS Education for Scotland • Nomination of a palliative and end of life care education champion to facilitate the sharing and spreading of good practice • Development and use of bespoke education packages nationally and locally, including, advance care planning, communication skills, DNACPR, end of life care pathways, palliative care in acute settings.
	Strategic plans, research activities, quality of care reviews and improvement support programmes on enhanced access to high quality palliative and end of life care	• Implementation of the governance structure, including partnership between HealthCare Improvement Scotland; NHS Boards; NHS Education for Scotland; Scottish Partnership for Palliative Care • Funding arrangements between NHS Boards and voluntary hospices as detailed in the document A Partnership for Better Palliative and End of Life Care: Creating a New Relationship between Independent Adult Hospices and NHS Boards in Scotland. CEL 12 due for review. • Availability of Scottish Palliative Care Guidelines (2014), including the NHS Lothian guidelines, electronically as well as hard copy • Re-shaping Care for Older People - web-based resources and e-bulletins developed via a multi-agency approach • Metrics and indicators to monitor palliative care delivery against NHS Board Palliative Care Strategy objectives/goals

3.6.3 Evidence of implementation of the strategies and delivery mechanisms

This section details the evidence of implementation of the Scottish Government's key strategies relating to terminal illness care.

There have been two national reviews of the Living and Dying Well strategy. NHS Boards were asked to submit Living and Dying Well delivery plans against the actions identified in the national plan. In the January 2011 review document (Scottish Government, 2011) it stated that the NHS Board reviews demonstrated substantial progress across Scotland across all the relevant actions, although there is limited evidence provided of the NHS Board progress in the report. The report did not appear to focus on all the objectives highlighted in the Living and Dying Well plan. The review reported in detail the progress of the short life working groups (SLWG) that were set up to undertake collaborative and development work and make recommendations to the National Advisory Group around a number of identified areas, such as, Palliative and End of Life Care Guidelines, referral criteria to Specialist Palliative Care.

The second national overview (Scottish Government, 2012) also reviewed the progress of Living and Dying Well and forms part of the Scottish Government's response to the Scottish Parliament Health and Sport Committee's wish to see evidence made available of progress in implementing Living and Dying Well. This review was supported by evidence from the 14 NHS Territorial Boards collected through individual detailed reports, although a caveat is noted that the level of detail provided by the NHS Territorial Boards varied greatly across geographical areas and topics. The review collated the NHS Territorial Board information that was collected through the individual reports, and reported this as progress and plan, challenges, good practice and future pointers across 15 topic areas.

In 2015 the Scottish Parliament's Health and Sport Committee published 'We need to talk about Palliative Care' (Scottish Parliament's Health and Sport Committee, 2015), which presented findings of its inquiry into palliative care. The decision to hold an inquiry into palliative care was prompted by 'the emergence of the importance of Palliative Care in the scrutiny of the Assisted Suicide (Scotland) Bill and Scottish Government's announcement of the development of a new Strategic Framework' (Scottish Parliament 2015). Evidence was collated from:

- Oral evidence sessions from: The Scottish Government; Care Inspectorate; Scottish Public Services Ombudsman; HIS.

- Service visits, including the Marie Curie Hospice in Glasgow, Children's Hospice Association Scotland Rachel House.

- Written views

- Research, including, commissioned research on international comparisons of measurement of data used in P&EoLC (Clark 2015)

Building on the progress reviews of Living and Dying Well, and other actions and policies, the evidence published in 'We need to talk about palliative care', clearly contributed to the development of the new Strategic Vision. In particular, the focus on the development of ways to better describe service provision and the development of key measures to demonstrate the impact of palliative and end of life care on key outcomes. It also detailed that the quality and level of data provided by NHS boards regarding palliative and end of life care funding and hospice funding was mixed. Some boards were unable to separate out general palliative care funding, others provided an estimate.

Current implementation support has been identified in the Strategic Vision, with the expectation that by April 2016 the strategy's commitments will have informed and be reflected in implementation and improvement plans. A National Implementation Support Group will be established to support this process, working in partnership with and reporting to the P&EoLC National Advisory Group. There will also be strong representation from the Stakeholder Group.

Some examples of evidence to support the implementation of the delivery mechanisms are demonstrated in Table 10. The Strategic Framework builds upon Living and Dying Well and therefore links between previous strategic aims and the current commitments are made.

Table 10. Scotland: Examples of evidence of implementation of strategies and reported achievements.

Topic	Progress and plans	Future pointers
L&DW Assessment and Review of Palliative and End of Life Care Needs **SFA: Commitment 9**	• Health Boards use tools to identify patients with palliative care needs (GSF-PIG, SPICT) and uptake of the Palliative Care DES generally reported to be high. • ePCS are being rolled out across all territorial Boards.	• More clarity towards broad-based implementation of effective tools and approaches across settings required. • Developments in palliative care in acute settings will contribute to completion of DES data. • ePCS should be incorporated within the electronic KIS rather than being separate. • Develop and enhance indicators and measures that can be embedded in routine care to support the delivery, monitoring, quality improvement and

		benchmarking of services
L&DW Planning and Delivery of Care for Patients with Palliative and End of Life Care Needs **SFA: Commitment 7**	• A range of approaches to ACP are reported, including, STACCATO; ACP OOH Handover forms, LPCAT. • Introduction of 'Just in Case' boxes to promote anticipatory prescribing. • Referral guidelines for specialist palliative care in place	• Requirement to track how practice is actually changing in terms of identifying when a conversation should occur. • Improve equity of access across geography and for non-malignant disease. • Identify electronic systems can best ensure that care planning conversations are effectively recorded and appropriately shared through the electronic system. • Maximise continued access to the KIS and the ECS.
L&DW Communication and Co-ordination **SFA: Commitment 8**	• Palliative Care guidelines were reported to be in place by all Boards, well over half were using the Lothian Guidelines. • Service information directories to support palliative and end of life care pathways in place in most boards.	• Making guidelines available electronically. • Raise awareness of available information. Rationalise a number of 'national' palliative care resources and establish good linkage between the NHS Inform Palliative Care Zone, patient information as part of the Clinical Guidelines project and local service directories. • Enhance reliability of clinical guideline implementation. • Clinical and economical evaluations of new and emerging models of palliative care delivery.
L&DW Education, Training and Workforce Development **SFA: Commitment 3**	• Some Boards have programmes which appear to offer wide coverage and fairly comprehensive training and education for staff of care homes. • NHS Fife has published a Bereavement Training Programme.	• Promoting the use of a resource developed by the Living and Dying Well Care Homes Steering Group which will allow stakeholders in this sector to identify easily relevant education, evidence, resource and practice examples. • Accessing the new Bereavement Hub network. • Development of a new end of life care framework, specifically to foster an integrated and collaborative approach to educational provision

		• Development of defined core competencies on P&EoLC expected for all roles within the health care system (linked to descriptors of attainment).

A range of reported evidence is used to support the current progress of the strategies and this includes, data detailing the number of GPs who have submitted an ePCS record for each Health Board and the total number of ePCS records submitted each month; patients on Palliative Care Register; Quality Outcomes Framework (QOF) data; Scottish Paediatric Surveillance Unit audit data; Midlothian Care Homes project (MHS Lothian Board and Marie Curie) with follow-on evaluation. It also includes Health Boards that are undertaking pilot studies or evaluation of current activity, e.g., NHS Greater Glasgow & Clyde has piloted electronic referral to hospices and is rolling this out; new models of working with care homes.

Some topic areas are reported as having an incomplete picture of progress which lacks detail, because of the reporting format and inconsistency in completion. This is specifically linked to palliative care in acute settings; there is also patchy evidence of implementation of assessment of palliative care tools in different settings.

Here are further examples of activities that are considered to be good practice in the implementation of the strategic goals.

- Evaluation of the benefits of 'Just in case boxes' by NHS Highland
- NHS Lothian are piloting a paediatric anticipatory care pathway
- ACCORD Hospice has run a project to promote linking between different stakeholders
- NHS Highland – LEAN project on access to 24hour care
- Having a dedicated clinical/palliative care lead for ePCS
- NHS Borders – all practices have signed up to STACCATO, a locally developed anticipatory care planning tool.
- NHS Lanarkshire – the LTC team have developed an ACP tool which has been piloted in care homes and rolled out to other settings
- Good Life, Good Death programme
- PATCH - supporting specialist palliative care in hospitals
- Implementation of end-of-life tools in care homes

3.6.4 Commissioning and Funding

In the last year Scotland has experienced major reform in relation to the integration of health and social care. The newly formed Integration Joint Boards (IJB) will manage £8 billion of the health and social care resources across Scotland, of which palliative and end

of life care will be one component. IJBs will be responsible for health and social care partnerships in their areas. An additional 3.5 million pounds was attached to the Strategic Framework for Action. Within the Strategic Framework for Action the second commitment focuses on developing guidance to support health and social care partnerships with the development of the content of their Strategic Commissioning plans in relation to palliative and end of life care services.

3.7 Wales

3.7.1 Background

In 2013 the Welsh Government published '*Together for Health - Delivering End of Life Care*'. This document set out the Welsh Government's expectations of the NHS in Wales in delivering high quality end of life, regardless of diagnosis, circumstances or place of residence. This framework for action built on the Palliative Care Planning Report (Sugar, 2008), which set out recommendations for palliative care provision in Wales with clear actions up to 2011. This latest framework built on the achievements of the Sugar (2008) Report and was aligned with the Government's overall policy on health and health services, as set out in '*Together for Health: A 5 year vision for the NHS in Wales (2011)'.*

The vision for the Welsh population (Welsh Government, 2013) focused on:

- People in Wales having a healthy, realistic approach to dying, planning appropriately for the event
- People in Wales having access to high quality care wherever they live and die whatever their underlying disease or disability, devoid of any prejudice in relation to their personal situation

The vision of this strategy was presented within six delivery themes:

1. Supporting Living and Dying Well
2. Detecting and Identifying Patients Early
3. Delivering Fast Effective care
4. Reducing the Distress for Terminal Illness for Patients and their Families
5. Improving Information
6. Targeting Research

Each of the delivery themes included the following level of detail: Delivery aspirations; Specific priorities, including the responsibilities of Local Health Boards, Local Government and Public Health Wales NHS Trust; Population Outcome Indicators and NHS Performance Measures. A high level Action Plan detailed how the strategy was to be supported, noting time scales and organisational responsibilities.

3.7.2 Current strategies and delivery mechanisms that influence terminal care in Wales

Table 11 details the current strategies and delivery mechanisms that influence terminal care in Wales.

Table 11. Wales: Current strategies and delivery mechanisms that influence terminal illness care

Policy Documents	Key areas of Strategy	Delivery Mechanisms
PCPGW (2008) PCIB (2011) Welsh Government (2013; 2014; 2015) NHS Wales (2015)	Supporting Living and Dying Well	Support and deliver training for GPs and primary care teams/professionals to provide care in community settings
		Health and social care professionals to access relevant educational courses
		Support the delivery of training and support for carers
		Investment in Specialist Palliative Care Teams
		Creating new posts: Lead Pharmacists in each Local Health Board to support improvement of medicine management; SPC Nurse for Paediatrics
		People die in place of preference or usual place of care
		Advance care planning
		Launch of Dying Matters - Byw Nawr
		Transition arrangements for child to adult palliative care services, including Care Transfer Documentation and Emergency Care Plans, 'virtual' clinic

		Adoption of the All Wales DNACPR policy
	Detecting and Identifying Patients Early	The use of Palliative Care Registers (PCR) for patients with less than one year to live, in particular non-cancer patients
		CaNISC used to capture non-cancer patients once referred to specialist palliative care services
		MDT team meetings to discuss patients on a PCR
		Referral to specialist palliative care services
		Use of Marie Curie 'triggers' to palliative care
	Delivering Fast and Effective Care	Delivery of high quality evidence based care services in line with The Welsh 'Quality Markers End of Life Care (2012), across a range of service providers
		Assessment of urgent referrals to specialist palliative care in a defined timescale (within 2 days)
		Reduction of: unnecessary hospital admissions; length of hospital stay; deaths within 3 days of an emergency admission; total number of emergency admissions in final year of life
		Increase in bed capacity of nursing and residential care homes in line with the needs of the population
		National programme of 7 day working

		Completion of national clinical audits to drive service improvement
		Provision of specialist facilities and community hospice at home' style provision
		Service redesign of specialist units and existing community services
		Peer review of palliative care
		Patient satisfaction surveys, including iWantGreatCare
		Launch of the #HelloMyNameIs social media campaign
		Access to palliative care medication in the community
	Reducing the Distress of Terminal Illness for Patients and their Families	Planning, securing and delivering well-coordinated palliative and end of life care to people on a 24/7 basis
		All Wales audit of the Integrated Care Priorities document
		WICP audit and variance returns
		Funding streams for specialist palliative care service which are above the minimum levels advised by the PCIB
		Regular surveys of patient, and their families, experiences of palliative care

			Patient and families Reference Group to support the work of the PCIB
			Accessibility of CaNISC
			Integration and application of the Welsh Care Decisions Last Days of Life document
			Increasing the availability of respite for people and their families
		Improving information	Use and development of CaNISC to record and use clinical information for all palliative care patients
			Local Health Boards to annually report performance against specific end of life quality indicators to the Implementation board
			Publish information about the effectiveness of end of life care services
			Provision of trend and analysis of mortality, place of death etc., to inform local service planning by PHW and Velindre NHS Trusts
			Analysis and benchmarking of information to inform LHB work in national clinical audit and peer review
			Publication of information of NHS and voluntary sector performance
			Review of available information to ensure it is targeted to meet the needs to patients and their families

	Targeting Research	Engaging with the NISCHR
		Partnership working with cancer research organisations throughout Wales
		Patient involvement in clinical trials
		Protected research time for clinically active staff
		Use of key research facilities, such as Marie Curie Research Centre, Research Governance toolkit

Within the strategy there are clear outcome measures that are expected to be used to assess the implementation of the strategy:

The strategy sets out how performance will be monitored; and an initial outcome framework will be developed during 2013. The following outcome indicators have been set but the data sets in relation to the indicators and measures may not yet be in place and new data sets may be required:

- % of people dying in place of preference
- % of people with PC needs on a Palliative Care Register 6 months prior to death
- % of people who die in usual place of care
- % of people who die intestate

The strategy applied NHS performance measures and identified these as outcomes. The delivery aspirations, in relation to the six key areas and responsibility of local health boards, are also evidence of outcome indicators.

3.7.3 Evidence of implementation of the current strategies and delivery mechanisms

At a national level there have been two annual reports published (Welsh Government, 2014; 2015) and these considered the implementation of the current strategies and delivery mechanisms identified in the Welsh Government's key strategy document. Evidence is presented (labelled Assurance measures) from data that is routinely collected about: place of death; number of patients recorded on a PCR; number of people assessed within two days of referral to SPC; admissions to hospital; care home places etc. This data is used to provide evidence of implementation of the strategy in the key areas identified in the strategy, priorities are also outlined (see Table 8 for examples across the 6 delivery mechanisms). Nevertheless, not all data collected is purely focused upon patients with palliative care needs or who are at the end of life; so the data may not always provide evidence of outcomes relating to the strategy. For example, the data used to illustrate reducing the number of deaths within three days of an emergency admission is not compared against previous data but is used to highlight that two thirds of people dying within three days are aged 75 and over.

There is limited evidence of research, pilot work and evaluation of some of the delivery mechanisms across the themes. Public and patient surveys are used, such as, iWantGreatCare; during 2014/15 1824 reviews were submitted about palliative care teams and end of life services across Wales. The reviews were reported as overwhelmingly positive, and there had been an improvement in the results from the previous year. Research by Dying Matters had reported an increase in numbers of people who had completed wills. Data collected about CaNISC use - increase in completion of full assessment within three months. Betsi Cadwaladr University Health Board and the WN Primary Care Institute for Wales undertook a study to understand the experience of caring

for dying patients at home and explore aspects of a 'good death'. Another reported example is the evaluation of a nurse-led clinic based service in a GP practice. The Challenge Project aimed to work in partnership to improve and develop effective palliative and end of life care for people with Dementia, and their families. The project integrated the specialist knowledge and skills of staff at the Hospice of the Valleys in Blaenau Gwent with the knowledge and skills of the Alzheimer's society. Findings demonstrated that less than 10% of patients who died during the study period died in hospital.

Every Health Board in Wales was expected to develop their own Delivery Plan for the Welsh Government End of Life Strategy and this has been achieved. Each has now produced an annual report commenting on progress using the outcome indicators identified in the strategy.

Table 12. Wales: Examples of strategies and achievements by theme

Delivery Mechanism	Assurance Measures	Future Priorities
Supporting Living and Dying Well	Reducing total and emergency admissions in the final year of life. Emergency admissions in the last year of life had reduced. There had been a reduction of bed days by 42,000 from 2013 to 2014. There has been an increase in the number of patients referred to SPC who have an ACP in place in 2014 compared to the previous year.	Reducing unnecessary emergency and hospital admissions through effective advance care planning. Ensuring that people are better prepared for their deaths. Focus on primary care - priorities around end of life care
Detecting and Identifying Patients Early	There has been an increase in the number of patients recorded on a palliative care register, an increase of 15.7% since 2012-13. Reduction in response time for dysphagia assessment from 44.6 days to 22.3 days between February 2014 and February 2015.	More consistent early identification of patients who are probably in the last year of life, who may require palliative care support.
Delivering Fast and Effective Care	Implementation of a national programme of 7-day working by palliative care clinical nurse specialists. Access to care at weekends improved; support for general staff enhanced; rapid discharge of patients to die at home supported.	There has been an increase in the number of patients who are urgently referred to SPC not assessed within 2 days; this is expected to increase. The reasons for not seeing an urgent referral within 2 days needs to be recorded consistently. Ensuring there are sufficient nursing and care home places available to

		meet future needs for end of life care for an ageing population.
Reducing the Distress of Terminal Illness for Patients and Their Families	Increased use of the Welsh Integrated Care Priorities (WICP) guidance for care in the last days of life across all services throughout Wales. WICP has an inbuilt quality assurance and audit mechanism known as variance reporting	More validated evidence of hospice at home services.
Improving Information	A shadowing programme has been set up for the Specialist Registrars to develop their skills and experience in the field of young adult palliative care and transition to adult services.	To move towards electronic documentation across all settings
Targeting Research	From 2010 to March 2015 635 patients were recruited into NISCHR palliative care portfolio studies, including, pain and pain assessment, fatigue, breathlessness. There has been an annual increase in the number of patients recruited into Health and Care research Wales palliative care studies.	To increase support of organisations to facilitate independent participation in research.

There are further examples of activities that are considered to be strengths in the implementation of the recommendations put forward in 'Together for Health – Delivering End of Life Care':

- Pilot study with care homes across different health boards to encourage ACP for their residents - increased number of residents with ACP, slight rise in rate of people who died in their care home, hospital admissions avoided in some instances
- Enabling staff in a variety of settings to complete education and training relating to general and specialist palliative care, such as, distance learning modules
- Post of Clinical Lead for transition in palliative care - funded by One Wales palliative care fund
- Care transfer document and emergency care plans for young people, especially those in transition between services
- Virtual clinic for young adults using the internet
- GP facilitators working with Health Boards to encourage the registering of patients with a non-cancer diagnosis
- Improve connections with Black, Asian and Minority Ethnic (BAME) communities - a project set up by Marie Curie

- 'Just in case' boxes made available across Cwm Taf to ensure access to medication when needed for patients in the community. Controlled drug safe installed in acute hospitals
- Access to telephone lines coordinated by Nightingale House Hospice: palliative care consultant advice line and patient, relative, carers and health and social care professionals
- Completion of electronic patient assessment and admission documentation which is then printed and placed in patient notes for those teams unable to access the electronic system this ensuring continuity of care
- Web-based research governance toolkit developed by the Marie Curie Research Centre, Cardiff, to support independent hospices participation in research

3.7.4 Commissioning and Funding

In 2009 NHS Wales underwent major organisational change, removing the purchaser/provider split. Responsibility for commissioning of palliative care services, identified in the 2008 Sugar Report, had been with a variety of organisations, including Local Health Boards, NHS Trusts, Health Commission Wales. Following the restructuring, single Health Boards have been responsible for the planning and delivering all P&EoLC services within a geographical area. In terms of funding, the Sugar Report recommended that there should be substantial additional funding to achieve and sustain a minimum core service level. As with most nations, Wales has faced the challenges of continuing to improve the quality of health care, whilst trying to balance rising costs and demand. In this context the Welsh Government has taken on the principles of prudent healthcare in response to these challenges, with a specific focus on end of life care (Welsh Government 2016). In the latest annual report there was mention of the prudent healthcare approach to the planning and delivery of end of life care. In this document it was defined as 'taking a wise and considered approach to planning and delivering healthcare so it will be sustainable into the future'. This was underpinned by a set of principles which placed an emphasis on genuine co-production; making the most efficient use of skills and resources; reducing harm and ineffective interventions; taking a properly evidenced based approach. In particular, the Welsh Government, in collaboration with Marie Curie (Wynne 2014), has identified that:

'Taking a prudent healthcare approach as a way to ensure people who are approaching the end of their lives receive the best care and support possible will mean some significant changes:

- Changing professional and public perceptions of what the health service can provide and what treatments, such as palliative care, can achieve;

- Changing relationships so more people are supported to discuss how they wish to live their lives and decide on appropriate treatments as genuine partners in their care;
- Changing responsibilities, which will mean empowering communities to work together to improve their response to people who are dying and those who have been bereaved'.

3.8 What works well?

Results for Task 1.5: *In light of the evidence what aspects of policy, strategy and delivery mechanisms work well in relation to caring for terminally ill people within the UK and how could these be used across nations?*

As detailed in the earlier sections there are a huge number of policies that focus on caring for terminally ill people across and within the nations. Within the policy guidance there are a range of current strategies and delivery mechanisms that influence the delivery of terminal care. In light of this the review has attempted to consider what aspects of policy, strategy and delivery mechanisms may be useful in relation to caring for terminally ill people and sharing across nations. Nevertheless, it is important to note that there is variability regarding the nature of the evidence that is provided to determine the implementation of policy, strategy and delivery mechanisms in relation to caring for terminally ill people within the UK. To this end it makes it difficult to determine what works well across the nations.

What this scoping review can achieve in relation to this objective is:

- The mapping of core components within the strategies that all nations consider to be important in ensuring that high quality palliative and end of life care services are delivered to service users.

- The identification of key elements of delivery mechanisms, linked to the core components that contribute to the implementation of the strategies.

Across the four nations' policy documents these are the core components that emerge as being important in the care of terminally ill people:

- Raising awareness of death and dying

- Identification and assessment of service users, and their families, with palliative care needs

- Planning and delivery of fast and effective care to service users, and their families, in a variety of care settings

- Education of the public, service users and health and social care professionals, including workforce development

- Research and Audit

- Commissioning and funding

The similarities across the nations means that the content of the policies could be considered appropriate in terms of guiding approaches to terminal care. This communicates that all nations see terminal care as a priority.

3.8.1 Raising Awareness of Death and Dying

Within the four nations policy documents there has been an increasing emphasis on promoting the public health approach regarding the care of people with terminal illness, with a particular focus on raising the public's awareness of death, dying and bereavement. This includes recognising the role of the wider community in supporting people to live and die well. There are a number of reported initiatives that appear to be valuable in this context. England, Wales and Northern Ireland currently access the experiences of patients, and families, through a range of national survey data. The data from these surveys contribute to future service planning; identify gaps in current service delivery; contribute to policy development; as well as seeking a better understanding of the issues that matter most to people, and their families, who are living with a terminal illness.

All the nations reported the importance of providing appropriate and timely information to the public, patients, and their families, health and social care staff, commissioners and service planners surrounding, for example, care and treatment, clinical decision making, the health needs of a population, service delivery and promoting greater awareness and understanding of good end of life care. To this end all nations provide information in the form of palliative care service directories. The further development of information hubs could further contribute to the dissemination of information. In Scotland, for example, NHS Inform launched a Palliative Care Zone and there is the intention to establish connections between the Zone and local service directories and patient information as part of the Clinical Guidelines project.

3.8.2 Identification and assessment of service users, and their families, with palliative care needs

All nations are clear that the identification of patients with palliative care needs is crucial, and that this has to include patients: with a range of diagnoses, from differing age groups, from diverse cultural groups and in a range of care settings. Once a patient is identified this enables the assessment or review of a person's, and their family, palliative and end of life care needs which then influences the development of an individual care plan, depending on the stage in the patient's illness trajectory. All nations report using a Palliative Care Register to record those patients with identified palliative care needs; these are generally based on the Gold Standards Framework. Systems that assist health and social care practitioners not only in identifying patients but also developing personalised care plans are useful. An example of this is identifying complexity of patient need as identified in the Palliative Care Funding review. In Northern Ireland the ELCOS system is currently in use

providing a colour-coded system to assist practitioners in the development of an individual care plan for a patient, and their carer/family, depending on the stage in the patient journey. It strongly emphasises the need for effective communication and the provision of information for patients at all stages. RQIA found that the ELCOS model has been widely shared across Northern Ireland and has been very useful in designing information systems to support the delivery of high quality palliative and end of life care. It has been found to be a useful framework to underpin holistic assessment and is widely used in training initiatives.

3.8.3 Planning and delivery of fast and effective care to service users, and their families, in a variety of care settings

Enabling patients, and their families, to make decisions about their future care choices and preferences is a key component of all the nation's Palliative and End of Life Care Strategies. There are a number of initiatives across the nations that enable the recording of wants and wishes, advance decisions to refuse treatment, enduring power of attorney etc. These include: Your Life and Your Choices: Plan Ahead, Northern Ireland; My Thinking Ahead and Making Plans, Scotland; Preferred Priorities of Care, England. Within the context of ACP England, Scotland and Wales have published Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) guidance to inform clinicians, patients and their carers to support clinical decision making regarding DNACPR.

 What is also important in relation to Advance Care Planning is that patients receive the most appropriate response and care to meet their changing palliative and end of life care needs, whether that be the delivery of general palliative care across a range of settings, including care homes; access to specialist palliative care as an inpatient or at home; care in the last days of life; through to out of hours care. Of particular note within the nation's policy documents is the commonality of focus on transition of young people with life limiting illnesses to adult services, with the recognition that negotiating access to adult services is complex and that adult services need to extend their scope and remit to better meet the needs of young people and their families. A number of initiatives are noted across the nations that may be useful in this context: a transition pathway; emergency care plans for young adults; development of a transition team; Clinical Lead for Children and Young Person's Palliative Care.

Continuity of care delivery is also noted as an area of importance, particularly in relation to anticipating and meeting the needs and preferences of patients and their family outside of normal service delivery. There are a number of initiatives reported in the nations' documents that are reported as good practice. These include:

- A NIAS Out-of-Hours Palliative Care Referral Pathway to enable patients to be safely and appropriately treated in their preferred place of care, without the need to transport them to an emergency department (Northern Ireland).

- ACP Out of Hours Handover Form (Scotland)
- Telephone advice line (Wales)
- 'Just in case' boxes for anticipatory prescribing
- Establishment of Pharmacist Facilitators

3.8.4 Education and workforce development

Education and training of generalist and specialist palliative care staff across a range of settings is a key feature of all the nations' policy documents. It is recognised that all staff need to be equipped with the appropriate knowledge, skills and attitudes to be able to deliver high quality and appropriate palliative and end of life care consistently wherever the patient and their family require it. All the nations acknowledge the barriers to facilitating education and training, which include time, lack of resources and funding. There are a range of initiatives that are being adopted to address some of these challenges, for example, e-distance learning courses; developing modules to focus on specific contexts, such as care homes; facilitator liaison posts.

3.8.5 Research and Audit

All the nations' policy documents acknowledge the importance of developing sustainable and innovative programmes of palliative and end of life care research to inform policy and practice. There is emphasis on strengthening partnerships in order to facilitate research engagement and activity across regions, organisations and disciplines. There are a number of initiatives that may be of value to develop research capacity further, for example, development of research forums/networks; online research governance toolkit (this has been developed in Wales for hospices in order to minimise workload for hospices in hosting research and making information on research processes accessible for all).

3.8.6 Commissioning and Funding

The review has identified that all nations report mechanisms for commissioning and funding services. A range of additional funding sources are secured to support the delivery of high quality palliative care services to all those who require it. What would be useful is a consistent approach to the collection and sharing of data relating to the quality, volume and costs of providing care. Public Health England has made noteworthy developments in this area through their national End of Life Care Intelligence Network and it has been recognised that through collaborative working a minimum data set has been established that has the potential to assist with service design, delivery and evaluation as well as audit and research. There is the opportunity to use the data outputs to inform commissioning and service development, an example of this is the Interactive Atlas that has been created by Marie Curie, allowing access to local data and the opportunity to compare across localities and regions.

4.0 Discussion

Summary

- This review has examined the current policies, strategies and delivery mechanisms that underpin terminal illness care within the UK

- A range of terms are used to describe terminal illness care in policy documents. Also, the scope of policy documents is often ambiguous, ranging from strategy, guidance, best practice and discussion documents. Therefore, these issues have the potential to impact upon the implementation of these policies at a regional and local level within the nations

- The findings indicate there is a clear difference across the nations in terms of the numbers of government policy documents. England has the most policy documents; Wales the least.

- Where there are a larger number of documents, particularly the case in England and to some extent Scotland, it could be suggested that the sheer number of documents, and the excess of information, makes it difficult for those commissioning and providing services to digest and implement some of this information.

- All nations regard terminal illness care as a relatively high priority since all have responded with policy recommendations and directives and have produced policy documents to that end.

- There is clear evidence across the nations that government policy has been interpreted and translated into administrative directives through the form of action plans, recommendations and outcome measures. Where clear directives are given by national government to regional entities this appears to maintain the focus on delivery mechanisms, such as Wales.

- All nations report substantial progress in the implementation of the strategies. Whilst there is some evidence of pilot/evaluative work relating to the strategies and delivery mechanisms, generally objective measurement of policy implementation is limited.

- There is some evidence that outcome measures are used to appraise the implementation, however use varies across the nations and it most cases such outcome measures are still being developed.

- The nations policy documents identify examples of best practice that evaluate

well, including, the use of Palliative Care Registers, Advance Care Planning tools.

- **The funding of terminal illness care is not clearly reported nor is it clearly defined within policy and recommendations.**

The aim of this review was to determine and examine the current policies, strategies, and delivery mechanisms that underpin terminal illness care within the UK. This is the first review to examine the policies that influence the care of people with a terminal illness across the four nations of England, Northern Ireland, Scotland and Wales. A number of key questions have been answered, with evidence provided, in order to facilitate a better understanding of the drivers for terminal illness care within and across the nations, and how these are being enacted. Future recommendations will be made relating to future policy and research.

4.1 Current policies that impact upon terminal illness in the four nations

Before discussing the current policies that impact upon terminal illness across the UK it is important to consider a number of issues that emerged during the review process. First, as highlighted in the methods section, there are a range of terms used to describe terminal illness care in policy documents. For example, 'palliative care', 'living and dying', 'end of life care' and 'supportive care'. These are subtly different concepts that determine how care is operationalised.

Second, during initial scoping it became apparent that there were a number of interchangeable terms used in relation to the nation's government terminal illness policy documents, such as: strategy, guidance, guidelines, review, best practice. This raised questions about the purpose and nature of the policy documents in terminal illness. Furthermore, within some of these documents combinations of the aforementioned terms were used and in some instances this made it difficult to distinguish between documents and determine the unique aims and objectives of each one. Where policy formation is seen as a top-down approach by government (e.g. Buse *et al* 2012) seeking to guide practice, establishing clear and logically consistent objectives is important. As a result of the inconsistency and lack of clarity of the nature of some of the documents relating to terminal illness care, this could impact upon the implementation of these policies at a regional and local level within the nations (Walt *et al*, 2008). Sources of access to policy documents also varied and the array of available platforms complicates retrieval of information.

Third, the review process highlighted that 'health policy' literature relating to terminal illness is widespread and does not just consist of top-down papers produced by the four nations' governments or associated health agencies. Although it was not possible within

the remit of this scoping review to scrutinise all the policy literature that impacts on terminal illness care within the UK, we were able to consider the relationship between it. As we have illustrated in our typology of literature in terminal illness care, there is a range of literature that is often labelled as policy that may impact upon the nations' government policy documents. This is produced by 'bottom-up' publishers such as, voluntary sector organisations, patient groups, royal colleges, professional associations and others, with the intention of contributing to and shaping policy and practice for terminally ill people (Bull *et al* 2014). Within the nations' policy documents reference is made to voluntary organisation literature.

This report has provided a descriptive classification of government policy documents that impact upon terminal care across the four nations. We have focused our analysis on the Level 1 policy documents, but it is important to note that there is clearly a relationship between the Level 1 and Level 2 government documents. For example, where there is evidence of disease specific policies, such as respiratory illness or dementia, there is an expectation that the Level 1 policies provide the detail regarding terminal illness care. Therefore, the policy documents across the differing levels need to be considered and implemented jointly. Moreover, approaches to provision of health and social care are different across the nations and this is reflected in wider policy documents, for example, whether purchasing and provision of services are split.

All of the nations have developed End of Life Care Strategies. These documents are broad policies that enunciate government-wide directions, all of them detailing a vision and plan for raising awareness of death and dying within society and the delivery of high quality care to people with a terminal illness. Whilst some of the nations have clear and current end of life care strategies (England, Scotland, Wales), it is fair to say that despite an ongoing strategic programme of work to implement end of life care priorities, there is limited evidence of a current and overarching end of life care strategy in Northern Ireland. In the case of England and Scotland, two strategy documents have been published; here the second document builds upon and develops the vision for terminal illness care identified in the initial strategy. Under the umbrella of these strategies more specific policy has been developed which focuses on a variety of subject matter, including additional policy levers, such as, context of care; commissioning and funding; specific care practices.

The findings indicate there is a clear difference across the nations in terms of the numbers of government policy documents. Currently England has the most government policy documents (62%) (n=76), Northern Ireland (n=12) and Wales (n=9) the least. Nevertheless, England makes up 84% of the UK's population so perhaps we would expect a much larger number there. England has published numerous policy documents of differing types, including NICE, on a range of aspects that relate to terminal illness care, including reviews of current policies by organisations commissioned by the government. On closer scrutiny

where there are a larger number of documents, particularly the case in England and to some extent Scotland, it could be suggested that the sheer number of documents, and the excess of information, makes it difficult for those commissioning and providing services to digest some of this information. Whilst these policies may be of interest and may endorses the vision and levers relating to terminal illness care the volume of publications may mean that they do not always attract sustained attention of managers or those who provide the services. Also, over time in the context of multiple policy documents it becomes difficult to identify what has been removed, and what is continuous. What is clear is that the nation's terminal illness care policy environment is becoming increasingly complex in terms of inter-organisational, cross-border and network relationships, as well as being influenced by global decisions and domestic action. There is an attempt for policy making to expand networks in terminal illness care, for example, taking into account people's experiences, values and beliefs and expanding networks.

This has implications for policy interpretation and implementation (Powell *et al*, 2009) where it may become difficult to determine what aspect of policy is important/relevant. Where Level 2 documents are relevant this clearly increases the challenge. This is compounded by the wider literature that contributes to the development of policy as indicated in the aforementioned typology of literature. Thus overall there is the possibility that the impact of the documents and their message can become diluted. Furthermore, it could be suggested that the production of more policy directives does not guarantee or equate with the desired improvements in care for terminally ill people and their families (Powell *et al* 2009). Furthermore, many of these documents appear to restate or refashion what has gone before. This is particularly the case for England and to some extent Scotland. The smaller number of additional documents from Scotland, Wales and Northern Ireland in comparison to England may be the result of:

- Differences in population size
- Evidence-based guidance and other good quality evidence originating in England need not be repeated in the other nations but can simply be cited
- Later developmental stage due to later introduction date of the initial strategy
- Differences in national government structures

Across the nations it is clear that to some extent the policies are underpinned by evidence, for example, Cochrane reviews, voluntary sector service evaluation. They are also underpinned by concepts which direct the vision for terminal care illness. Some of these concepts are value-based and focus on the concepts of the public health approach to living and dying, and the 'good death'; these are considered relevant approaches in the context of terminal illness care. Other concepts reflect the changes to the social, political and economic landscape, for example, in England's latest strategy document the approach to terminal care is based on the House of Care model (Coulter *et al*, 2013; NHS England, 2016b). This is a conceptual model setting out a vision for long term conditions care which

may or may not be appropriate for the delivery of care to terminally ill people. It is unclear at this point how useful such conceptual approaches are to guide the delivery of care to terminally ill people.

Closer scrutiny of the documents across the nations also revealed that there is not always clarity regarding the population to which the recommendations relate. Although policy documents are in the process of being developed for children and young people and improvements are being made in relation to adaptations of services for different population groups (based on epidemiological, social and cultural need), largely generic approaches to interventions are evident. Even though evidence suggests that bespoke approaches may be more beneficial than the 'one-size-fits-all' approach typically taken in the policy documents.

4.2 Level of priority given to the care of terminally ill people across nations

What has emerged from this review is the lack of clear and consistent metric applied across the nations assessing the investment or spending on terminal illness care. A metric regarding the 'level' of priority is not available and is not published by UK nations. Nevertheless, it is clear that all nations regard terminal illness care as a relatively high priority since all have responded with policy recommendations and directives and have produced policy documents to that end.

A metric which would enable comparison of the level of priority which is given to terminal illness across the four nations could be based on one or more factors which are considered relevant. These could include for example:

- Annual spending
  - per capita spend on 'terminal illness care' (or its synonyms) calculated in a similar way for each nation
  - proportion of overall health spending, or health and social care spending
  - proportion of overall government spending
- Quantitative and qualitative measures of current policy literature
  - number of documents published in a given timeframe
  - aggregate number of pages published in a given timeframe
  - numbers of citations of high quality evidence (e.g. good quality systematic reviews)
- Process factors
  - stakeholder engagement
  - explicit process
  - information management
  - consideration of context and values
  - revision mechanism

- Outcomes
  - stakeholder understanding
  - shifted priorities/reallocation of resources
  - improved decision-making quality
  - stakeholder acceptance and satisfaction

4.3 Strategies, delivery mechanisms that influence terminal illness care across the nations

Translating policy into practice can be challenging. This review has highlighted that England, Northern Ireland, Scotland and Wales have based their strategies for terminal illness care on characteristics of the local population; the likely incidence of people with terminal illness; funding availability; local resources and local variations in service delivery. These provide an important backdrop when considering the development of delivery mechanisms for policy implementation. Overall, there is clear evidence across the nations that government policy has been interpreted and translated into administrative directives through the form of action plans, recommendations and outcome measures. Furthermore, a range of appropriate administrative groups and methods are established to coordinate, communicate and deliver the strategies' directives across the nations. The delivery mechanisms also include a range of relevant, identified services that contribute to the meeting of the needs of terminally ill people, including service delivery to patients and their families, education, service improvement and research. On further scrutiny, where clear directives are given to by national government to regional entities this appears to maintain the focus on delivery mechanisms, for example, Wales. Structural changes to the wider organisation of health and social care services and provision may pose additional challenges to the delivery mechanisms that influence terminal illness care.

4.4 Evidence of implementation of the strategies and delivery mechanisms that influence terminal illness care across the nations

It has been suggested that effective interventions are one thing, but effective implementation of interventions across health services are quite another (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). Indeed, it is clear that developing evidence based practice (EBP) in health settings is fundamental and that implementing services and interventions without a clear framework and theoretical underpinning makes interpretation of what works and why extremely difficult (Nilsen, 2015). Evidence suggests that the period from the exploration to full implementation phase is 2-4 years (Fixsen *et al*, 2005) and as a result policies and recommendations for services such as palliative care are unlikely to be embedded fully within the first three years post publication.

It is important to recognise that a changing political and socio-economic landscape, and a changing interface between national and local government, influences the implementation of terminal illness care policy across the nations of the UK. Therefore, there are challenges

in demonstrating policy implementation in relation to terminal illness care and as already noted; there is a lack of detail in regards to how implementation of guidelines and policy has taken place. This scoping review brings some clarity to the evidence of policy implementation across the four nations although due to the cyclical nature of implementation of these strategies (often taking 2-4 years), it can only offer a snapshot of the current position.

In relation to implementation all nations identified the infrastructure and subsequent delivery mechanisms in terms of who would be responsible for implementation, such as government, health boards, health trusts, working groups, interagency partnership, employment of lead posts etc. Furthermore, all nations report substantial progress in the implementation of the strategies; this is demonstrated through national and regional annual reports/discussion documents where evidence of best practice and pilot/evaluative work is detailed. Nevertheless, whilst there is some evidence of pilot/evaluative work relating to the strategies and delivery mechanisms, this is limited and evidence of policy implementation is generally supported by local self-report mechanisms from Health Boards, or equivalent, and review of documentation. Moreover, the delivery mechanisms are not consistently linked to the outcome measures identified in the key strategy documents. Therefore, robustness of implementation has to be considered in light of a limited evidence base. Evidence of national reporting is not always easily accessible or clear. In the absence of a national annual report it is not clear where to search for recent evidence of implementation. For example, in England and Scotland national reports are replaced by other government and non-government documents.

There is some evidence that outcome measures are used to appraise the implementation of the strategies. Nevertheless, there is some variation of outcome measures used and it is fair to say that across all the nations these are still being developed. For example, Wales provides discrete outcome measures which can be measured (% of people who die intestate; % of people who die in usual place of care). Nevertheless, it is not always clear whether these are sensitive enough to capture the overall aims of the strategy. Northern Ireland clearly has the least evidence in terms of outcome measures although it is unclear whether there is a causal relationship between the evidence of policy implementation through the use of outcome measures and improvements in care for terminally ill patients. This is a challenge for policy makers, and there is recognition across the nations that the collection of necessary national data to drive terminal illness care is complex. Furthermore, capacity to sustain ongoing audit and data availability is an issue.

4.5 Aspects of policy, strategy and delivery mechanisms that work well in relation to caring for terminally ill people across the nations

The findings have highlighted the diversity of evidence concerning implementation of policy, strategy and delivery in relation to caring for terminally ill people within the UK. The

subjective rather than objective nature of this evidence causes difficulty when attempting to determine what works well across the four nations. Nevertheless, it is clear that all nations identify core components that are important in ensuring that high quality palliative and end of life care services are delivered to service users. For example, the evidence assessed in this review highlights common practices and aspiration including the move toward consistent use of Palliative Care Registers across nations.

Furthermore, key elements of delivery mechanisms, linked to the core components that contribute to the implementation of the strategies, are identified. For example, very specific guidance appears to be easier to follow, such as 'Care in the last few days of life'; 'Palliative care indicators'; DNACPR. Also, where regional entities are charged with responding to Government policy and providing evidence of implementation, there may be clearer lines of responsibility. For example, in each CCG in England there is to be a lead person chosen locally.

In relation to what works well, the policy documents do identify what are examples of best practice that evaluate well. Nevertheless, few, if any, service evaluations consider the impact of EoLC in public health terms and little account is taken of the accessibility of the service in relation to the general population.

Finally, the funding of terminal illness care is not clearly reported, and nor is it clearly defined, within policy and recommendations. There appears to be a lack of clarity when defining the resources and budgets that should be provided to support EoLC. There is an expectation that the costs will be considered separately although in reality the budgets are subsumed within general care as opposed to identifying budgets for specialist palliative care.

5.0 Conclusion

The nations' policy documents are key drivers for commissioning, planning and delivering palliative and end of life care services to people with a terminal illness. To this end they need to be clear and focused.

Policy directives need to be translated into clinical practice and therefore the implementation of the strategies needs to be monitored to ensure this is happening as intended. There is reported evidence that each nation has developed delivery mechanisms that appear to enable services to be delivered to patients, and their families, with palliative care needs. On this basis it is clear that all the nations' policies have been implemented to a certain extent and this has been achieved through effective partnership working across a range of organizations and personnel. But there needs to be more effective monitoring of implementation. This could be achieved by continuing to embed indicators in routine clinical practice at local, regional and national levels and of course would be clearly linked to existing national indicators.

There is clearly a lag time between the publication of policy, guidelines and recommendations and the full implementation of these principles into practice. It cannot be assumed that all EoLC services and provision are working to the most recent policy. Moreover, the quality and consistency of implementation is perhaps one of the most important factors regarding the quality of EoLC. In regards to future provision, high quality design and implementation is required to ensure that consistency occurs across the four nations with clear measurable milestones and metrics to ensure quality monitoring and evaluation can occur.

Future research is required to assess the extent to which EoLC services are being delivered as intended or proposed by policy across the four nations. The variety of depth and style of policy and recommendations cited in this report suggest a lack of congruence between nations and even regions within these regions and in-depth cross-sectional research could elicit greater understanding of how these policies have been implemented. Research could include stakeholder interviews and surveys as well as full service evaluations with agreed metrics. Other analyses could be employed to include cohort tracking and service user and carer reviews.

There does not always appear to be congruence between EoLC provision, the policy that underpinned these and the evidence that informed the policy. Evidence based practice (EBP) is clearly becoming fundamental to service design and delivery and this review has illustrated a lack of cohesion between empirical evidence and the resultant service. This science to service gap is a facet of implementation science that has been highlighted as a potential addition throughout this review and something that would enhance EoLC across the four nations. Those commissioning services should ensure that services clearly design

and deliver those services as intended and have an appropriate framework to monitor and evaluate the efficacy and quality of care across all nations.

6.0 Glossary of terms and definitions

APC - Advanced Care Planning

BHF - British Heart Foundation

BMA - British Medical Association

CHSCR - The Centre for Health and Social Care Research (SHU)

COPD - Coronary Obstructive Pulmonary Disease

DoH - Department of Health

ECHO - Extension for Community Health Outcomes

ECR - Electronic Care Record

ELCOS - End of Life Operational System

EOL - End of Life

ePACC - Electronic Palliative Care Coordination Systems

e-NISAT - Northern Ireland Single Assessment Tool
(NISAT)

GMC - General Medical Council

HCPC - Health and Care Professions Council

HSC - Health and Social Care Board (Northern Ireland)

KIS - Key Information Summary

LPCAT - Lanarkshire Palliative Care Assessment Tool

LTC - Long Term Condition

MND - Motor Neurone Disease

NCPC - National Council for Palliative Care

NHS - National Health Service

NIAS - Northern Ireland Ambulance Service

NICE - National Institute for Health and Care Excellence (formerly National Institute for
Health and Clinical Excellence)

NISCHR - National Institute for Social Care and Health Research

NPF - National Performance Framework

P&EoLC - Palliative and End of Life Care

PC - Palliative Care

QOF - Quality Outcomes Framework

RCT - Randomised Control Trial

RoR - Review of Reviews

RQIA - The Regulation and Quality Improvement Authority

SHU - Sheffield Hallam University

SLWG - Short Life Working Group

SPC - Specialist Palliative Care

SR - Systematic Review

WHO - World Health Organisation

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8.0 Project team

Dr Jeff Breckon is the Director of the Centre for Health and Social Care Research (CHSCR) and is a BPS Chartered Sport and Exercise Psychologist. He has published and presented internationally a number of high quality reviews ranging from systematic, reviews of reviews and scoping reviews using both quantitative and qualitative methods. Commissioned projects have included evidence reviews for Public Health England, the NHS executive and the MS Society. Dr Breckon will oversee the project and support the development of the review process and write up phase of the final report.

Professor Bill Noble was a GP and hospice doctor for 16 years before specialising in Palliative Medicine in 1996. He is Editor-in-Chief of BMJ Supportive & Palliative Care and was appointed Executive Medical Director of Marie Curie Cancer Care in July 2013, where he is responsible for clinical governance, research strategy and service design. He continues to practice palliative medicine in Sheffield, and in 2015 was appointed Honorary Professor of Community Palliative Care at Sheffield Hallam University.

Dr Julie Skilbeck is a Senior Lecturer in Nursing and has clinical, educational and research expertise in palliative and end of life care. Her current research focuses on frailty in later life. Julie has substantial experience of completing a range of palliative and end of life care studies, which have been published and presented both nationally and internationally. Dr Skilbeck will provide expertise in relation to the reviewing of clinical interventions evidence and an in-depth perspective of the impact of national guidelines toward palliative care.

Dr Richard Stevens is a Researcher experienced in palliative and end of life care, public health and the built environment and trained in information science, politics and sociology. He has expertise in systematic literature reviews, project management, developing online information services, questionnaire design, qualitative interviews and report-writing.

Melanie Gee is an Information Scientist, with 18 years' experience of literature searching in the fields of science and technology, health and social care, in both published and grey literature. She has designed and executed literature searches for a number of research projects including rapid reviews, critical reviews, systematic reviews and realist syntheses. Melanie will work with Richard Stevens and Deborah Harrop to carry out the literature scoping, synthesis and interpretation in line with the agreed methodology.

Deborah Harrop is an Information Scientist with over ten years' experience in the higher education library and information sector in the health, social care and bioscience subject area. She is an expert on literature review methods and at managing the literature review process for funded projects and/or for publication. She is skilled in designing and undertaking complex multi-faceted literature searches as well as reference, citation and author searches, and bibliometric activities. Deborah also collates and screens bibliographic data and undertakes data extraction and synthesis, and often assumes overall

responsibility for producing the literature review. Deborah will work with Richard Stevens and Melanie Gee to carry out the literature scoping, synthesis and interpretation in line with the agreed methodology.

9.0 Appendices

9.1 Search strategy

The searches have been written up for MEDLINE using the EBSCO interface and are detailed below.

Explanation of search terms used: ti = title field; ab = abstract field; af = author affiliation field; asterisk (*) denotes any character; "" = phrase search; N = proximity operator.

1. "terminal care".ti,ab
2. "terminal illness".ti,ab
3. "end of life".ti,ab
4. palliat*,ti,ab
5. "supportive care".ti,ab
6. "living and dying".ti,ab
7. "death and dying".ti,ab
8. hospice*.ti,ab
9. terminal care/
10. palliative care/
11. palliative medicine/
12. hospice care/
13. hospice and palliative care nursing/
14. hospices/
15. OR/1-14
16. terminal.ti,ab
17. dying.ti,ab
18. OR/3-4,8,16-17
19. care.ti,ab
20. caring.ti,ab
21. ill*.ti,ab
22. OR/19-21
23. 18 AND 22
24. 15 OR 23

25. policy.ti,ab
26. policies.ti,ab
27. strategy.ti,ab
28. strategies.ti,ab
29. service* N3 delivery.ti,ab
30. "delivery mechanism*".ti,ab

31. SDO.ti,ab
32. guidance.ti,ab
33. guideline*.ti,ab
34. "best practice".ti,ab
35. recommendation*.ti,ab
36. directive*.ti,ab
37. implementation.ti,ab
38. policy/
39. guidelines as topic/
40. practice guidelines as topic
41. health planning guidelines/
42. OR/25-41

43. england.ti,ab,af
44. "northern ireland".ti,ab,af
45. scotland.ti,ab,af
46. wales.ti,ab,af
47. britain.ti,ab,af
48. "british isles".ti,ab,af
49. uk.ti,ab,af
50. "united kingdom".ti,ab,af
51. england/
52. northern ireland/
53. scotland/
54. wales/
55. great britiain/
56. channel islands/
57. OR/43-56

58. 24 AND 42 AND 57
59. 24 AND 42 AND 57 reviews only
60. 24 AND 42 AND 57 reviews only, 20040101-20160331

9.2 Exclusion criteria

1. Relevance

Exclude where the general topic of a document cannot be located comfortably under the broad heading of terminal illness or End of Life Care or palliative and supportive care or hospice care. For example, where symptom palliation refers only to a small part of an intervention or is not necessarily concerned with terminal care at all.

2. 'Policy document' status

Exclude where a publication cannot easily be considered a 'policy document' or having the potential to be considered as such. Where a document represents the 'best evidence' on a given intervention it could inform a policy paper on that topic, but in this review was not considered a policy paper in itself. There are many such documents, so to define all of them as 'policy documents' was beyond the scope of this study.

For this review authorship is a key factor in whether a paper can be considered a policy document. 'Who writes policy?' is a contentious issue, but documents have been excluded where the author(s) cannot be assigned to one of the following categories.

A. **Government body**

Government agency or health or social care service or any government-sponsored body which has powers over any part of the UK (e.g. Dept of Health, NHS, NICE, Scottish Govt, Welsh Assembly, local health boards, local authorities, European Union).

OR

B. **Relevant professional group**

Relevant health or social care professional organisation (e.g. BMA, APM, royal colleges) or significant groupings of senior health or social care personnel or other experts brought together to create policy.

Papers which meet criterion from points 1, 3 4 and 5, but are not considered a policy document will be classified in accordance with the 'policy pyramid' shown in Figure 2.

3. Study quality

If the document is not authored or published by a 'policymaker' (i.e. not NICE/Dept of Health/Scottish Government/BMA or a similar significant organisation) then it must be good quality evidence in order to be considered a potential 'policy document' on a given topic. Conversely, a short comment document by a known policymaker could be included, though ostensibly it is a low quality paper.

4. Nation addressed

The document must relate to either England or Scotland or Wales or Northern Ireland, or to some combination of two or more of those, or to the UK as a whole. Documents about other nations, or those which are mainly international in scope, may be useful for background discussions, but should be excluded here unless there is a clear impact on the UK or a constituent nation.

5. Publication date

Literature published before 2004 is excluded as this was the date the NICE Guidance on Palliative and Supportive Care in Cancer was published.

9.3 Examples of Level 2, 3 and 4 documents

Examples of Level 2 documents

NHS England (2016). NHS mandate 2016-17
https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017

Department of Health (2008). Better care: better lives. London, Great Britain. Department of Health.

Department of Health (2011). Better care at home and in care homes: contract inserts. London, Great Britain. Department of Health.

Department of Health (2011). Case for change: community-based services for people living with dementia: evidence. London, Great Britain. Department of Health.

Department of Health (2015). Department of Health guidance: response to the Supreme Court Judgment/Deprivation of Liberty Safeguards. London, Great Britain. Department of Health.

Department of Health (2005) National Service Framework for Long-term Conditions. Stationery Office, London.

Department of Health (2009) Living well with Dementia: A National Dementia Strategy. Stationery Office, London.

Examples of Level 3 documents

Addicott, R and Ross, S. (2010). *Implementing the end of life care strategy: Lessons for good practice*. London: King's Fund.

Age UK. (2014). Living life with dementia: Local age UK contributions to quality outcomes for people living with dementia and their carers. London: Age UK.

Calanzani, N., Koffman, J and Higginson, I.J. (2013). Palliative and end of life care for black, asian and ethnic minority groups in the UK: Demographic profile and the current state of palliative and end of life care provision. London: Marie Curie Cancer Care.

Examples of Level 4 documents

Hall, S., Kolliakou, A., Petkova, H., Froggatt, K. & Higginson, I. J. (2011). Interventions for improving palliative care for older people living in nursing care homes. Cochrane Database of Systematic Reviews, (3), CD007132.

Sallnow, L., Richardson, H., Murray, S. A. & Kellehear, A. (2015). The impact of a new public health approach to end-of-life care: A systematic review. Palliative Medicine, *30*(3), pp.200-211.

Stone, K., Papadopoulos, I. & Kelly, D. (2012). Establishing hospice care for prison populations: An integrative review assessing the UK and USA perspective. *Palliative Medicine, 26*(8), pp.969-978.

UK = England, Scotland, Wales, and Northern Ireland (and the full name is the "United Kingdom of Great Britain and Northern Ireland"). England = Just the part of the island that is England. God Save the Queen! The British Islands is a legal term, meaning those parts of the British Isles which are a part of the United Kingdom or the Crown Dependencies (i.e. the British Isles minus the Republic of Ireland). These errors only affect areas within Scotland; population estimates for England, Wales and Northern Ireland are unaffected. Whilst the estimated age distribution of the UK population is affected for the period, the total estimates of the UK population remain valid. Further information on the causes of the errors, their impact and how decisions were reached on the approach taken is available in the Quality Management Information document available on the ONS website. Contact: Neil Park. Release date: 28 June 2018. Next release: June 2019. About this dataset. National and subnational mid-year p