

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

Executive Summary

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Executive summary

1.0 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' considered five key objectives.

1.1 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 included 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 Methods

The literature review process was carried out 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. 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 1.

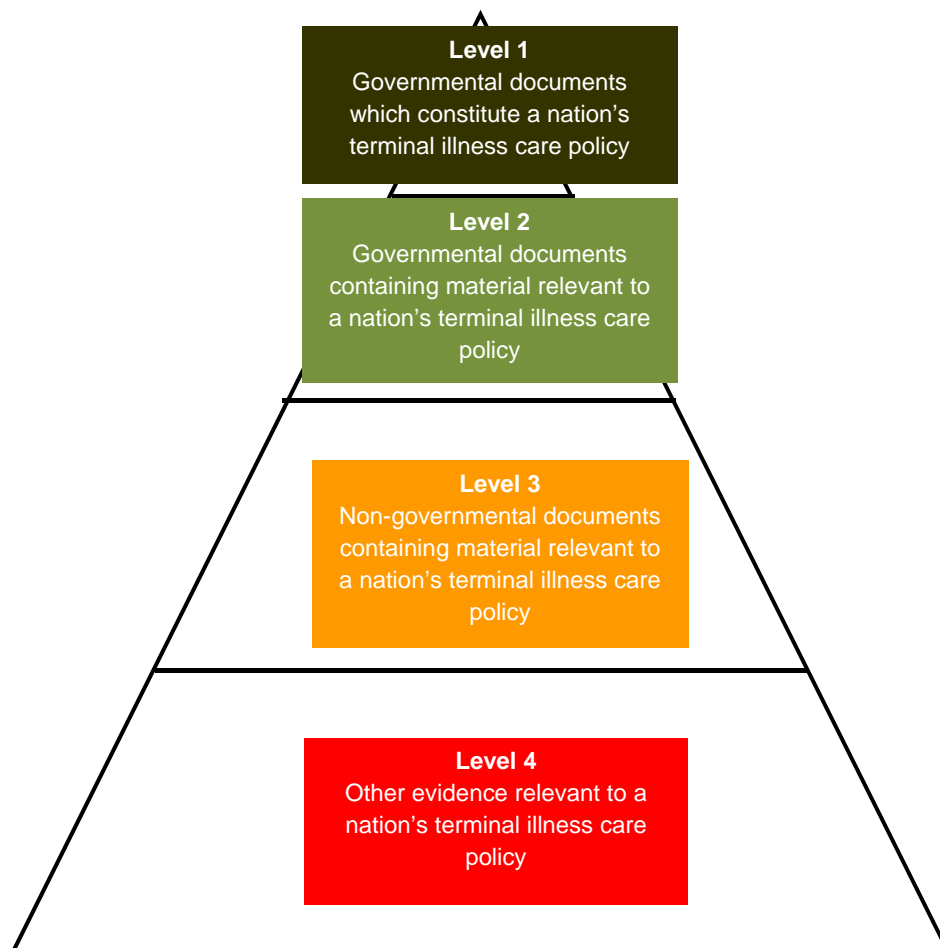


Figure 1: Diagram illustrating the typology of literature in terminal illness care policy for each nation

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.

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.

Using pre-defined inclusion and exclusion criteria, all literature was assessed for eligibility for inclusion in the review. All relevant documents were scrutinised by the review team and categorised as Level 1 to 4;

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

2.2 Methodology for classification of the policy 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.

2.3 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 2. 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).

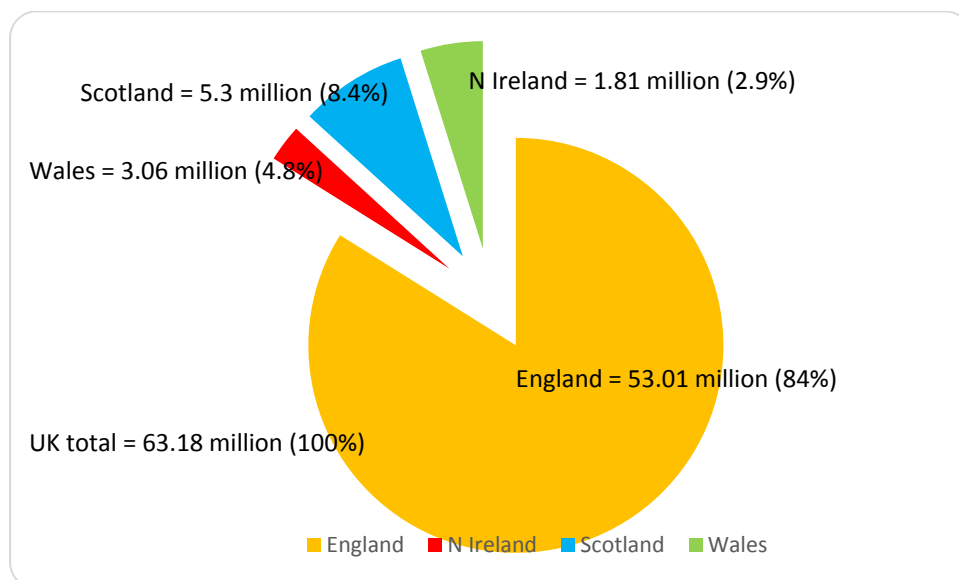


Figure 2: Breakdown of UK population by nation. Source: Office for National Statistics (2011).

3.0 Results

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

There appears to be a significant increase in policy documents and guidelines year on year from 2008 for all four UK nations. As Figure 3 (see below) and each of the results tables (2-5 in the full report) illustrate, there is an imbalance in the number of policies and strategies that influence terminal illness care across the four nations.

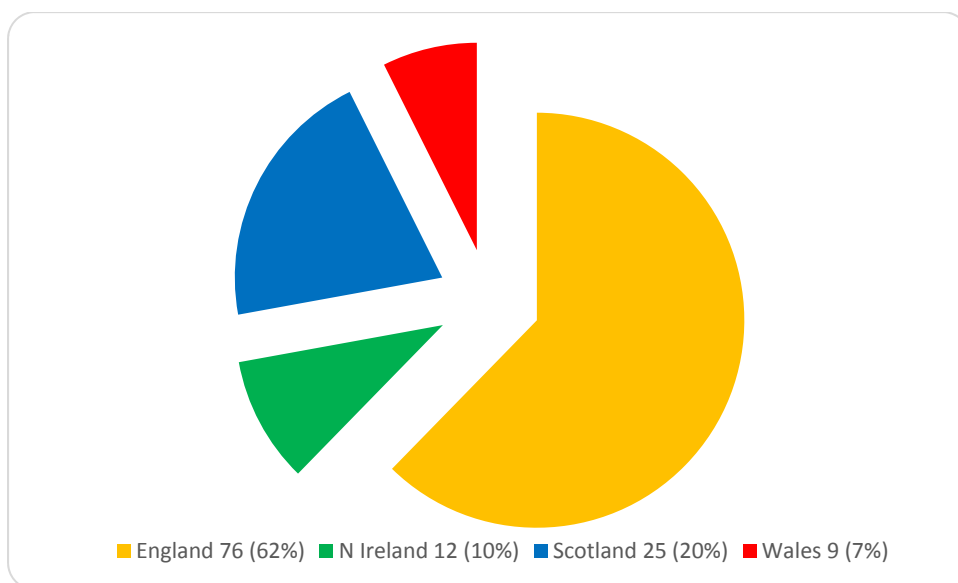


Figure 3: Comparison of total Level 1 documents by nation.

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. More recently, 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' was published. This has been considered a refreshment of the End of Life Care Strategy to align it with current needs of the population and the changing health and social care landscape"

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.

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).

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).

When a comparison is made of Level 1 documents per million population, England no longer seems to have a large amount of policy papers (see figure 4). Instead, by this

measure Northern Ireland and Scotland appear to have a larger number of documents relative to England.

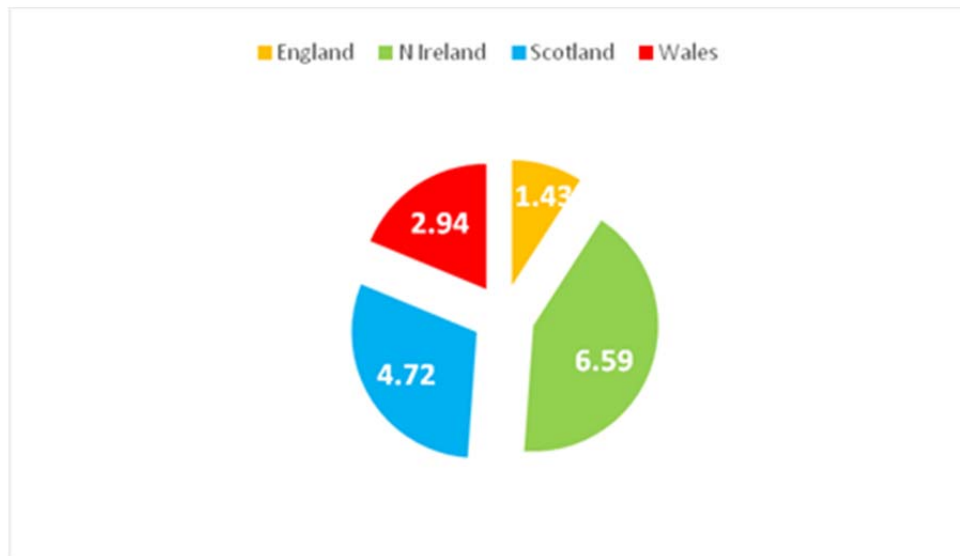


Figure 4: Comparison of terminal illness care policy documents per million population by nation

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

3.3.1 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.

3.3.2 Northern Ireland

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

3.3.3 Scotland

Scotland's terminal illness care policy is made up of a raft of 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.

3.3.4 Wales

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 care, 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.

3.4 What works well?

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 achieved 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 emerged 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 mean 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.

3.4.1 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 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.

3.4.2 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.

3.4.3 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.

3.4.4 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).

3.4.5 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 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 have been made relating to future policy and research.

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 summary, the key points that emerged include;

- 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 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.
- 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. However, a metric regarding the 'level' of priority is not available and is not published by UK nations.
- 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 in 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.

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.

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