ScotPHN report

Scottish Public Health Network (ScotPHN)

**Palliative and end of life care in Scotland:
The rationale for a public health approach**

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Foreword

A civilised society can be judged by how it treats its weakest members, including those who are dying. Of course in a naïve sense we are all dying from the time we are born; however the focus here should be on those who are approaching the end of their lives.

Very often, especially with prehistoric societies, historians assess the material culture of death and make inferences concerning funeral practice from what remains. Sometimes, where there are historical data, which can be used to piece together insights into the values and beliefs associated with death and dying, particularly what happens after a death has occurred. In this, much of the focus is on those who remain alive and need to understand what, if anything, happens beyond death. What is less common, is a sense of the way in which such societies cared for those who were dying.

For us, the issue of how we care for those who are reaching the end of their lives is the primary concern. The debate is less on the appropriateness of how a death is marked, but about how we help those dying to maintain their dignity and independence whilst providing effective and compassionate care. Like all the care which is provided within our society, it has to be planned for and resourced appropriately, it needs to put the wishes of the person dying at the centre of what is provided and it needs to recognise the importance of supporting family and friends through the processes of death and bereavement.

Death and dying has not for many years been a mainstream concern for public health in Scotland. The reasons for this are complex and need not concern us here. It has however become increasingly clear that there are important gaps in how society and services, including health and social care services, deal with death, dying and bereavement. Awareness has been growing that in a number of key areas, a focus on what has been termed a 'public health' approach to death and dying can help develop a broader and more transparent dialogue nationally, locally, within communities and families about death and dying and people's expectations of how that is to be managed.

This report has been developed to help colleagues in Public Health across Scotland reconnect with the population health aspects of palliative and end of life care. It is hoped it will help colleagues working with Integrated Adult Health and Social Care Boards to further develop end of life care services, whilst supporting and encouraging the development, implementation and evaluation of asset based approaches to death, dying and loss within local communities. It is also hoped that colleagues within hospitals, clinics, general practices and other NHS and healthcare facilities in Scotland will find this work helpful in the context of the recently published report by Scotland's Chief Medical Officer "Realistic Medicine".

I am most grateful to Michelle Gillies at ScotPHN, who has been the lead author for this report and to the project Steering Group for their essential contributions to the content and focus of the work. I am also particularly grateful to all the team at ScotPHN who have made sure that the overall development process ran smoothly.

I commend this report to you.

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Abbreviations and Acronyms

BAME	Black, Asian Minority Ethnic Groups
BAS	British Attitudes Survey
CHAS	Children's Hospice Association Scotland
CPP	Community planning partnerships
DNACPR	Do not attempt cardiopulmonary resuscitation
EAPC	European Association for Palliative Care
ePCS	Electronic Palliative Care Summary
GSF-PIG	Gold Standards Framework Prognostic Indicator Guidance
GLGDGG	Good Life, Good Death, Good Grief
GMC	General Medical Council
HLE	Healthy Life Expectancy
HPPC	Health Promoting Palliative Care
HNA	Health Needs Assessment
LE	Life Expectancy
LCP	Liverpool Care Pathway
MCN	Managed Clinical Network
NHS	National Health Service
PELC	Palliative and End of Life Care
PPD	Preferred place of death
PPC	Preferred place of care
PHE	Public Health England
SCDC	Scottish Community Development Council
ScotPHN	Scottish Public Health Network
SFA	Strategic Framework for Action
SPICT	Supportive and Palliative Care Indicators Tool
UK	United Kingdom
USA	United States of America
WHA	World Health Assembly
WHO	World Health Organisation

Glossary of Terms

Asset based approaches are concerned with facilitating people and communities to come together to achieve positive change using their own knowledge, skills and lived experience of the issues they encounter in their own lives.

Community development is a way of strengthening civil society by prioritising the actions of communities, and their perspectives in the development of social, economic and environmental policy.

Community engagement is developing and sustaining a working relationship between one or more public body and one or more community group, to help them both to understand and act on the needs or issues that the community experiences.

Co-production describes a relationship between service providers, service users and wider community resources that draws on their knowledge, ability and resources to develop solutions to issues that are claimed to be successful, sustainable and cost-effective, changing the balance of power from the professional towards the service user.

Dependency Ratio is the number of children aged under 16 and the number of people of state pension age per 100 people of working age. It is a ratio of the population that could be considered economically inactive to the population that could be considered economically active. The reality of course is much more complex and assumptions that all children and older people are not economically active whilst all people of working age are, may not hold. However it provides a useful, if not crude, summary measure to examine the relative age structure of the population.

End of life care is palliative care for people approaching the end of life, approximated to those that are likely to die within the next 12 months.

Generalist Palliative Care is an integral part of the routine care that is based on the understanding and practice of palliative care principles, delivered by all health and social care professionals to those living with a progressive and incurable disease in all care settings.

Hospice care is an approach to caring for people based on the principles and practice of palliative care.

Inequity is inequality between groups of people that is not justified by differences in preferences or need. In relation to care this may arise when there are unjust differences in access to, or quality of, care or where equal care is provided to people with different needs.

Integration Authorities The body that is responsible for planning integrated care, Integration Authorities decide which integrated adult health and social care services will

be provided, how they will be funded and what they should look like. Integration Authorities may direct the NHS Health Boards and Local Authorities to deliver those services. More information on the integration of adult health and social care services can be found [here](#).

Health inequalities are systematic differences in the health of people occupying unequal positions in society, most commonly in Scotland associated with socio-economic inequalities but also are a result of discrimination.

Healthy life expectancy (HLE) is an estimate of how many years a person might live in a 'healthy' state. This is a key summary measure of a population's health.

Knowledge exchange is a process that brings together academic staff, users of research and wider groups and communities to exchange ideas, evidence and expertise.

Life expectancy (LE) is an estimate of how many years a person might be expected to live.

Life-limiting conditions describe diseases with no reasonable hope of cure that will ultimately be fatal. More commonly in relation to babies, children and young people life-limiting conditions are termed life-shortening conditions.

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancer.

Need is defined as an ability to benefit from a service or intervention.

Palliative Care is 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. (Appendix 5)

Public Health is the science and art of promoting and protecting health and wellbeing, preventing ill-health and prolonging life through the organised efforts of society

Specialist Palliative Care is palliative care provided by specially trained multi-professional specialist palliative care teams, accessible in any care setting.

Executive Summary

As a society the value we place on life is reflected in the way that we care for our most vulnerable groups, the sick, elderly, frail and dying. In Scotland around 54,000 people die each year and 216,000 people are significantly affected by the loss of a loved one. Most people die following a period of long-term illness. They, and their carers, need practical support, compassionate care and thoughtful medical intervention to give quality and meaning to their life as their health declines.

Palliative and end of life care (PELC) has evolved from terminal care of people with cancer to an approach to providing holistic care to people with life-limiting illness and their carers across the life course. Changing population demographics and prevailing cultural attitudes to death, dying and loss present a specific challenge to meeting rising demand for PELC services at a time of resource constraint. Across Scotland many people with life-limiting illnesses and their families experience excellent PELC. However at population level inequities in access to and quality of PELC services exist and unmet need is high.

This report examines the rationale for applying a public health approach to PELC, exploring where and how public health approaches could be applied to support local service planning and delivery.

What we did
This work had five strands:
1. A literature review to identify current issues in PELC provision in Scotland.
2. A review of the legislative framework and policy context relevant to PELC provision in Scotland.
3. An exploration of available epidemiological data on socio-demographic and cultural influences on death, dying and loss in Scotland.
4. A national survey mapping the provision of specialist PELC in Scotland.
5. A literature review on public health approaches to PELC.

These strands were informed by interviews with a number of key informants and discussion with a range of stakeholders.

What we found
PELC as a public health issue
Death, dying and loss are universal experiences associated with significant burden and cost. PELC is a safe and effective way to reduce morbidity. The provision of high quality PELC is an ethical responsibility of health care systems. In Scotland, PELC provision is neither equitable nor sustainable. An inter-sectoral, interdisciplinary population level response is required to address this. PELC should be restored as an area for public health action.

Future population demographics driving demand for PELC
The population in Scotland is growing and ageing. The prevalence of multi-morbidity and frailty is rising. The availability of informal care is diminishing and demand for formal care rising. This takes place in the wider context of the integration of adult health and

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social care services, at a time of resource constraint, with a policy drive to delivering person centred care at home, or in a homely setting.

Estimating PELC need at population level
There are no reliable estimates at population level of PELC need in adults. Comparison of the number of people recorded on PELC registers in primary care in Scotland to population level estimates of need for end of life care based on death certification suggests that a large proportion of the population who have a PELC need are not formally identified, implying unmet need.

Recently published estimates derived from administrative data indicate that each year around 195 babies, children and young people with life-limiting conditions die in Scotland. Of the estimated 15,404 babies, children and young people living with a life-limiting condition in Scotland 2013-14, 1 in 7 were considered to be unstable, deteriorating or dying. A comparison of these estimates with activity from CHAS (the principle provider of specialist PELC to babies, children and young people) suggests significant unmet need.

Systemic inequities in access to and quality of PELC
There is evidence of inequities in access to and quality of PELC according to diagnosis (cancer *vs.* non-cancer), age, ethnicity and socioeconomic status. These have been widely recognised since the inception of the hospice movement and have persisted despite attempts to systematically and comprehensively address these through increasingly prescriptive national strategy and policy.

Definitional issues
Lack of a shared language and shared understanding of the scope and goals of PELC and lack of clarity around the roles and responsibilities of generalists and specialists is a significant barrier to the effective delivery of PELC services. This has been exacerbated by a lack of prospectively validated tools to identify and assess PELC need in different populations across the continuum of care.

Evidence base on the effectiveness and cost effectiveness of PELC
There is a consensus that specialist palliative care services are more effective and cost effective than conventional care. The evidence base around which models are effective and cost effective in different populations and different settings of care, is lacking. The evidence to support the adaptation of specific approaches developed for use in the specialist setting, for use in other settings by generalists, is sparse. There is very little evidence around how best to support carers.

Anticipatory and advance care planning
Anticipatory and advance care planning are important in establishing preferences and priorities for PELC. However there are barriers to health and social care professionals, people with life-limiting conditions and their carers communicating openly and honestly about death, dying and loss.
Preferred place of death

Achieving preferred place of death (PPD) has emerged as a major policy theme that is increasingly being used as a measure of the quality of PELC. At least half of all people that die in Scotland each year do so in hospital. There are no national data on PPD in Scotland. Data from a population-based study in England identified hospital as the least preferred PPD. If applicable to Scotland, these data suggest significant unmet need. PPD may change with imminence of death. Among bereaved relatives in England, while few people believed that their relative would have wanted to die in hospital, a majority felt that it was the right setting for them. To achieve the policy ambition of delivering care at home, or in a homely setting, alternate 'homely' settings for people who are not able, or do not want, to be cared for or die at home, particularly those with multi-morbidity and the elderly are required. PELC services need to be responsive to the changing preferences and priorities of people with life-limiting illness and their carers.

Health intelligence and data deficits
There is a paucity of robust, comprehensive and timely data on the provision, activity and quality of PELC at local and national levels to support the design, delivery and quality assurance of evidence based services to meet the preferences, priorities and needs of local populations and inform evidence based policy. Meaningful indicators, that can be embedded in clinical practice to monitor the provision, activity and quality of PELC at local and national levels to evaluate practice and policy and enable international comparisons are lacking. There is currently no national collection of data on the experience of PELC.

Social and cultural attitudes to death, dying and loss
While most of the general population have experience of death, dying and loss, cultural barriers to open discussions about these issues are pervasive and associated with avoidable harms. In theory, the public is becoming more comfortable talking about death, dying and loss although there is little evidence of this translating into concrete action. The media plays an important role in framing the public discourse on death, dying and loss.

Public health approaches to PELC: A health systems approach
Public health practice and tools can inform the design, implementation, delivery and evaluation of PELC interventions, services, programmes and policies at local, national and international level. Areas where public health tools and practice could be focused to contribute to the PELC agenda include: leadership and advocacy; strategy and policy; quality assurance, indicators and standard setting; health intelligence and data; academic research and development; and education and training.

Public health approaches to PELC: Health Promoting Palliative Care
Health Promoting Palliative Care (HPPC) is a theoretical approach to addressing the avoidable harms associated with a societal wide reluctance to openly discuss death, dying and loss. HPPC aligns the core principles of PELC with the key intentions of the Ottawa charter, framing death, dying and loss as a social experience that requires a social response. The academic theory of HPPC has been slow to translate into

evidence based practice. Nevertheless there is growing enthusiasm for the HPPC approach in the UK and internationally. To date, projects adopting this approach in the UK have undertaken a spectrum of activity from awareness raising, information provision and public education campaigns through to community engagement and community development. In Scotland this approach is being advanced through the 'Good Life Good Death Good Grief' Alliance (GLGDGG). A number of barriers to developing, implementing and evaluating HPPC approaches have been identified from the literature, including a changing strategic environment, professional attitudes, social taboos, concerns around trust and risk, lack of resource (including funding), lack of clarity around definitions of and approaches to HPPC, and limited opportunities for shared learning. There is a need and a desire to develop the evidence base around the HPPC model in social and political context of the UK in order to support individuals, communities and organisations developing, implementing and evaluating HPPC interventions and support the exchange of knowledge and best practice. The extension of community development models to inform the design, implementation and delivery of PELC services is currently aspirational in Scotland.

The role of health promotion specialists in PELC
In the context of a wider policy agenda toward early intervention and supported self-management there is scope to develop the role of health promotion specialists in PELC, adapting and applying core health promotion skills, attitudes and knowledge, to support the delivery of PELC and advance practice in this area.

The role of public health specialists in PELC
Public health approaches have the potential to inform complementary service based responses to meet PELC needs and societal responses to address the avoidable harms associated with a societal-wide lack of openness about death, dying and loss. Public health action is not the sole remit of public health specialists, however, with a core set of skills, knowledge and attitudes, public health specialists could make a valuable contribution to the work already underway in this area.

Developing sustainable solutions through co-production
The challenges facing newly integrating health and social care boards in delivering equitable sustainable PELC services to those with a capacity to benefit from them are complex. Through a shared understanding of the issues stakeholders can work together to develop sustainable solutions.

The Scottish Government's Strategic Framework for Action on Palliative and End of Life Care (SFA) was published on 18 December 2015 as this report was being prepared for publication. The SFA maps the future direction of PELC in Scotland. Encouragingly, the SFA recognised the importance of adopting a public health approach to PELC and the valuable contribution that the public health workforce could make to this agenda. This is a timely opportunity for the Scottish Directors of Public Health to ensure PELC is aligned with public health practice in Scotland.

National Recommendations

As a starting point a number of high-level, national recommendations have been made that could, through co-production between agencies and stakeholders, contribute to the work already underway in this area. Unless otherwise indicated we envisage the implementation of these recommendations being facilitated by the National Advisory Group for Palliative and End of Life Care:

1. Scottish Government should explicitly acknowledge that death is an inevitable, and normal, part of life in its strategic narrative.
2. Scottish Government should ensure that PELC is visible in relevant health and social care strategies and policies.
3. A strategic approach to framing a population debate on the issues around death, dying and loss is required; this should include engagement with the media. This debate should seek to promote more open and meaningful dialogue between the pubic and health and social care professionals, and endeavour to establish a clearer terminology that resonates with the public, and translates from policy into practice, of what PELC is and does.
4. All generalist and specialist health and social care professionals should be supported and empowered to provide high quality PELC care.
5. A PELC intelligence network should be established with a remit to collect, analyse, interpret and disseminate data and evidence relating to PELC need, provision, activity and outcomes in Scotland to support local Integration Authorities develop, implement and evaluate Strategic Commissioning Plans and drive quality improvement. This will require leadership from Scottish Government. Public health specialists should work with partners to support this agenda.
6. A strategic approach should be taken to develop a sustainable and innovative programme of PELC research that directly informs clinical practice, health and social care policy and reduces in inequalities in access to and quality of PELC[a]. Academic leadership and succession planning are required to develop the academic infrastructure across a range of specialities where PELC is of interest.
7. Structures that provide an open platform for stakeholders across Scotland to share emergent examples of good practice and experience of what works, for whom and why, facilitating knowledge exchange, informing evidence-based decision making and driving quality improvement in PELC should be maintained and supported to develop their role further[b]. This requires inter-sectoral capacity and commitment.
8. There is a need to develop HPPC approaches, such as those undertaken by members of the GLGDGG alliance, in Scotland. Formal evaluation of HPPC initiatives should be encouraged and supported to build the evidence base relating to this area. Public Health specialists can contribute to this agenda.

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[a] The Scottish Research Forum, established following the recent publication of the Scottish Government's 'Strategic Framework for Action on Palliative and End of Life' has the potential to make a significant contribution to this area.

[b] Examples include local palliative and end of life care networks, existing national structure such as the Scottish Partnership for Palliative Care and emergent national structures such as the newly established Scottish Research Forum.

9. The GLDGGG alliance provide practical resources to enable local communities to develop, implement and evaluate local HPPC initiatives; through co-production, these resources should be further developed to meet the emergent needs of local communities adopting HPPC approaches. Learning from asset-based approaches in other fields has the potential to inform and enhance the development of HPPC approaches in Scotland[c].

10. Indicators that can be embedded in routine clinical practice and at local, national and international level to support service design, delivery, monitoring, quality improvement and benchmarking are required. These should be aligned with existing national outcomes. Indictors should be produced through co-production with stakeholders. Public health specialists should support this agenda.

11. Consideration should be given to undertaking a national study of bereaved peoples' views on the quality of care provided to their loved one in Scotland.

12. Workforce planning and development should be considered at a national level but also addressed in local Strategic Commissioning Plans.

Recommendations for Public Health
In addition to the areas of public health support identified in the national recommendations, the Scottish Directors of Public Health and all public health specialists should:

13. renew their interest in PELC as a public health issue.

14. explore how best to develop the existing roles of health promotion specialists in PELC.

15. explore how best to encourage and support the development, implementation and evaluation of HPPC initiatives by local communities.

16. advocate for PELC to be located within the wider framework of actions to address inequalities.

17. provide leadership and strategic support to Integration Authorities and community planning partnerships in planning, delivering and continuously improving PELC services.

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[c] Existing structures such as The Scottish Co-Production Network and The Scottish Community Development Centre provide a range of generic and field specific co-production and asset-based resources as well as a platform to support knowledge exchange.

Introduction

Death, dying and loss affect us all. In Scotland around 54,000 people die each year[1] and 216,000 people are significantly affected by bereavement[2]. It is estimated that 69-82% of people who die each year will need support to maintain their wellbeing as their health declines[3]. Palliative and end of life care (PELC) is an approach to providing holistic care to improve quality of life for people with life-limiting illness and their carers[4]. Initially developed to meet the needs of people with cancer at the end of life, this approach has been extended to meet the multi-dimensional needs, throughout the life course, of anyone with a life-limiting illness[4].

In common with most of the developed world, Scotland is experiencing demographic and epidemiological transitions[1]. The population is ageing[5]. People are living longer; living with, and dying from multiple morbidities. With medical advancements the number of babies, infants, children and young people living with life shortening conditions is increasing[6]. Gains in healthy life expectancy (HLE) have not kept pace with gains in life expectancy (LE), resulting in an expansion of morbidity in later life in some groups[7]. Population growth will be most rapid in the elderly in whom the burden of multi-morbidity is greatest; the number of people in Scotland aged 75 years and over is projected to increase by 86% from 2012 through 2037[1]. The ageing population has significant implications for the provision of both formal and informal care.

As a society, the value we place on life is reflected in the way we care for our most vulnerable groups; our crisis of modernity has become how we provide compassionate care to the elderly, frail and dying[8]. Social and cultural change has resulted in the medicalisation of death[9]. An entire generation has come to expect that all aspects of dying will be taken care of by professionals and institutions, undermining personal and community resilience in coping with death, dying and loss as part of the cycle of life[9].

Population demographics and prevailing social and cultural attitudes to death, dying and loss presents a specific challenge to supporting people living well until their death and achieving a good ending to their life. Demand for PELC services is rising. At an individual level many people with life-limiting illnesses and their families experience excellent PELC. At a population level, inequities in provision and quality of PELC services exist and unmet need is high[10,11].

The provision of equitable, sustainable PELC is an ethical imperative for health and social care systems[12]. Delivering this at a time of resource constraint and increasing demand is challenging[13]. Newly integrating health and social care systems are under pressure to deliver more with less. The integration agenda has brought a commitment to deliver high quality person centred care in all settings, with a focus on provision at home and in communities[14]. The majority of people in Scotland die in hospital or an institutional setting[15], however, most of the last 6 months of life is spent at home with family, friends and informal carers[16]. Framing PELC as a 'health service problem' disempowers people and communities as it fails to recognise that people with life-limiting conditions and their carers have resources available to them beyond those provided through professionals delivering medical and social care[17]. Allowing people

and communities to use and develop these resources to address the avoidable harms associated with death, dying and loss is a sustainable solution to building resilient people and communities[9,17]. How do we achieve this without losing sight of the need to provide high quality, holistic, person-centred PELC services now for people with life-limiting illness that have a capacity to benefit from them?

In this report we explore the rationale for a public health approach to PELC. In the opening chapter the principles and practice of public health are described. In Chapter 2, PELC is defined and the evolution of PELC practice in the UK is considered. To understand why we need a public health approach to PELC the demographic, epidemiological and societal influences on death, dying and loss in Scotland are examined in Chapter 3, framed within the wider political and policy landscapes. Next, the current challenges in delivering PELC in Scotland are explored. Chapter 4 reviews the literature to consider what a public health approach to PELC might look like. Finally, the opportunities and challenges in applying a public health approach to PELC in Scotland are summarised. A series of briefing papers accompany the report, providing additional information on selected areas for interested readers.

In this report we do not present solutions; sustainable solutions can only be achieved through co-production. In this report we frame the problem. In doing so we create an open space, an opportunity for people, communities, professionals, planners and policy makers to reflect, and open a dialogue. As a starting point we make a number of high-level recommendations to support co-production and further development of the work already underway in this important area. Through a shared understanding of the challenges that we face we can begin to look for opportunities to address these, together building resilient citizens and communities.

Aims and objectives

The overall aim of this project was to evaluate where and how public health approaches to PELC could add value to local service planning and delivery.

Specific objectives were to:
1. Describe the current legislative framework and policy context in PELC in Scotland;
2. Describe current practice in PELC in Scotland;
3. Collate and appraise the available epidemiological data on PELC in Scotland, identifying gaps and opportunities to fill these gaps;
4. Describe and evaluate the literature on public health approaches to PELC, examining (i) population based approaches and (ii) asset-based approaches; and
5. Identify opportunities to apply public health approaches to policy and practice in PELC in Scotland.

Scope

Assisted suicide was beyond the scope of this project. In Scotland, the issues surrounding assisted suicide have recently been scrutinised through a legislative process, details of which can be found by clicking here.

Methods

The project was undertaken from June 2015 through December 2015, using ScotPHN's standard approach to project development and delivery. This included a period of consultation (October to November 2015) with members of the Scottish Palliative and End of Life Care National Advisory Group and other key stakeholders.

Two literature reviews were conducted to inform the report. In the first, a number of bibliographic databases (CINAHL, MEDILINE, Psychinfo, Embase and Cochrane) were searched using the terms 'palliative care' and 'end of life' to identify the current issues in the field of PELC in Scotland. The search was limited to English language articles published in the last decade. Systematic and literature reviews were prioritised before a more detailed exploration of the primary literature where indicated. A supplemental search of the grey literature was conducted. Evidence from the UK was considered most relevant to the current project and was prioritised. The second literature review identified public health approaches to PELC. Full details of the literature search strategy can be found in Appendix 1. The titles and abstracts of all articles retrieved were screened and where relevant, full texts reviewed. The literature review was presented as a narrative synthesis of evidence.

A number of informal telephone interviews with key informants were carried out to explore their views on and experience of the contemporaneous challenges of delivering PELC in Scotland and public health approaches to PELC (Appendix 2). During the project the lead author attended a workshop on PELC provision conducted as part of the Ministerial review of out of hours (OOH) primary care services that provided an opportunity to informally discuss these issues with a broad range of stakeholders. In an iterative process, the interviews were informed by the literature review and the literature review was informed by the interviews.

Key policies and strategies in relation to PELC in Scotland were mapped with an aim of providing an overview of the policy direction and identify emergent themes rather than comprehensively listing all the policies and strategies that might directly or indirectly influence PELC. The policies and strategies reviewed were not placed within a hierarchy of importance but presented in a chronological narrative.

Epidemiological data from a number of routine sources and, where relevant, the peer reviewed published literature were collated, presented and appraised to describe the socio-demographic and cultural influence on death, dying and loss in Scotland.

To explore the organisation of specialist PELC in Scotland a national survey to map specialist provision was undertaken in collaboration with colleagues from the University of Glasgow. The methods for this are outlined in Appendix 3[18].

What is public health?

The UK Faculty of Public Health defines public health as *"The science and art of promoting and protecting health and wellbeing, preventing ill-health and prolonging life through the organised efforts of society"*[19].

This definition has five components. Firstly, recognition that public health is a science, empirical and evidence based. Secondly, recognition that public health is an art requiring creativity and innovation. Public health blends objective science with subjective and complex lived experiences. Action or advocacy may be required in the absence of evidence; nuance must be interpreted and value judgements made. Thirdly, the importance of prevention and early intervention across the life course to maximise health and wellbeing. Fourth, a shared responsibility for achieving this through a whole system population approach where individuals, communities, professionals and government work as equal partners. Many factors, personal, social, environmental and economic, act independently and cumulatively across the life course to determine health and wellbeing. Addressing the wider determinants of health and wellbeing is a core public health function. Finally, it is implied that this activity takes place within governance frameworks. A number of core public health values are alluded to in this definition: equity, empowerment, effectiveness, evidence-based, fairness and inclusivity. It is important to note that this definition is generic. It does not define the boundaries of public health practice according to person, place or disease. Public health priorities change over time as threats to health and wellbeing emerge and evolve.

The public health workforce

Public health has a tiered workforce that includes public health specialists (people with specialist training in public health), people directly involved in public health activities through their work (for example pharmacists, dentists, environmental health officers) and people indirectly involved in public health activities through their work (for example teachers, town planners, the social care workforce). Public health is multi-disciplinary. Each tier of the workforce contains highly skilled people with a core set of transferable skills and competencies. The diversity of the public health workforce means that it is highly adaptable, enabling inter-sector working.

Public Health functions and the core domains of practice

The World Health Organisation (WHO) Europe have identified 10 essential functions of public health systems that should be delivered locally, regionally and nationally through an integrated approach (Appendix 4)[20]. In the UK public health function is broadly organised into three core domains: health improvement, health protection and improving services[19]. Health improvement is characterised by activity to improve the health and wellbeing of people and communities through enabling and encouraging people to make healthy choices and addressing the wider determinants of health and wellbeing. The role of health protection is to protect the public from potential threats to health and emergencies that are caused by infectious disease or chemical, biological, radiological,

nuclear or other environmental hazards. Improving services focuses on the design and delivery of high quality, safe, cost effectiveness and equitable services. Health intelligence underpins all public health activity. Health intelligence is vital to assess the needs of a population, set priorities and measure and monitor the quality, cost effectiveness and equity of interventions, services and policies. Used correctly, health intelligence is a powerful tool for advocacy.

Key challenges for modern public health

A historical perspective on the evolution of public health in the UK context drawing on the conceptual framework developed by Hanlon and co-workers[21] is outlined in Briefing Paper 1. Many of the major advances in reducing population level morbidity and mortality over the last century can be attributed to public health action, predominantly non-medical, structural interventions to facilitate social and environmental change. Latterly, the alignment of public health with clinical medicine and a service-based focus on individuals' problems, needs, deficiencies and choices has not delivered sustainable or equitable solutions to the growing morbidity and persistent health and social inequalities experienced by modern societies. Health and wellbeing are societally determined; to make healthy societies a multifaceted response that recognises the complexity of the challenge and achieves a culture for health and wellbeing through co-production and asset-based approaches is required.

The role of public health specialists is evolving from 'fixers' to 'facilitators'. Core public health skills and competencies are crucial to fulfilling this new role. Public health specialists will need to use health intelligence with different audiences as a tool to enable partnership working, establish focus, agree priorities, commission services to meet local priorities and define meaningful outcomes. Leadership, advocacy, engagement and relationship building will be crucial to developing inter-sectoral capacity and commitment. A service response will still be required, but services will need to be re-orientated and aligned with the priorities and needs of local populations. Policy and practice will need evaluated and evidence of effectiveness and cost-effectiveness established. Shared learning will be crucial to identifying elements of success and up-scaling these. Developing a shared understanding of the evolving roles and responsibilities of the diverse public health workforce and demonstrating to partners (including funders) the added value of public health when the 'facilitator' role may be invisible is a major challenge. Added to which are inherent difficulties establishing and maintaining partnerships for inter-sectoral working, relating not least to organisational cultures, resource constraints, governance, politics and power.

There is an urgent need for a wider societal discussion to establish the concept not just of health, but also of wellbeing in the presence of poor health, disability or loss. We must focus on what matters to people, the lived experience. We need to negotiate where, as mutual citizens rather than 'users' and 'providers' or 'lay people' and 'professionals' our own responsibilities lay. Only then can we, as a society, decide what collective action to take to improve health and wellbeing for the whole population.

What is palliative and end of life care?

The WHO define palliative care 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*"[4]. The full WHO definition of palliative care is outlined in Appendix 5. In producing a definition for children's palliative care, the WHO have recognised that children's palliative care is different from, although closely related to, adult palliative (Appendix 5).

There are seven key components of this definition. Firstly, palliative care is an approach to delivering high quality care. Secondly, care is holistic, encompassing physical, psychosocial and spiritual domains of need thereby requiring interdisciplinary working. Thirdly, the family, not the individual, are recognised as the unit of care. Fourth, the aim of care is to prevent and relieve suffering, and improve quality of life. These are the core values of good care. It follows then that this approach should be delivered across all levels and settings of care by all health and social care professionals as normal practice; palliative care is not the exclusive remit of specialists. Fifth, this approach to care is for anyone living with and dying from life-threatening illness. The term life threatening refers to a spectrum of illness from potentially curable to incurable. A life-threatening illness may progress to become life-limiting, with no reasonable prospect of cure; through thoughtful medical intervention and care it may be possible to extend life and improve quality of life. In babies, children and young people the term life-shortening is preferentially used to describe life-limiting conditions. Sixth, care is not time-limited or based on prognosis, but based on need. Palliative care should be integrated with active treatment and extend throughout the life course to death and, for families, beyond (where bereavement care is indicated). Finally, the full definition recognises death is an inevitable, and normal, part of life. A number of other definitions exist. These are reflected upon in Appendix 6.

A number of terms are used interchangeably and inconsistently in relation to palliative care including hospice care, supportive care, terminal care, end of life care, palliative care and palliative approach. Throughout this report we will refer to palliative care as defined by the WHO[4]. End of life care is palliative care for people approaching the end of life. The process of dying can be difficult to identify and prognosticate. It may take hours, days, weeks or months. In this report end of life care will refer to palliative care for people who are likely to die within the next year[22].

The evolution of specialist palliative care in the UK

Institutional care of the dying has been provided by secular organisations funded through philanthropy since the Middle Ages[23]. Cicely Saunders is credited with establishing the modern hospice movement in Britain in the 1960s to meet the end of life care needs of patients with cancer[23]. Prior to the 1970s the NHS focused on curative and rehabilitative interventions to extend life with little interest in the provision of organised, institutional end of life care[23]. The hospice movement grew rapidly and

organically throughout the 1980s[24]. An exponential increase in the number of independent hospices was associated with expansion of specialist palliative care, including recognition of palliative medicine as a medical specialty, extensive education and training programmes and growth in academia and health policy[24].

Recognition of the high quality end of life care provided by independent hospices and public support for the hospice movement led to attempts to 'mainstream' specialist palliative care provision by the NHS[25]. This presented a number of opportunities (expansion of multi-disciplinary specialist hospital and community services, and NHS funding, albeit inconsistent) and challenges (reorientation of care toward a health service model with a limited clinical service perspective on whole person care, expansion of the professional groups involved in care and a reductionist view of community involvement to fund-raising and volunteering)[25].

Informed by the work of others, successive government strategies, policies and initiatives have redefined the scope of palliative care, introducing the concept of integrated PELC, delivered from the point of diagnosis throughout the life course (Figure 1)[26]. Recognition that people with non-cancer life-limiting illnesses could benefit from PELC has mandated provision based on need not diagnosis[4,26]. Recognition that babies, children and young people with life-shortening conditions have specific needs that cannot be met through services designed for adults has mandated the development of dedicated PELC services [27].

At policy level then PELC has evolved from highly specialist end of life care for people with cancer to holistic care throughout the life course delivered across the continuum of care as a matter of routine practice for people with any life-threatening illness[26].

Figure 1. Conceptual models of palliative and end of life care[26]
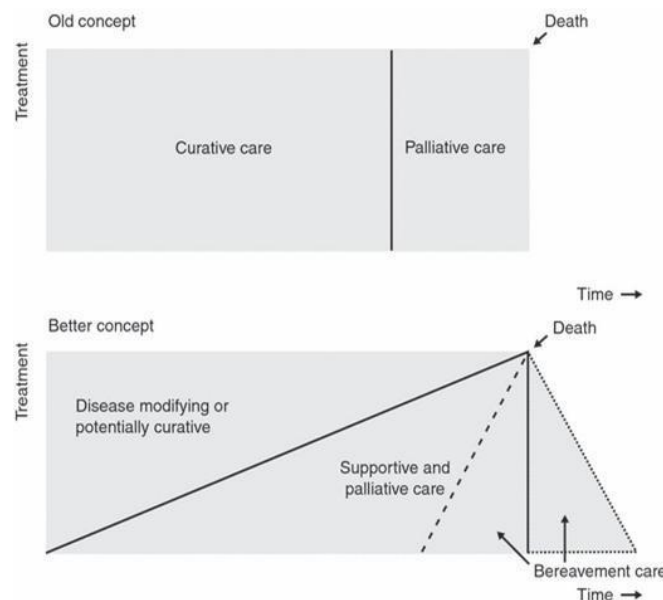
Note: A second transition from supportive and palliative care into end of life care may occur a number of days before death

Why do we need a public health approach to PELC?

This section provides an overview of the political, policy, socio-demographic and cultural influences on death, dying and loss in Scotland before examining the key issues in delivering equitable, sustainable high quality PELC for those with a capacity to benefit from it.

Political landscape

A full account of the current political landscape in Scotland can be found in Briefing Paper 2. The political landscape in Scotland is currently characterised by major public sector reform, driven by concerns over the sustainability of public services at a time of increasing demand (increasing public expectations, increasingly expensive technologies and treatments, changing population demographics and the consequences of deep-rooted social inequalities) and resource constraint[13].

Legislative framework

A full account of the national and international legislative frameworks in relation to the provision of PELC can be found in Briefing Paper 3. There is no dedicated PELC legislation in Scotland. In 2014 the World Health Assembly published a resolution recognising the provision of equitable integrated palliative care services as an "ethical responsibility of health systems"[12]. Member States are required to report their progress against the resolution, including the integration of PELC across the continuum of care, at the 69th World Health Assembly in 2016. There have been calls for PELC to be formally recognised as a human right[28]. Advocates interpret the right to "the highest attainable standard of physical and mental health" as a legal requirement for governments to provide PELC (Article 12.1 of the International Covenant on Economic, Social and Cultural Rights) [29].

Policy context

Health strategy and policy in Scotland has been remarkably consistent over the last two decades with a number of key themes emerging. These are outlined in detail in Briefing Paper 4. Against a backdrop of wider health and social care integration with a strong focus on early intervention and support for self-management, PELC has gained increasing prominence in government strategy and policy in recent years. This has driven the development of palliative care MCNs[30], clinical standards[31], and formal funding arrangements between NHS Health Boards and voluntary hospices[32]. PELC has emerged as a core element of many clinical pathways associated with multi-morbidity in a range of settings,[33-35] although notably less so in relation to mental health.

In 2008 Audit Scotland systematically and comprehensively examined the activity, quality and costs of PELC services across Scotland, confirming significant variation in availability and quality of PELC services[10]. In response the Scottish Government published the first national strategy for PELC, 'Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland,' with an aim to deliver high quality,

equitable, patient-centred PELC for people living with and dying from advanced, progressive or incurable illness[26]. Progress has been made toward the key intentions of Living and Dying Well,[36,37] however, a 2012 update identified specific challenges still to be addressed[37]. These included the need for a cultural shift to foster openness about death, dying and loss, the embedding of new tools to identify and assess need in clinical practice and investment in cross-sector infrastructure to enable timely communication and ensure collaborative working and co-ordination of care. The difficulty of making statements on progress in the absence of data on outcomes, and in some cases, data on activity, was highlighted. In 2012, the Scottish Government published a 'Framework for the Delivery of Palliative Care for Children and Young People in Scotland'[38].

With an ambition to deliver high quality holistic care in a homely setting to those who have the capacity to benefit from it, the principles of PELC may have been present in the Scottish Government's '20:20 Vision', but death, dying, and loss were not explicitly mentioned[14]. This is an important omission. There is a need for high-level acknowledgement that death, dying and loss are inevitable human experiences; through policy and practice the avoidable harms caused by death, dying and loss can be mitigated, but death cannot be prevented.

The political context and strategic narrative of '20:20 Vision' will shape the future direction of PELC in Scotland[14]. In December 2015, The Scottish Government published a 'Strategic Framework for Action of Palliative and End of Life Care' (SFA) to provide a current, comprehensive and cohesive strategy for PELC in Scotland[39]. This was informed by a Scottish Parliamentary Inquiry into PELC provision in Scotland that considered access to palliative care, communication around PELC and metrics used internationally in PELC[40]. The SFA set out a vision of everyone in Scotland who needs it, having access to PELC by 2021. Specific aims and objectives to ensure PELC needs are identified, access to PELC is equitable and to enable people, professionals, communities, statutory and non-statutory organisations to develop and use the assets available to them to better deal with death, dying and loss were articulated. Importantly, the SFA recognised the need for a public health approach to PELC and the valuable contribution that the public health workforce has the potential to make to this agenda. The national implementation group and additional funding of £3.5 million over four years will support implementation of the SFA.

Epidemiological data

In this section the socio-demographic and cultural influences on death, dying and loss in Scotland will be explored using available epidemiological data.

Population Growth

Scotland's population is growing[1]. The population on Census Day in 2011 reached the highest level ever at 5,295,000 representing a 5% increase from the 2001 Census. The population is projected to reach 5,780,000 by 2037. By 2033 it is predicted that the number of deaths will exceed the number of births and population growth will be driven by net in-migration.

Population Ageing

Scotland's population is ageing[1]. Population ageing will be driven by a change from high fertility and mortality rates to low fertility and mortality rates. This is termed a demographic transition. From 2012 through 2037 it is projected that the:
- number of children (<16 years) will increase by 5% from 0.91 to 0.96 million.
- number of people of working age will increase by 4% from 3.35 to 3.48 million.
- number of people of pensionable age will increase by 27% from 1.05 to 1.33 million.
- number of adults aged 75 years and over will increase by 86% from 0.42 to 0.78 million.

Life Expectancy and Healthy Life Expectancy

People in Scotland are living longer[1,7]. The expectation of life at birth is projected to increase from 76.5 years in 2013 to 81.9 years in 2037 for men; 80.4 years to 85.4 years for women. Healthy life expectancy (HLE) is also improving[1,7]. In 2013, HLE at birth was 60.8 years for men and 61.9 years for women. In women gains in HLE have paralleled gains in LE and the gap between the two, the time spent in an 'unhealthy' state, has remained constant. In men, the gap has widened suggesting an expansion of morbidity. Both LE and HLE are socially patterned with people in the most socioeconomically deprived groups experiencing significantly shorter LE and HLE than people in the least socioeconomically deprived groups.

Trends in the annual number of deaths

Between 1986 and 2014 the number of people dying each year in Scotland fell from 63,467 to 54,239 reflecting falling mortality rates[1]. Driven by overall population growth, it is projected that the number of people dying each year will begin to rise in 2015. By 2037 the number of people dying each year will have risen by 12% to 61,600.

Trends in cause of death

Long-term trends in cause of death confirm that Scotland has undergone an epidemiological transition; the pattern of cause of death has changed from predominantly communicable to non-communicable diseases[1]. In 2014, 29% of deaths were attributable to cancer, 20% cardiovascular disease and 12% respiratory disease. Between 1986 and 2014 the proportion of deaths attributable to cardiovascular disease fell from 42% to 20% reflecting advances in primary, secondary and tertiary prevention

of cardiovascular disease. Reflecting population ageing, the proportion of deaths attributable to cancer increased from 23% to 29% over the same period. It is projected that the number of new cases of cancer in Scotland will increase by 33% between 2008-12 and 2023-27. An increase in the proportion of deaths attributable to other conditions associated with ageing, for example as neurodegenerative conditions, is anticipated although under-recording of such conditions on death certificates is recognised.

Burden of disease

A recent study analysing administrative data from Scotland has provided the most comprehensive estimates of the burden of life-limiting illness in babies, children and young people in Scotland to date[6]. The overall prevalence of life-limiting illness in Scotland was estimated to be 95.7 per 10,000 people aged under 25 years old in 2013-14. The prevalence was highest among those aged under 1 year old (192.1 per 10,000) and lowest in those aged 21–25 years (72.5 per 10,000). Between 2009 and 2014, the overall prevalence increased in all age groups except babies and infants where it remained stable. This suggests that increasing prevalence is due to improved survival rather than an increasing incidence. In absolute terms, the number of babies, children and young people living with a life-limiting condition increased from 12,039 in 2009-10 to 15,404 in 2013-14. Life-limiting conditions in babies, children and young people are most commonly congenital anomalies, oncological and neurological diagnoses; by age 21–25 years old the most prevalent diagnoses are oncological. The prevalence of life-limiting conditions was found to be higher than expected among babies, children and young people of South Asian ethnicity and those from the most socioeconomically deprived areas.

Overall, an estimated 42% of the Scottish population have one or more chronic morbidity, increasing with age from 1.9% in those under 25 years old to 81.9% in those 85 years and over[41]. By age 50 years, half the population have at least one co-morbidity; aged 65 years, most have multiple co-morbidities. Multiple morbidity is associated with higher mortality, reduced functional status and increasing use of health and social care resource. With population growth, the prevalence of chronic disease will rise and the absolute number of people living and dying with multiple co-morbidities will increase.

Estimating PELC need

A recent study concluded that population based estimates of PELC need in high-income countries could be reliably derived from death registration data (underlying and contributory causes)[3]. The authors estimated that between 69–82% of people who die have PELC needs. Applying these figures, between 37,424 and 44,476 of the people who died in Scotland in 2014 had PELC needs. These figures provide a reasonable estimate of the need for end of life care. However, they do not provide a reliable proxy measure for overall PELC need because they do not capture people living with life-limiting illness who may have illness trajectories spanning decades with fluctuating PELC needs. In 2013-14 just 12,050 people were recorded on a primary care register as being identified with a PELC need[42]. The discrepancy between these figures implies significant unmet need.

Of the people who died in Scotland in 2013-14, 91% of their last 6 months of life was spent at home or in the community; 9% was spent in an acute hospital setting[16]. A recent census study in Scottish hospitals found that 1 in 10 people admitted to hospital would die within that admission; 1 in 3 died within a year of admission[43]. With increasing age, the probability of dying during hospital admission, or in the year following hospital admission, increased. It is not known what proportion of the people who died in this study had a PELC need identified and met during or following their admission. The findings from this study were replicated in a 2013 update[44].

Each year around 195 babies, children and young people with life-limiting conditions die in Scotland; this has fallen from 208 in 2004-05 to 188 in 2012-13[6]. Of the estimated 15,404 babies, children and young people living with a life-limiting condition in Scotland in 2013-14, 2,201 were estimated to be unstable, deteriorating or dying. Babies and infants were most likely to be assessed as unstable, deteriorating or dying, followed by those aged 16 years and over. Each year the Children's Hospice Association for Scotland (CHAS) receive 115 new referrals and provides holistic care for an estimated 380 families. An estimated 60 babies, children and young people die each year in CHAS hospices. These figures imply significant unmet need, however, overall conclusion cannot be drawn as access to PELC from other providers including generalists, is not known.

Trends in place of death

In 2012, 53% of those who died in Scotland died in hospital, 27% in a care home and 25% at home or in a non-institutional setting[15]. Over a decade (2003–12) the number of people in Scotland dying at home or in a non-institutional setting has increased marginally from 23% to 25% and the number of people dying in hospital has fallen from 58% to 53%[15].

Among babies, children and young people, 73% of those who die each year do so in hospital, 6% in hospice and 21% at home. The proportion who die in hospital is much higher (90%) in babies and infants (<1 year old) than for all other age groups[6].

National data on preferred place of death (PPD) are not available in Scotland. However in England, almost two thirds (63%) of respondents in a population based study in 2010 identified their PPD as home; the least identified PPD of death was hospital[45]. If generalisable to Scotland, these data suggests significant unmet need in relation to PPD.

Informal carers

In the 2013 Scottish Health Survey, 16% of adults and 4% of children reported providing regular care for a person with long term ill-health, a disability or problems relating to old age, suggesting that 759,000 adults and 29,000 children are unpaid carers in Scotland[46]. Carers come from all socio-demographic backgrounds however they are most often women of working age; young carers are more likely to come from a lone parent family[46]. A quarter of carers in Scotland provide 50 hours or more of care per

week. Of the 171,000 carers aged over 16 years old who provide 35 hours or more unpaid care, a third are also employed[47]. A recent report by Marie Curie noted that informal carers contributed an estimated £219 million toward the cost of care for people with one of four cancers (lung, breast, prostate and colorectal) accounting for approximately a third of the total cost of care provision[48].

Families and households

Households are getting smaller with a tendency toward sole occupancy, which has implications for access to informal carers[47]. People are more likely to live alone as they become older[47]. In the 2011 census a third of households in Scotland were single person households; 13% were single person household aged 65 years and over[46]. It is projected that by 2037 there will be 488,200 people aged 65 years and over living alone, an increase of 51%. Among those aged 85 years and over, the number of people living alone is projected to increase by 161% by 2037[49].

Dependency Ratio

Driven by an increasing number of people of pensionable age, the dependency ratio is projected to increase from 59 per 100 to 66 per 100 from 2012 through 2037[1]. This may indicate an increasing financial burden associated with the ageing population that will have an impact on carers, families and the wider economy.

Wider societal and cultural influences on death, dying and loss

There is evidence that most people in the UK have had experience of death, dying and loss at some point in their life[50]. Talking openly about death, dying and loss can help people achieve their preferences and priorities for care and death, and supports carers[9]. The 2014 Dying Matters survey found that the majority of the public, 72% believed that people in Britain were uncomfortable talking about death, dying and loss; 71% agreed that if people felt more comfortable talking about death, dying and loss it would be easier to have our end of life wishes met[51]. In contrast, 70% of people in the 2013 British Attitudes Survey (BAS) reported that they felt comfortable or very comfortable talking about death[50]. Although most people were able to state their preferences in relation to end of life care, only a third had discussed these with someone else, just 35% of respondents had written a will, 11% had made a funeral plan and 5% had an advance care plan in place. The reason respondents most commonly gave for not having made plans for their death was that death was perceived to be a long way off. However, among those aged 75 years and over the reason most commonly given by respondents for not have made plans for their death was that other people did not want to talk about death. Almost two thirds of respondents said that they would be most likely to start planning for their death to ease the burden on family and friends.

A 2009 evidence synthesis examining public attitudes to death, dying and bereavement noted that many studies elicit views on hypothetical issues therefore findings do not necessarily map to real life decision making which is highly contextualised, changes according to circumstances and greatly influenced by past experiences[52]. Translating a theoretical willingness to discuss death, dying and loss into action is challenging but

has the potential, at a population level, to improve quality of life for people with life-limiting illness by providing a sense of control over the circumstances of their death.

Key findings from epidemiological data

- The population in Scotland is growing and ageing.
- The number of people living with and dying from complex and chronic multi-morbidity is increasing.
- The number of deaths each year is projected to increase as the population grows.
- Demographic changes will impact on the availability of informal carers at a time when people are increasingly living on their own with implications for the provision of formal care.
- Combined, these data suggest that demand for PELC services will rise.
- There are no reliable estimates at population level of PELC need in Scotland; this is a barrier to service planning.
- A comparison of the number of adults recorded on PELC registers in primary care in Scotland to population level estimates of need for end of life care based on death certification suggests that a large proportion of the population who have a PELC need are not formally identified. This implies unmet need, although the possibility that PELC needs are being met through high-quality generalist care, cannot be excluded.
- Estimates derived from administrative data of the overall prevalence of life-limiting conditions in babies, children and young people in Scotland have recently been published. A comparison of these estimates with activity from CHAS (the principle provider of specialist PELC in this group) suggest significant unmet need.
- At least half of all people who die in Scotland do so in hospital; three quarters of babies, children and young people who die in Scotland do so in hospital. There are no national data on PPD in Scotland but data from a population-based study in England found hospital to be the least PPD; this suggests significant unmet need.
- To achieve the policy drive of ensuring care (and death) at home or in a homely setting in the context of an ageing population who are increasingly living alone with diminishing support from informal carers, alternate long-term 'homely' settings for care (and death) are required.
- The majority of the public have direct experience of death, dying and loss.
- While the public report feeling comfortable talking about death, dying and loss they perceive that the wider population are not comfortable talking about these issues.
- At a population level, hypothetically 'feeling comfortable" talking about death, dying and loss does not translate into conversations about death, dying or loss or concrete action to making plans for death.
- There are avoidable harms associated with a societal wide reluctance to talk openly about death, dying and loss.

Current challenges in PELC

The section that follows explores some of the current challenges in delivering high quality, equitable, sustainable PELC services to those with a capacity to benefit from them in Scotland. This section has been informed by a formal literature review and informal discussions with a range of stakeholders.

Identification of PELC need

Studies (largely from the USA, in people with cancer receiving specialist palliative care) have shown that people who receive early integrated PELC survive longer with a better quality of life[53], experience fewer aggressive end of life interventions[54], report greater satisfaction with care[53,55] and are more likely to achieve their PPD[55], than those who do not. However, a community based study in Scotland reported that only 20% of people who died from organ failure and 75% of people who died from cancer requested or were identified for PELC; people received PELC on average eight weeks before death, limiting their ability to benefit from it[56]. Identification of a PELC in this study was based on inclusion on the practice palliative care register. People in this study may have received a palliative care approach without being recorded on the practice register, or indeed being aware that they were receiving PELC.

Archetypical illness trajectories mapping the evolving multidimensional PELC needs of people with cancer, organ failure and frailty have been characterised[57-59]. A group from Edinburgh has led a programme of research to characterise multidimensional trajectories of decline experienced by people living in Scotland in the last phase of life. In an acute trajectory of decline, typically associated with cancer, existential and psychological distress often appear at diagnosis, at discharge home, at recurrence and around dying. In trajectories associated with organ failure, acute anxiety and social issues typically occur during physical exacerbations. People living with multi-morbidity also experience multi-dimensional distress in the last phase of life. At an individual level multidimensional illness trajectories may help identify, anticipate and plan for key transitions. At a population level they may help planners and policy makers conceptualise PELC services and develop models of care to meet the evolving needs of different groups. However, as treatment and care modalities evolve, the relevance of these theoretical models will diminish. Moreover, the models do not provide any detail on the nature of need or how best to meet this. In practice, illness trajectories can vary markedly among people with the same illness, particularly so for non-cancer diagnoses where the clinical course can be highly uncertain[57].

There is increasing interest in the use of prognostic indicators to identify PELC need[60], particularly in people living with organ failure[61]. A range of prognostic tools has been validated in selected populations, however, their value in routine clinical practice and generalisability to wider populations is untested[60-62]. Importantly, prognosis does not necessarily predict need[60-62].

Across Scotland a wide range of tools to identify and assess PELC needs in different settings and among different populations, are in use[37]. The appropriateness of these tools has not been established and lack of a standardised approach to implementation

has hindered the development of an evidence base[37]. For example, a recent systematic review identified three tools currently in use in the UK to identify people with a PELC need in primary care, GSF-PIG, SPICT (www.spict.org.uk) and Quick guide, none of which have been prospectively validated or widely implemented[63]. Tools to identify PELC need can aid clinical practice if used when people intersect with health and social care services at key milestones throughout their journey[64]. Integrating assessment of PELC with life-long care provides continuity and co-ordination of care and, if required, access to specialist palliative care for people with life-limiting illness[64]. Holistic assessment of need is required to address all dimensions of care for both people with life-limiting illness and their carers throughout their journey[64].

Dimensions of need

PELC provides holistic care across all dimensions of need, including physical, psychosocial and spiritual needs[4]. These are not mutually exclusive but interconnected, evolving over time, from the point of diagnosis, through various transitions, to death and for carers, through bereavement. Babies, children and young people with a life shortening condition will have additional social and educational needs to ensure physical, emotional, social and cognitive development throughout childhood[6,27].

Physical symptoms in life-limiting illness commonly include pain, anorexia, weight loss, nausea and vomiting, hiccups, breathlessness, swallowing difficulties, constipation or diarrhoea, fatigue, and insomnia[65]. These may arise as a result of a life-limiting illness, on-going active, rehabilitative or palliative treatment, or comorbid diagnoses. Often symptom burden is high[66]. Psychological co-morbidity is common and may be experienced on a continuum from poor concentration, low mood and insomnia through to psychiatric morbidity including major episodes of anxiety or depression and suicidal ideation. Confusion and delirium are often present at the end of life. Symptom management at the end of life is particularly important to ensure a dignified death. Being pain free is a priority for many people in their final days[67]. Scottish Guidelines for the management of symptoms in PELC have been produced[68].

Functional decline often mirrors physical symptoms with practical implications for people and their carers[58,69]. Declining functional status may result in the need for a period of rehabilitation, additional input from allied health professionals, access to equipment or additional support for informal carers. Crises may arise at times of worsening physical symptoms and functional decline that, without adequate resource, may result in transitions between care settings.

Progressive life-limiting diagnoses can have a profound impact on a persons' role within a family and wider society, altering the sense of self and identify[57,63,68]. Deteriorating health status leads to increasing dependence and in turn social isolation for people with life-limiting illness and their carers, impacting both on quality and quantity of life[69-71]. For example, social isolation and loneliness increase the risk of premature death and the magnitude of this risk is comparable to that from other well-established risk factors such as obesity and physical inactivity[72]. A 'fourth age,' a normative ageing phenomenon has been described in the elderly characterised by inevitable

physiological and functional (and for some cognitive) decline associated with a "*social death*" with loss of autonomy, loss of companionship, increasing dependency and loss of cultural and social capital which combined threatens dignity[59]; dying with dignity has been identified as one of the top three priorities for people at the end of life[67].

Perhaps the most neglected dimension of care is spiritual care. A 2010 systematic review of the literature on spiritual care at the end of life found little evidence that spiritual care needs, which increase toward the end of life, are being assessed or met[73]. Spirituality and spiritual care are difficult to define. Broadly speaking spiritual needs are those that relate to the meaning and purpose of life. For some people there will be a strong connection to religious organisations with associated rituals. For others spiritual care is about relationships and connectedness. In this context then spiritual care may be administered by a companion, or in conjunction with physical care encompassing the human aspects of providing compassionate and respectful care: listening, connecting, mindfulness, sharing narratives, examining inner belief systems, finding hope, and affirming meaning in life and death[74]. Time and open honest communication are key elements of spiritual care and barriers to its delivery in health and social care settings where professionals are often pressed for time, focus on task orientated 'doing' rather than relationship building 'being' and often lack the skills, confidence and experience (and willingness) to discuss spirituality[74]. Good spiritual care is "an art requiring creativity and caregivers who were relational, willing, human, reflective and spiritually self-aware"[74]. Commentators have raised concerns over 'medicalising' spiritual care[73]. A community response to spirituality could contribute to building personal and community resilience to death, dying and loss in an era where a greater number of people are dying at home often following a prolonged period of illness. However, if modern spiritual care is little more than a 'common humanity' approach to care then this is arguably the responsibility of all health and social care professionals[74]. A gap has emerged from the discontinuity between policy, practice and public expectation[74]. NHS Education Scotland and the Scottish Government have produced guidance on spiritual care and chaplaincy in the NHS[75].

Carers and families

In Scotland the rights of carers as equal partners in the planning and delivery of care have been embedded in primary legislation and policy[76,77]. Caring can be a positive and rewarding experience[71]. However, a significant proportion of carers, many of whom will have their own concomitant health problems, report that caring has had a negative impact on their mental and physical health and wellbeing; this is directly correlated with the duration and intensity of caring[71]. Many carers also experience financial hardship and social exclusion as a direct result of their caring role[71]. The majority, around 70%, of respondents in the 2012-13 Scottish Health Survey who identified themselves as carers said that they received no support with their caring responsibilities; where support was provided this was most commonly identified as being from family and friends[46].

There are specific challenges in caring for a baby, child or young person with a life shortening illness[6,27]. Parents may not be recognised as carers by health and social

care professionals. However, in addition to providing informal personal care, many parents take on the responsibilities of health care providers with little preparation for the role, for example, administering complex treatment protocols and co-ordinating care. Parents are legally responsible for their child and may be required to make difficult decisions regarding therapeutic interventions. They may exist in a constant state of anxiety, living with uncertainty, witnessing their child suffering and coming to terms with the loss of a 'normal' childhood. Balancing this role which may be pervasive with being a mum or dad can be mentally, physically and emotionally exhausting. Many children with life shortening conditions are part of a wider family unit that includes siblings, for whom parents are also primary caregivers. Siblings may experience complex emotions including guilt, anger, resentment, sadness and loneliness. Managing the impact of their own emotional response, while managing those of their children, may contribute to chronic distress experienced by parents. The response of extended family and wider society to a baby, child or young person with a life shortening condition may present additional challenges.

The evidence base around how best to support carers is weak. A 2011 systematic review identified 33 studies evaluating outcomes for carers; 17 reported findings from a range of targeted carer interventions[78]. Few studies employed a randomised control design. Comparison between studies was limited because the timing of interventions and inconsistency of outcome measures. The review concluded that despite a growth in the evidence base there was still insufficient evidence to suggest the interventions evaluated significantly improved carer outcomes.

The needs of carers do not end with the death of their loved one. Indeed, physical, psychosocial and spiritual needs of carers and families may increase with bereavement[79,80]. Whilst death can happen at any time across the life course, for a parent, the death of a child (at any age) is particularly traumatic; parents do not expect to outlive their children. Good care of people who are dying results in better outcomes for those left behind. Carers and families may face a range of practical challenges in the short-term following the loss of a loved one such as registering a death or organising and paying for a funeral. There is increasing evidence for example that many families in the UK are unable to afford the cost of a funeral[81]. The Citizens Advice Bureau in Scotland assists just over one case per day regarding funeral costs[82]. Many employers offer just three days of paid bereavement leave following the death of a close relative, including the death of a child or parent. In the longer term moving house, returning to the workplace or adjusting to a different standard of living can present specific challenges. Bereavement care, helping people deal with the emotional and practical problems following loss of a loved one, is associated with better outcomes for the bereaved if commenced prior to death[79,80].

Bereavement impacts not just on the bereaved but also their wider social networks. For each person that dies each year in Scotland it is conservatively estimated that four people will be significantly affected by their death[2]. For most people grief is an appropriate and adaptive response[79,80]. Empathetic listening and emotional support are sufficient to meet their needs. Medical intervention may disrupt this process, preventing

people from finding their own solutions and building supportive networks that in turn build personal and community resilience support[79,80,83]. The need for formal bereavement support is associated with lack of social support networks. Asset based approaches to building social capital may therefore have great potential in this area[83].

A significant proportion, 5-10%, of people experience complicated grief that may last from months to years with a major impact on health and wellbeing[79,80]. This group may require additional support. A tiered service response with interventions ranging from acknowledgement and information based services, to one-to-one and peer support, to cognitive behavioural therapy, has been developed to meet this need[2,79,80]. Formal risk assessment tools to identify those that require bereavement support are of limited value in clinical practice[79,80]. There is therefore little information about unmet need[79,80]. Whilst there is evidence to support interventions for people with complicated grief reactions, there is no evidence to support universal interventions and the evidence base around cost-effectiveness is lacking[79,80].

Anticipatory and advance care planning

A core element of personalised care and self-management, anticipatory care planning for people living with chronic conditions has become embedded in routine clinical practice[84]. An anticipatory care plan is a document in which iterative discussions between a person with a chronic condition and those involved in their care are recorded. The aim is to proactively identify needs, preferences, priorities and goals across the continuum of care. The national Framework for the Delivery of Palliative Care for Children and Young People in Scotland identified the importance of assessment of care needs (including the needs of parents and siblings) and multi-agency anticipatory care planning in providing guidance to service providers[38].

Advanced care planning is a process where an individual indicates their preferences for care should they lose capacity or be unable to express a preference in the future. For some people advanced care planning takes place in the context of ill-health; others proactively engage in advanced care planning the context of good health. Discussions in advanced care planning might involve an exploration of a person's understanding of their concerns, values and goals for care. A statement of wishes or preferences for care and death can be made which may cover appropriate levels of intervention: 'Do not attempt cardiopulmonary resuscitation' (DNACPR) instructions; organ donation; post mortem examination; writing a will; and funeral arrangements. This is not legally binding. Advance directives are legally binding and may cover issues relating to ceilings of treatment in the event that an individual loses capacity to consent. The key legislation in this area is the Adults with Incapacity Act (2000), which legally defines advance decisions to refuse treatment and the process of nominating a proxy to make decisions in a person's best interests, as well as power of attorney[85]. Power of attorney may contain continuing powers (relating to finance and property), welfare powers or both that come into effect when a person no longer has capacity. As part of 'Living and Dying Well', the Scottish Government introduced The Children and Young People Acute Deterioration Management Plan (CYPADM), a national policy for resuscitation planning for children and young people[86]. The CYPADM facilitates proactive discussions

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between a child or young person (where appropriate), their parent or guardian and the clinical team to ensure that in the event of an acute deterioration, children and young people only receive the treatment that is in their best interest. This documentation is available to all professionals (health care, social care and educational) across all settings of care.

Advance care planning allows professionals to ensure that if needs rapidly change individuals' preferences and priorities are met. It is crucial that advance care plans are regularly reviewed, updated and clearly documented. Infrastructure is in place in Scotland to ensure effective and timely communication of this information, when recorded, across setting (community, acute, NHS24 and ambulance service) and in the 'out of hours' period through the Electronic Palliative Care Summary (ePCS).

In the context of PELC, good advance care planning allows time and space for people to express their grief and explore existential issues. It supports autonomy, allowing people to retain their identity and dignity with disease progression. It may also lessen the burden on carers and families. A recent systematic review reported that advance care plans increase compliance with wishes for care including achieving PPD, reduced intensive interventions and hospitalization at the end of life, increased hospice care and improved quality of life[87]. It should be noted that most of the studies identified were from the USA and many lacked an experimental design. The authors concluded that additional studies across a range of settings with standardised outcome measures and experimental designed were required. Evidence on the economic impact of advance care planning is lacking[88].

Advance care planning requires excellent communication skills and time. Professional education to support frontline practitioners develop the prerequisite skills is crucial to success. In Scotland the development of training and education programmes to support implementation of advanced care planning were developed through 'Living and Dying Well'[26,36,37].

Communication

General practitioners are well placed to engage people with life-limiting conditions in advanced care planning. Data from England suggest that a significant proportion (25%) of general practitioners have never initiated a conversation about end of life[51]; the extent to which these findings are generalisable to Scotland is unclear.

Medical training has traditionally focused on treating disease rather than optimising wellbeing. Despite the inclusion of palliative care in undergraduate medical training and recognition as a post graduate clinical specialty since the 1980s, many professionals may perceive ageing and dying as a failure rather than a normal and inevitable part of life. Many professionals struggle to openly and honestly discuss the inherent uncertainties around death and dying, particularly so for people with non-cancer life-limiting illness in whom prognosis is unpredictable and the death can occur suddenly[89-93]. Instead, conversations between people, their carers and the professionals involved in their care, centre around disease management, often focusing on the physical

dimensions of care[91]. This is a barrier to information sharing that may disempower people and their carers, erode confidence and trust, and lead to misunderstandings that can cause significant distress[90-93].

There is evidence that not everyone with a life-limiting condition wants to discuss end of life issues; this is true for both cancer and non-cancer diagnoses[91]. Some people and their carers (and the professionals involved in their care) perceive palliative care to be a 'death sentence,'[69] and worry that identifying a PELC need may result in reduction or withdrawal of active treatment[94]. For some, open discussions of death and dying can make it harder to cope, taking away a sense of hope and cause suffering[95]. People may prefer to focus the narrative of their illness on maintaining existing levels of wellbeing and preserving autonomy[95]. For others, poor information giving means that they lack an understanding of the implications of their diagnosis and prognosis, which impairs quality of life with disease progression, and is a barrier to end of life discussions[91,93]. It is estimated that almost half of the population have inadequate levels of health literacy, lacking the knowledge, skills, understanding and confidence to take an active role in their care[96]. Culture and belief systems also shape discussions[97].

The progressive neurodegenerative nature of some non-cancer diagnoses mean that conversations about death and dying are extremely challenging because of diminishing mental capacity and assessment of needs, priorities and preferences becomes increasingly difficult with disease progression. Advance care planning can present its own challenges in this group. People with dementia for example express concern about making decisions for the "future unknown self"[98]; professionals express concern over their ethical and legal requirements to provide active and often aggressive intervention even when this is likely to be futile or potentially harmful[99].

Generalists and specialist

Generalists, not specialists, deliver the majority of PELC. Yet, health and social care professionals report confusion over the goals and scope of PELC[93,100-102]. In policy, a distinction between generalist and specialist palliative care provision may have been articulated but the practical interpretation and implementation of this has proven challenging and clarity around the roles and responsibilities of generalists and specialists is lacking[102].

Precise estimates of the proportion of adults with life-limiting conditions who have a complex need that may require specialist intervention are not available; data from a recent study estimated that 2,201 babies, children and young people living with life-limiting illness in Scotland in 2013-14, approximately 14% of all babies, children and young people living with a life-limiting illness, were unstable, deteriorating or dying[6]. There is a growing awareness that specialist palliative care providers do not have sufficient capacity to meet future PELC need. Significant expansion of specialist palliative care to meet service provision is unlikely and may not be desirable[103-105]. To significantly increase capacity rapid workforce development (recruitment, training and retention) would be required. Such financial investment is improbable in the current economic climate. Besides, it is doubtful that expansion of specialist provision would

meet rapidly rising demand. Until recently palliative care specialists worked almost exclusively with people with cancer; expertise in providing end of life care for people with cancer does not necessarily equip palliative care specialists with the skills and knowledge to care for the aged as they experience a natural and inevitable physiological, functional and possibly cognitive decline, or to care for those with multiple co-morbidities. There is evidence that generalists and professionals from other specialisms do not refer people with non-cancer diagnosis who have a PELC need to specialist services; expansion of specialist services without addressing barriers to referral will widen inequities. The provision of PELC is the responsibility of *all* health and social care professionals, regardless of specialism. Delegation of PELC provision to palliative care specialists risks further fragmentation of services and deskilling other professional groups.

Improved partnership working across settings could offer one sustainable solution, utilising the breadth and depth of knowledge of palliative care specialists through education, training and support to embed the principles of PELC in routine clinical practice. However, a recent review by *Oishi and Murtagh* described inter-professional working in primary care as "*relatively ineffective despite the importance of collaboration having been repeatedly emphasized*"[102]. Good communication between providers, a clear definition of roles and responsibilities, opportunities for shared learning and education, appropriate and timely access to specialist palliative care services and coordinated care were seen as factors supporting partnership working between generalist and specialists services[102,106]. Specific training and skills may be indicated for professionals from different specialties, for example cardiology, neurology, respiratory, renal medicine, who deliver generalist palliative care to their patients and families as part of routine clinical practice.

Effectiveness and cost effectiveness of PELC

The effectiveness and cost effectiveness of PELC can be considered at two levels[106]. The first is the effectiveness of specialists PELC services or models of care when compared to standard care, that is clinical care provided to people with life-limiting illness by any health care professional who is not part of a specialist palliative care team. It should be noted that in the UK specialist PELC provision is reserved for people with complex needs that cannot be met by generalists. Although the goals of treatment in terms of meeting multidimensional needs are the same for specialist and generalists PELC, the population of people receiving care may not be comparable. Nevertheless in assessing the effectiveness and cost effectiveness of specialists; PELC services or models of care a comparator is required and by convention this is the gold standard alternative, generalist care. The second level considered is the effectiveness of adapting interventions, services and approaches developed in the specialist setting for use by generalists in other settings. It is important to consider that as a specialism paediatric PELC is relatively new and as such the evidence base at both levels is limited.

(1) Effectiveness and cost effectiveness of specialist PELC services or models

There is consensus that specialist palliative care is more effective and cost effective than conventional care, but synthesising evidence on the most effective and cost effective models of care is challenging[107-109]. Models of care are heterogeneous and reporting is poor. There is a lack of methodologically sounds studies, in different populations, across different settings and with standardised outcomes to allow comparison between models of care. Cost effectiveness analyses are sparse. Contextual factors around implementation that may provide important opportunities for learning are rarely shared. Service models are typically described according to setting of care as follows:

Hospital based

Hospital based specialist palliative care programmes have developed from the recognition that a significant proportion of people with a PELC need will be hospitalised during their journey. Hospital based models may include an integrated service, a specialist palliative care inpatient unit or a liaison/consulting service. In an integrated service specialist palliative care is co-located and co-manages patients in specific settings. Examples from North America include integrated services in Accident and Emergency Departments or the Intensive Care Unit. This model can be applied in the ambulatory care setting, for example co-locating oncology and palliative care outpatient clinics thereby facilitating early palliative care during active treatment. Inpatient specialist palliative care units assume responsibility for patient care. Often people admitted to specialist inpatient units have complex needs that cannot be met in another setting. In contrast specialist liaison services providing advice and support to a referring clinical team without assuming responsibility for patient care; a multidisciplinary team, which may in practice consist of a single consulting specialist doctor or nurse may provide this. This is less resource intensive and may have greater flexibility and reach but may lack a critical mass of staff to provide adequate support in the 'out of hours' period. Compared to standard care, people who receive specialist palliative care liaison services report greater carer satisfaction, better information giving and greater psycho-emotional support[110].

Hospice based

Bereaved relatives rate the quality of care in hospices as higher than that in any other setting[111]. In recent years there has been growing enthusiasm for delivering hospice care outside independent hospice units in settings that include homes, care homes and more recently virtual space[112]. Several studies have confirmed the benefits of hospice care for people with life-limiting illness and their carers when compared to standard care[113]. Benefits include improved pain control, improved satisfaction with care and a greater likelihood of achieving PPD. Evidence of a significant benefit in other aspects of care including psychosocial, emotional and function outcomes and for carers bereavement, is less convincing. There is little evidence around which model of care work best in which population.

One unique aspect of the independent hospice movement is the role of unpaid community volunteers who contribute to virtually every aspect of hospice life. A 2013 report by The King's Fund highlighted the value of volunteers in improving people's

experience of care, building social capital and community cohesions, supporting integrated care, improving public health and reducing health inequalities[114]. Volunteers were said to be of particular value to those who rely most heavily on services, for example, the elderly and those with multiple co-morbidities. The report recommended clearly articulating the value of volunteers and adopting a strategic approach to volunteering.

Home based
Among the top priorities for people approaching the end of life are being surrounded by loved ones, having dignity and privacy and being in familiar surroundings[67]. Home based PELC care programmes aim to keep people at home or their usual place of care. Home based programmes increase satisfaction with care, reduce symptom burden and increase the likelihood of dying at home; evidence on cost-effectiveness is inconclusive[115]. This model of care requires carers, informal and formal, to support a person to stay at home. In practice, home based programmes are often delivered by district nurses and general practitioners supported by specialist palliative care teams, most often specialist nurses. Communication and co-ordination of care, advance care planning to clarify goals of treatment and specialist services engaging with and enabling primary care team and carers are important elements of home based models[109]. There is evidence that some care is delivered less well at home than in other settings. For example, bereaved relatives report that relief of pain is poorer at home than in other care settings[111]. In particular there are issues with the quality and continuity of care in the 'out of hours' period that may result in unwanted and distressing transitions between care settings when a person's clinical condition or preferences for care change rapidly[100].

Supporting dying people and their carers in the community in the out of hours (OOH) period is a priority[40]. PELC provision and care for the frail and elderly in the out of hours (OOH) period were considered in a national review of OOH primary care provision in Scotland led by Sir Lewis Ritchie that reported on 30 November 2015.[116] The review acknowledged the need for people at the end of life and their carers to be able to directly access care and assistance through a local 24/7 helpline without going through NHS24. The need for safe and secure electronic information sharing across care settings and the importance of anticipatory care planning were highlighted. The review advocated the development of local PELC pathways to ensure that people with a PELC need, their carers and the professionals providing care, know how to access resources; the role of community nursing support, allied health professionals and third and independent sectors organisations in providing care and support was noted. Recommendations to support the delivery of care in non-acute setting, at home, in hospices and care home, were made.

Care Home based
If end of life care is becoming care of the aged, then arguably care homes are the hospices of the future. An increasing proportion of our ageing population who have complex multidimensional needs are living and dying in care homes. Care homes also have an important role in providing intermediate care that focuses on rehabilitation and

enablement; residents may transition between modes of care. People in care homes have less access to specialist palliative care, report poorer symptom control and their relatives report lower levels of satisfaction with their care[11]. Staff recruitment in care home setting can be problematic and attrition rates are high which has implications for the development and maintenance of a skilled workforce. Communication is often poor and advance care planning inadequate which may contribute to transitions between care settings including unnecessary hospitalisations, although in Scotland there is evidence that this is improving[117]. The evidence base around how best to deliver PELC in care homes is weak. In the context of an ageing, multi-morbid population and limited access to informal care, care homes are likely to become increasingly important settings for the delivery of PELC. There is an urgent need to develop the evidence base to support practice in this area.

(2) Effectiveness of adapting interventions, services and approaches
There is less evidence to support the adaptation of specific approaches developed for use in specialist setting for use in other settings by generalists[107]. This can be illustrated by the experience of the Liverpool Care Pathway (LCP) [118]. The LCP is a good practice approach to delivering complex timely high quality end of life care developed by palliative care specialists in the hospice setting. In the UK it was introduced to the acute hospital setting with no prospective evaluation and variable levels of support and training for the non-specialist staff who were asked to implement it in routine clinical practice. While there were examples of this approach significantly improving end of life care for many, a narrative emerged of the approach being used as a generic 'tick-box' protocol by rushed and poorly equipped staff with distressing accounts of death being undignified and hastened through over prescribing of sedatives and withdrawal of hydration and nutrition. An inquiry followed, the findings of which were published in the 2013 Neuberger report, 'More Care Less Pathway'[118]. The report identified systematic shortcomings in implementation of the approach, poor quality uncompassionate care, low levels of skills and training in the care of people who were dying and poor communication with dying people and their carers. The LCP was withdrawn from clinical practice across the UK and replaced in Scotland by a national good practice statement outlining the principles of high quality end of life care[68]. More recently, a cluster randomized control trial examining the implementation of the LCP in the acute setting in Italy did not provide any evidence of improved patient or carer outcomes when compared to conventional care[118]. These examples highlight the importance of prospective evaluation and on-going monitoring of interventions, services and approaches developed in the specialist setting for use by generalists in other settings.

Inequities in access and quality of PELC
Inequities in access to and quality of PELC have been widely recognised since the inception of the hospice movement. These have persisted despite attempts to systematically and comprehensively redress them through increasingly prescriptive national strategy and policy[26]. A 2015 report commissioned by Marie Curie examined the evidence of equity of provision of PELC in the UK[11]. A cancer diagnosis was identified as the primary determinant of access to specialist palliative care services. People with non-cancer life-limiting illnesses have similar symptom, carer burden and

psychosocial needs as people with cancer. However they are less likely to receive generalist or specialist palliative care, report poorer outcomes including pain control and less satisfaction with quality of care and are less likely to achieve their PPD. People from Black, Asian or minority ethnic groups (BAME) in the UK were found to have similar access to PELC as people of white ethnicity. Interestingly they were more likely to access to community based health and social care services but less likely to report satisfaction with care in the last three months of life. People in socioeconomically deprived areas were found to have similar access to community based support but felt less supported and less satisfied with the quality of care than people from affluent areas. Advanced age was associated with less access to specialist palliative care. Gaps in high quality care across all settings were identified with evidence of poor co-ordination of care and confusion about roles and responsibilities of generalist and specialist.

It should be noted that much of the evidence presented in the Marie Curie review, particularly around quality of care, came from the VOICES study, a national survey of bereaved in England and Wales[111]. The VOICES study exclusively collects information from the friends or relatives of deceased adults, not babies, children or young people. Comparable national data for Scotland are not available. The most recent national survey in Scotland was the 2008 Audit Scotland report[10]. Examining data from 2006-07 Audit Scotland identified marked variation in the provision of specialist palliative care services according to age, diagnosis and area (rural areas had less access to both generalist and specialist services). Data according to socioeconomic deprivation and ethnicity were not available. While almost three quarters of people died in hospital or in a care home, 80% of the large sample of bereaved families surveyed considered that their relative had died in an appropriate setting. The report highlighted lack of support for carers.

There have been concentrated and co-ordinated efforts to address the inequities identified in the Audit Scotland report[10,36]. It is not possible to assess progress against this benchmark because of a lack of systematically collected, valid, reliable and readily available data on PELC provision, activity and outcomes[36-39,120]. Defining meaningful outcomes in PELC is challenging. However this is essential for measuring and improving quality, efficiency, effectiveness and equity of services and assessing the impact of policy. A suite of PELC indicators was developed by Health Improvement Scotland through 'Living and Dying Well'[121]. However collection of data on these metrics was not embedded in routine clinical practice, was complex to administer, and these factors became an insurmountable barrier to national data collection. The EAPC has recently produced guidance on outcome measurement in PELC that could inform future developments in this area[122]. In developing metrics it is important to consider the collection and collation of data that will enable international comparison[120].

Inequalities

Health and social inequalities in Scotland are deeply rooted[13]. Socioeconomic deprivation is a significant determinant of where, when and how people die[107,123]. It is important that services and interventions are delivered and developed to be sensitive

to the health and social care needs of individuals. To reduce health inequalities, services must aim to achieve equivalence of outcome not access. This may require additional resource. For example, there is evidence that achieving a home death is more difficult in areas of socioeconomic deprivation[123,124]. To achieve comparable rates of home deaths in affluent and deprived areas, it is estimated that twice the level of resource would be required in deprived communities[124]. PELC must be located within a framework of wider actions to address health inequalities.

Preferred place of death

A consensus across cultures and socioeconomic groups has emerged on the factors that constitute a 'good death'[52]. These include being pain and symptom free; being with friends and family; not being a burden; and being listened to and respected. Many people consider dying at home, in a familiar environment, surrounded by loved ones a key component of a good death. There is no clear evidence that dying at home is better than dying in another care setting, and caring for a dying friend or relative at home is challenging[113]. As death approaches, up to 20% of people's preferences for place of care and death change[125]. Toward the end of life a greater proportion of people, most notably those with experience of it, chose hospice as their PPD. Hospice is considered by many to be a home-like environment and death in a hospice may be perceived to be the next best thing to a home death[113]. A change in PPD may be precipitated by poor symptom control, reversible deterioration in clinical condition or carer crisis[125]. It should be noted that in the VOICES study, although just 3% of respondents believed that their deceased relative would have wanted to die in hospital, of those that did die in hospital, 73% felt of respondents felt that this was the right place for them[111]. It is important to be mindful that for some people dying in their usual place of residence is neither desirable nor achievable. A complex series of factors interact to determine actual place of death[125]. Choice and safety should not be compromised by ambition to achieve targets or implement policy. In practical terms careful consideration should be given to the provision of alternate 'homely' settings of care for those who do not want to, or are not able to, die at home[113].

Achieving PPD has emerged as a major policy theme and is increasingly being used as a measure of quality of PELC[26]. There is good evidence that expressing a PPD influences actual place of death; iterative advance care planning is crucial to achieving this[125]. A third of people in a general population based survey in England in 2010 stated that achieving their PPD would be their top care priority[45], suggesting that to most people, dying well is more important than place of death[113]. Home was the PPD for 63% of respondents in this survey followed by hospice (29%). Individuals who had experience of hospice care were more likely to report a preference to die in a hospice[45]. Hospitals were the least preferred option for place of death. Over time (2003-10) preference to die at home or in hospice care increased and preference to die in hospital decreased. National data for Scotland are not available. However, a retrospective review of case notes from 1,127 people who died that had engaged with specialist palliative care services in Edinburgh between 2009 and 2010 found that 60% of patients expressed the hospice as their PPD compared to home (37%)[126]; the discrepancy between PPD in these two studies is likely to reflect the populations studied. In keeping

with the general population study, those who had experience of in-patient hospice care most often identified the hospice setting as their PPD while those who did not have experience of in-patient hospice care were more likely to identify home as PPD. Less than 1% of people identified hospital as their PPD. People who did not nominate a PPD were more likely to die in hospital. The majority of those with hospice as PPD achieved this (93%), compared with 72% of those whose PPD was home. Incongruence between preferred and actual place of death may indicate unmet need.

Public Perceptions on death, dying and loss

Medical advances have created a 'death-denying' culture[9,17]. Over a number of decades the social context of death and dying has been lost; professionals in institutions have increasingly taken responsibility for managing death and dying[9,17]. Despite the universality of death, an entire generation has limited experience of supporting the dying and bereaved[9,17]. The consequences of a society wide lack of openness about death, dying and loss include many people who are dying and their loved ones being unwilling or unable to openly discuss their preferences and priorities for care and death, views on organ donation, prepare a will or plan a funeral[9,17,50,51]. Limited experience of death, dying and loss affect informal community support networks and may leave the bereaved isolated and turning to professional services for support perpetuating a reliance on professionals[9,17]. In '*More Care, Less Pathway*', Neuberger noted[118]:

"*No matter how much effort is put into training clinicians in good communication skills, unless everyone in society – members of the public, the press, clinicians, public figures – is prepared to talk openly and honestly about dying, death and bereavement, accepting these as a normal part of life, the quality of care and the range of services for the dying, their relatives and carers will remain inconsistent". In the absence of a public discourse about death, dying and bereavement, professionals are likely to become "the whipping-boys for an inadequate understanding of how we face our final days*".

It is noteworthy that the report did not identify actions to address this key finding. The need for wider societal approaches to address the public's reluctance to engage in discussions about death, dying and loss has been recognised in national policy across the UK; in England this agenda is being advanced nationally through the 'Dying Matters' coalition[127] and in Scotland through the 'Good Life, Good Death, Good Grief' (GLGDGG) alliance[9,128].

The media has an important role in framing the public discourse on death, dying and loss. Media framing of an issue seeks to define a problem, diagnose a cause and in doing so make moral judgements as to attribution before offering a solution. The media shape public attitudes and define the limits of what is politically acceptable, which in turn influences policy[129]. This can be illustrated by the example of the LCP[118]. Inappropriate use of the LCP by pressured staff in the acute sector, who lacked skills and training in caring for the dying, was framed as the intentional killing of patients to save money and achieve financially incentivised targets; claims which were not

substantiated by the Neuberger inquiry. Another example is media framing of decisions to deny a treatment or intervention of marginal or unproven benefit to people with advanced, incurable illness as cost cutting; this does not consider the issues around prolongation of life at the expense of quality of life in advanced disease, nor public opinion surveys which indicate that the majority of the general public (79%) believe that quality of life is more important than how long they live[51]. A final example is the dominant media discourse around assisted dying which has left little scope for other public narratives of death, dying and loss[52]. Strategic engagement with the media offers the potential to re-orientate public narratives of death, dying and loss, and re-balance the population debate.

Key challenges identified from the literature on PELC

The development of modern PELC from its embryonic origins in the hospice movement is a remarkable achievement that should be celebrated. Many people have directly benefitted from high quality, person-centred holistic PELC as a result. However, at population level inequities in access to and quality of PELC have persisted, despite the implementation of supportive national policies and continued investment in, and expansion of, specialist services. The key challenges for PELC can be summarised as follows:

- Developing a shared language as a basis for a shared understanding of PELC.
- Clarifying the roles and responsibilities of generalist and specialist.
- Developing and prospectively validating tools to identify and assess need in different populations across the continuum of care within the context of wider health and social care planning and delivery.
- Building an evidence base on which models of care (existing and new) are most effective and cost effective in different populations across the continuum of care; different models will be necessary for different populations, for example, babies, children and young people, people living with rapidly progressive illness, frail older people or people living in care homes.
- Adapting, implementing, prospectively evaluating and monitoring successful approaches developed for use in specialist settings, for use by generalists in other settings.
- Building an evidence base on how best to support carers.
- Increasing engagement with anticipatory and advance care planning to ensure that preference and priorities for care can be met.
- Addressing unmet need in relation to PPC and PPD; identifying alternate 'homely' settings for people who are not able, or do not want, to be cared for or die at home, particularly those with multi-morbidity and the elderly.

- Collection, collation and dissemination of population-level, timely, reliable and valid data to understand the clinical and societal influences on the circumstances of death to inform the design and delivery of services and set priorities for research and policy.
- Defining and embedding in routine clinical practice meaningful outcome measures to monitor provision, activity and quality of PELC at local and national levels to evaluate clinical practice and policy, and enable international comparisons.
- Overcoming pervasive social and cultural barriers to open discussions about death, dying and loss that translate into concrete actions to plan for maintaining wellbeing in the face of declining health, and death.
- Strategic engagement with the media to frame the public debate about death dying and loss.

Service Mapping and Models

PELC provision can broadly be conceptualized across five levels:
1. Support caring for people with PELC needs from within communities including that provided by informal carers, family and friends, independent and third sector organisations.
2. Support caring for people with PELC needs in the community, for example, domiciliary care, home help, care home staff, sheltered housing, provided by health and (predominantly) social care services, independent and third sector organisations.
3. Generalist provision in primary care, for example, general practitioners, district nurses and community pharmacists.
4. Generalist provision by other specialties, for example, cardiologists, respiratory physicians, neurologists and associated nurse specialists.
5. Specialist palliative care.

Mapping national provision across the first four levels of PELC was not considered feasible within the timeframe and resource available to undertake this project. It was considered feasible to map specialist palliative care provision. However, in attempting to do so it became apparent that information to map specialist palliative care provision in Scotland is not readily available at a national level.

To inform this report a national survey, mapping specialist palliative care provision across Scotland was undertaken in collaboration with colleagues from the University of Glasgow (Appendix 3). This survey is on-going and a supplemental report outlining the findings of this national survey will be published in Spring 2016. This survey considered the organisation of specialist palliative care in Scotland, including models of care and range of service provision; data on activity and outcomes was not collected. A number of observations can be made from the preliminary data.

Primary health care teams including general practitioners, practice nurses, district nurses and other allied health professionals deliver the majority of PELC in the community. Community 'Marie Curie' nursing teams provide practical nursing care. A range of social services, home care, home help, sitting services and respite services are available to provide wrap around care for people with PELC needs in the community if required. Support and advice for people with a PELC need and their carers during the OOH period has been highlighted as a priority[40]. In most NHS board areas this is accessed via NHS 24. Recording detailed and up to date advance care plans in the electronic key information summary facilitates timely communication between health care professionals and can avoid unwanted interventions and transitions between care settings in the OOH period. Across Scotland access to telephone advice from a specialist in palliative care medicine is available 24/7 for health care professionals in the community and acute settings. A recent Ministerial Review of OOH and urgent care provision in Scotland has recommended that a new model of care be adopted; specific recommendations relating to the provision of PELC and care of people who are frail and/or elderly in the OOH period were also made and will shape future service development[116].

Community palliative care teams provide domiciliary, specialist palliative care advice and support but not 'hands on' nursing care. In practice, these teams often consist of a single clinical nurse specialist, funded by local hospices, or a 'MacMillan' nurse. The MacMillan charity provides pump-prime funding for these roles for 3 to 5 years, after which time, NHS board funding is required to sustain the service. Teams typically work in geographically defined areas and are linked in the community to primary care teams and care homes. Other members of the multidisciplinary, specialist, palliative care team are accessed through links with the hospice or specialist palliative care in the acute settings. There is significant variation as to the membership of a multidisciplinary team, which may include doctors, nurses, social workers, physiotherapists, pharmacists, occupational therapists, dieticians, psychologists and chaplains.

Within the acute hospital setting in-patient units and liaison services dominate provision. There is evidence of integrated working, including joint multidisciplinary team meetings and out-patient clinics, with oncologists and, to a lesser extent, renal physicians, cardiologists, respiratory physicians and neurologists. Hospice care is provided across a range of settings and services include in-patient, out-patient, day care, home care, hospice at home and tele-medicine. Some palliative medicine specialists are work jointly across the community, the hospice and hospital settings.

Referral criteria for specialist services vary but are in general loosely based on an ability to benefit from the specialist palliative care input, where an alternate service to meet need is unavailable. Irrespective of setting, specialist palliative care providers appear to have developed robust governance structures. Most engage in evaluation and audit. All report adhering to quality and clinical care standards. Some have developed programs of research, although these may be driven by individuals' interest rather than a strategic approach to research and development. All engage in education and training of their staff, and many contribute to education and training of other health and social

care professionals. A smaller number provide education and training for people using their services and carers, and fewer still provide education programmes for the wider community. Most have access to a significant number of volunteers who fulfil a variety of roles; for example, some have trained volunteers to provide befriending services to build community capacity. There is evidence of inter-sector, interdisciplinary partnership working.

Local funding arrangements and evolving national strategy and policy have shaped emerging models of specialist PELC in Scotland. One size does not fit all. To meet the needs of local populations a range of care and supportive services are currently provided for different people across the continuum of care. The balance between services is determined by local factors including existing provision, assessed needs, stakeholder views and resource availability. Many NHS boards have conducted health needs assessments to inform the development of local PELC services. All NHS boards have a designated PELC lead and many have established MCNs. Effective planning of services at local level is vital to delivering equitable, sustainable services to meet local need. The creation of Health and Social Care Partnerships and Integration Joint Boards has, and will continue to, shape the strategic planning landscape.

The Children's Hospice Association Scotland (CHAS), provides a national, specialist palliative care service for babies, children and young people. CHAS has two hospices that provide planned respite care, emergency support, end of life care and bereavement support. CHAS also provides a range of home care services (CHAS at home) and has three specialist nurses (Diana Children's Nurses) who work regionally to support the planning and delivery of paediatric palliative care.

Providing estimates of the need for PELC services against which to benchmark local provision is challenging. Benchmarking in the literature is typically based on service usage, not epidemiological data and is therefore of limited value as models of care and the populations have evolved from those studied[130]. An estimated 75% of people who die have a PELC need[3]. Estimates of the number of specialist palliative care beds to meet this need range from 40–78 per million population[131,132]. There are no reliable estimates around provision of specialist palliative care in the hospital setting. Estimates for staffing levels for community palliative care provision are 2 consultants in palliative medicine, 23 community nurse specialists and 0.8 social workers per million population[132]. There is very little information on the impact of socio-economic deprivation on service provision although one study estimated that twice the level of resourcing is required in deprived compared to affluent areas[124].

Bringing it all together: why we need a public health approach to PELC

The population in Scotland is growing, and ageing. The prevalence of multi-morbidity and frailty is rising at a time when the availability of informal care is falling. To meet the challenge of increasing demand at a time of resource constraint public sector services are undergoing major reform characterised by the integration of health and social care which has been aligned with a policy drive toward early intervention, support for self-management and the delivery of care at home, or in a homely setting.

Death, dying and loss are universal experiences; at a population level they have a major impact on health and wellbeing and are associated with significant cost. PELC can improve the health and wellbeing of people with life-limiting illness and their carers. High quality, equitable PELC across the life course for those with a capacity to benefit from it, is an ethical obligation of health care systems. As a society, how we care for the sick, elderly, frail and dying is a reflection of the value we place on life.

From the literature and discussions with stakeholders, a number of current and future challenges to delivering sustainable, equitable high quality PELC in Scotland emerged. There is an urgent need to develop a shared understanding of PELC and establish the roles and responsibilities of generalist and specialists. At population level, reliable estimates of PELC need, provision, activity and outcome are lacking. The evidence base around the effectiveness and cost-effectiveness of different models of care for different populations in different settings is limited. Achieving the policy ambition of personalised PELC care delivered at home or in a homely setting within this context, and at a time of resource constraint, is a significant challenge. Integration Authorities will require support to develop, implement and evaluate Strategic Commissioning Plans to deliver services to meet local preferences, priorities and needs. The role of the third and independent sectors in delivering PELC should be recognised by Integration Authorities and the strategic planning process should be inclusive of partner agencies.

More widely, cultural barriers to open discussions about death, dying and loss are pervasive. A lack of openness about death, dying and loss is associated with avoidable harms. In theory at least, the public are becoming more comfortable talking about death, dying and loss although there has been little evidence of this translating into concrete action. Strategic engagement with the media could be an important tool in re-framing the public discourse around death, dying and loss.

What is a public health approach to PELC?

This chapter will examine public health approaches to PELC. To inform this process a rapid literature review was undertaken (Appendix 1). The overview that follows is based on the findings from this review, and informed by discussions with stakeholders.

PELC as a public health issue

Early references to placing PELC within a public health framework emerged in the literature in the 1980s[133]. Since then there have been increasing call for PELC to be considered a public health issue,[107,134-136]. The most frequently articulated argument for this is as follows. Death, dying and loss are universal experiences that have a major impact on health and wellbeing at a population level and are associated with significant burden and cost. Demographic, epidemiological and societal factors suggest that, without action, this burden will increase. PELC is a safe, effective and (possibly) cost effective way to reduce morbidity, alleviating suffering and improving quality of life through addressing the multidimensional needs of people with life-limiting illnesses and their carers. How we care for the dying has been described as a "*measure of society as a whole and…a litmus test for health and social care services*" [138]. The current health service response to the provision of PELC is neither sustainable nor equitable. Public health approaches could inform both a health system and a wider societal response to address the avoidable harms associated with death, dying and loss, achieving population level improvements in health and wellbeing. PELC is therefore an area for public health action.

Public health approaches to PELC

From the literature review, two broad themes emerged as to public health approaches to PELC. The first is a health systems approach that focuses on using public health practice and tools to inform the design, implementation, delivery and evaluation of PELC interventions, services, programmes and policies at a local, national and international level. The second is a health promotion approach, 'Health Promoting Palliative Care' (HPPC) which frames death, dying and loss as a societal experience that requires a societal response to build resilience in citizens and communities[17,25].

A cautionary note of terminology
Before these themes are explored in detail, a cautionary note on terminology. The term 'Health Promoting Palliative Care' has become synonymous with a social, rather than a biomedical, model of PELC. This is variably referred to in the literature as the 'new public health', 'public health approaches to palliative care', 'compassionate cities' and 'compassionate communities'. To the public health workforce who may have limited experience in the field of PELC, 'health promoting palliative care' infers any action or intervention to maximise the health and wellbeing of people with a PELC need and their carers. This would include biomedical interventions as well as interventions to address the wider social and environmental determinants of health and wellbeing. Health

promotion interventions are therefore diverse in scope and approach and may include, for example, interventions to promote influenza vaccination in people with chronic respiratory disease or falls prevention for people with dementia; interventions to promote positive mental health and wellbeing among carers; interventions to improve health literacy among people with life-limiting illness; or interventions to support carers maintain employment while fulfilling their caring role. Interventions would also include, but not be limited to, approaches to minimise the avoidable harms associated with a society wide reluctance to openly discuss death, dying and loss.

In the passages that follow 'health promoting palliative care' will refer specifically to the social model of care, as described in the published literature, that aims to frame and address death, dying and loss as a societal rather than a personal or biomedical issue[17]. In focusing on this model, the value of other aspects of health promotion throughout the life course for people with life-limiting illness and their carers is in no way diminished. As our population ages and the number of people living for long periods with complex multiple morbidity increases these approaches to care (and self-care) will become increasingly important in maintaining the physical, functional and psychosocial health and wellbeing of people with life-limiting illness and their carers. This is simply a reflection of the emergent academic literature. It is important to consider that a narrow perspective on the health promotion role in relation to PELC may limit future engagement of public health specialists in this field. A shared language and understanding are necessary to create the conditions where people, their carers and interdisciplinary professionals can work collegiately to improve health and wellbeing.

Public health approaches to interventions, services, programmes and polices

From the literature a number of areas where public health tools and practice could be focused to make a significant contribution to this field were identified. These are outlined in the section that follows.

Leadership and Advocacy

Increasingly the argument for equitable PELC provision is being articulated as one of public health ethics related to social justice. There have been calls for PELC to be considered a fundamental human right[28]. Some commentators suggest that grounding PELC in public health ethics will advance this agenda further than placing PELC within a rights-based paradigm[136]. Leadership and advocacy can be used to drive change through various levers that may include primary legislation, development and implementation of strategy and policy, securing funding and establishing commissioning arrangement to achieve equity. Leadership and advocacy are required at local, national and international levels.

Strategy and Policy

The WHO has been instrumental in placing PELC on the international agenda from the 1990s onward[137], most recently in the World Health Assembly resolution of 2014[20]. In Scotland significant improvements in PELC arose as a result of the first national

strategy for PELC[25], with similar progress across the developed nations[138-140]. Strategy and policy are key drivers for action. The implementation of strategy and policy should be monitored to ensure it is being translated into clinical practice and assess impact.

Health systems, programmes and services

The WHO has been instrumental in integrating PELC into health care systems internationally through progressive public health policy[136]. Public health tools can be used to assess need (in the context of demand, supply and resource allocation) and explore how this can best be met at population level. This requires careful planning of systems, programmes and services and an understanding of the barriers to implementation and how these can be overcome. Establishing meaningful short, medium and long-term measures of outcome is important. On-going evaluation, focusing on effectiveness, cost-effectiveness, equity, experience and sustainability is crucial.

Quality assurance, indicators and standard setting

Quality assurance of services, programmes and systems should be embedded in practice as part of a continuous cycle of improvement. Actions include establishing clinical guidelines, setting standards and developing indicators to ensure consistent, high quality, evidenced based and safe practice. The latter are important to allow benchmarking locally, nationally and internationally to facilitate shared learning.

Health Intelligence and data

The collection, collation, analysis, reporting and dissemination of accurate, complete, relevant, timely health intelligence underpins all public health activities. Data are integral to planning, implementing, and evaluating interventions, services, systems and policy, and provide an epidemiological basis for further research and development. It is crucial that data are available at a local and national level to inform these activities. Assessment of needs, preferences, access to and quality of care are important measures. Skill and expertise are required to carry out health needs assessment to determine the extent to which needs are being met equitably and identify opportunities for improvement.

Public Health England (PHE) has made significant progress in this area through their national End of Life Care Intelligence Network that collects, analyses and disseminates inter-sectoral data relating to the quality, volume and costs of providing care[141]. A range of locality specific health profiles are available on a single, central online repository adjacent to tools for modelling and quality assuring services. Through partnership working with key stakeholders a national, minimum monitoring dataset has been established which supports service design, delivery, evaluation, audit and research. The expertise developed through this collaboration has promoted more effective and efficient data collection and analysis. Data outputs from PHE have been used by the third sector partner Marie Curie to create an interactive atlas that is freely available online and allows rapid access to locality specific information, providing opportunities to directly compare and contrast regional PELC metrics[142]. The Scottish entry, though present, has limited data.

Academic research and development

Collaborative, high quality research can generate a translational evidence base, identify future priorities for action and attract funding. Research has a valuable role to play in understanding preferences and priorities for care and death and developing sustainable effective and cost effective models of care to meet these across the continuum of care. Narrative based research may aid understanding of the lived experience, pointing to actions required to sustainably build resilient people and communities. Scotland has a critical mass of academics with an interest in PELC[120], and significant expertise in research methods, in particular the evaluation of complex public health interventions in other fields that could be harnessed to progress the PELC agenda. It is important to note that PELC is of interest across a range of specialities. Leadership and succession planning are required to create a culture that supports the development of academic infrastructure in specialties beyond specialist palliative medicine. The importance of research in progressing the PELC agenda was highlighted in the Scottish Government's recently published 'Strategic Framework for Action' which committed to supporting the development of a PELC Scottish Research Forum[39].

Education and training

Front line staff should receive appropriate education and training to equip them with the appropriate skills knowledge, attitudes and values to deliver high quality PELC.

Education and training opportunities for people with life-limiting illness and their carers should not be overlooked. These are central to facilitate early intervention and supported self-management. There is significant scope to develop the role of the health promotion specialist in this area. An awareness of the issues around health literacy and how these can be overcome is crucial to practice in this area. More widely, raising awareness at population level of death, dying and loss, has the potential to address some of the avoidable harms associated with a societal reluctance to openly discuss these issues. The public health community have considerable expertise in raising awareness in the general population of health related issues, for example, tobacco or alcohol use, or actively promoting interventions to minimise avoidable harms, such as primary immunisation campaigns or screening services.

Public health is "*what we as a society do collectively to assure the conditions in which people can be healthy*"[143]. It follows that public health action is the responsibility of individuals and communities, private, public, government and third sector organisations. There are many examples where public health approaches have been used in the design and delivery of PELC services to meet local needs with little or no input from the specialist public health workforce. In Scotland, for example, it was leadership and advocacy from the palliative care community that drove the development of palliative care guidelines to quality assure clinical practice and the development of the first national PELC strategy. Public health specialists have, however, developed a set of core competencies, knowledge, skills and attitudes that are of value when applying public health approaches to practice and policy, and could

make a meaningful contribution to this agenda as part of an interdisciplinary, inter-sectoral team.

The Health Promoting Palliative Care Model

The concepts of health promotion in the context of palliative care have been discussed fleetingly in the literature since the late 1990s. However, the Health Promoting Palliative Care (HPPC) model proposed by Kellehear has gained most traction[17]. This has been developed from the theoretical alignment of the core principles of PELC with the key actions of the Ottawa Charter[144], as articulated through Health Cities[145]. The approach is based on four central concepts:

- Compassion is an ethical imperative for health;
- Health is a positive concept even in the presence of disease, disability or loss;
- Compassion is a holistic / ecological idea; and
- Compassion implies a concern with the universality of loss.

Kellehear develops these central concepts further in nine statements that, read with the defining characteristics of Healthy Cities, define a Compassionate City[25]:
1. Has local health policies that recognise compassion as an ethical imperative;
2. Meets the special needs of its aged, those living with life-threatening illness and those living with loss;
3. Has strong commitment to social and cultural differences;
4. Involves the grief and palliative care services in local government policy and planning;
5. Offers its inhabitants access to a wide variety of supportive experiences, interactions and communications;
6. Promotes and celebrates reconciliation with indigenous peoples and the memory of other important comminute losses;
7. Provides easy access to grief and palliative care services;
8. Has recognition of and plans to accommodate those disadvantaged by the economy, including rural and remote populations and indigenous people and the homeless; and
9. Preserves and promotes a community's spiritual traditions and storytellers.

The relationship between health promotion and health promoting palliative care is outlined in Table 1[146]. Kellehear argues that death, dying and loss are social experiences that require a social, not a personal or a biomedical response. By restoring community involvement at the end of life, expectations and knowledge of death, dying and loss, change. This fosters healthier attitudes, normalising death, dying and loss thereby minimising the associated harms. This approach builds personal and community resilience. In turn PELC services can re-orientate, supporting professionals to work with communities providing care at the end of life. Community engagement and development is central to the delivery of this model.

This approach resonates both with policy direction and public health proactive in Scotland, which are increasingly orientated toward co-production and asset-based approaches[14]. This approach has been embedded in policy in Australia[147] for some

time and more recently recognised in UK policy[9,26]. In England this approach is being supported at a national level through the 'Dying Matters' coalition established in 2009[127]; in Scotland the GLGDGG alliance was established in 2011[127,148].

Both are asset-based approaches that aim to help people talk more openly about death, dying and loss, with a spectrum of activity from information provision, public education and awareness raising through to community engagement and community development. Briefing Paper 5 prepared by the Scottish Partnership for Palliative Care, provides detailed information on GLGGGD. The briefing highlights the diverse membership of the alliance and the breadth of partners engaging in a range of innovative HPPC activities in Scotland, from developing written information leaflets to producing short videos on death, dying and loss, from public lectures to art installations and festivals of storytelling and remembrance. GLGDGG provide small grants to support local communities develop HPPC approaches and provide networking opportunities for members. The need and desire to undertake evaluation in order to inform future development of this approach, practice and policy, and the challenges of doing so, are highlighted.

The recent Scottish Parliamentary Inquiry into PELC, commended *"programmes such as Good Life, Good Death, Good Grief for helping to bring difficult conversations around death and dying into the fore and making these conversations more approachable,"* and recognised "*the need for having a national (or 'top down') approach to public health campaigns but also acknowledge[d] the importance of local initiatives (bottom up) such as those mentioned[d] in enabling conversations about death and dying to take place at a community level*"[40]. The Committee identified a "*role for the Scottish Government to encourage a bottom up approach within local communities,*" urging the Scottish Government to use its Strategic Framework for Action to "*help support discussions around death and dying and also raise the public profile about the need for such conversations.*" [40]

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[d] Examples included the charity CaringBridge who set up a page to allow people to create a blog to communicate with friends, family and others on the internet; East Dunbartonshire Council working in partnership with Macmillan Cancer Support to develop a website to allow people living with life limiting conditions to identify community facilities and services to help them customise their support plans and build support networks; 'Solicitors for Older People Scotland,' a consortium of legal practices in Scotland working in partnership with Age Scotland to attend lunch clubs at which a lawyer discussed legal planning.

Table 1. Health promotion as outline in the Ottawa Charter and Health Promoting Palliative Care[146]

Health Promotion	Health Promoting Palliative Care
Build Healthy Public Policy Develop policies to remove the obstacles to health and empower people to make healthy choices	**Combat death denying health policies and attitudes in wider society** **Engage in development of public policy relating to palliative care and the support of dying people**
Create Supportive Environments Make all environments conducive to health – workplace, schools, leisure facilities, health services	**Provide social supports (individual and community)** For example, this might involve establishing support groups for those facing death, dying, loss and care and support structures for wider society involved in relevant issues (e.g. funeral directors, florists). Encourage inter-personal reorientation to provide people with the skills to cope with life-limiting illness
Strengthen Community Actions	Healthcare should be participatory where professionals work with as opposed to on others, recognising the importance of social relationships and strengthening existing networks
Develop Personal Skills Development of personal skills through provision of information and education to enable people to prepare for and cope with maintaining health and dealing with illness	**Provide education and information for health, dying and death** Include health and death education at all life stages
Reorient the Health Services Health promotion should not be confined to health services and needs to involve many groups and disciplines	**Encourage reorientation of palliative care services** To enable palliative care services to better understand and appreciate the potential of health promoting palliative care

Social and cultural norms are complex and take time to change, requiring strategic planning and long-term commitment from a solid research base[149]. However, much of the literature in this area is concerned with developing and refining the health promoting palliative care conceptual framework[150]. Academic theory has been slow to translate

into evidence-based practice with reports focusing on the development and implementation of interventions describing activities and outputs rather than outcomes.

In the UK, context projects to date, have most commonly involved public education and awareness raising, albeit in a range of settings through a variety of media[151,152]. A recent systematic review summarised the evidence relating to the impact of 'new public health approaches to end of life care', specifically, community engagement, mobilisation or social network development in end of life care[153]. The authors identified eight 'good to moderate' quality articles (covering six studies). Four articles reported interventions[154-158]; three involved training volunteers, either as peer educators in a UK study[156], or to provide palliative care in local villages[154,155] (two studies, covering the same data, were from Uganda, therefore their findings may not be generalizable to the UK). The final study examined carer outcomes in a quasi-experimental community based pilot study examining the role of a community network facilitator in Australia[157].
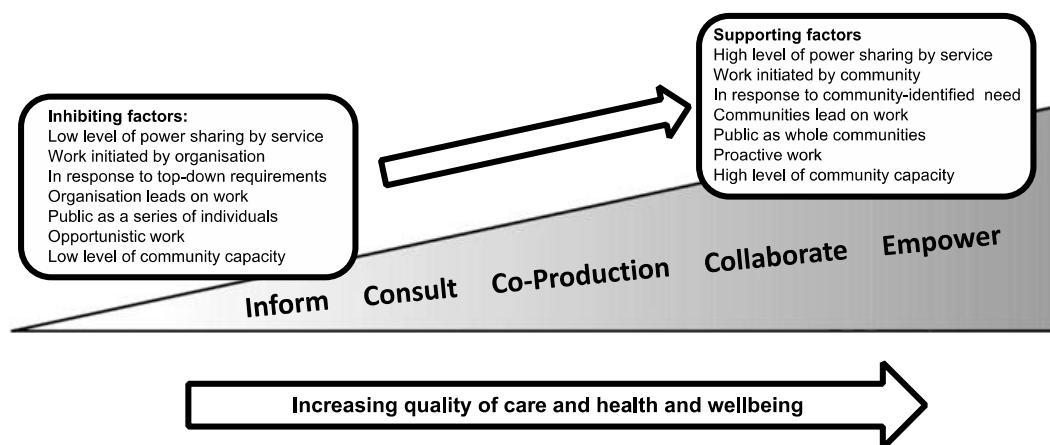
Of the remaining studies, one quantitatively analysed data examining friends in a caregiver role, using data from a national health survey[158]. Two (examining the same data) observed and documented naturally occurring changes in social networks for carers in Australia[159,160], and, one, naturally occurring social networks among the recently bereaved in Sweden[161]. Synthesising robust evidence from a small number of studies, with mixed methodologies, from a range of settings, is challenging[153]. There was evidence that naturally occurring social networks provided adequate support; only when there was evidence of dysfunction in social networks was professional help needed. Although social networks increased in size through caregiving, reciprocity decreased between people indicating very complex relationships and there was evidence that managing social networks was a strain on carers. A synthesis of evidence from qualitative studies suggested that people supporting those at the end of life or volunteers receiving education and training directly experienced benefits (increased confidence and ability, death literacy, individual learning, personal growth and reflection) that may have been felt more widely in the community, although sustained action was only possible where social networks were strong and social capital already existed.

An article not included in the systematic review produced by the Australian team of Horsfall and co-workers, examined the role of formal organisations in supporting caring networks develop through the health promoting palliative care approach which has been embedded in academic theory and policy in Australia for some time[162]. This study found that policy was not being substantially translated into practice, with limited awareness of and engagement with the health promoting palliative care approach from formal service providers.

Community engagement operates on a spectrum as conceptualised by *Sallnow and Paul* in Figure 2[163]. Arguably activity on the right of this diagram is more difficult to achieve but has the potential to create a sustainable equitable service model that is responsive to local needs and builds social capital. This model has been highly successful in Kerala, India where, operating within community governance structures

trained volunteers, supported by professionals and in partnership with local government, identify PELC needs in their area and organise a holistic response[164]. This provides a sustainable solution in a resource poor setting. There are no examples of this type of activity in the UK in relation to PELC although learning from other areas could be applied.

Figure 2. Spectrum of engagement in end of life care: developing community capacity[163]

Inhibiting factors:
Low level of power sharing by service
Work initiated by organisation
In response to top-down requirements
Organisation leads on work
Public as a series of individuals
Opportunistic work
Low level of community capacity

Supporting factors
High level of power sharing by service
Work initiated by community
In response to community-identified need
Communities lead on work
Public as whole communities
Proactive work
High level of community capacity

Inform   Consult   Co-Production   Collaborate   Empower

Increasing quality of care and health and wellbeing

Despite a limited evidence base the community development model in PELC has gained momentum in the UK[151,152]. In 2013, in a survey of 220 palliative care providers across the UK, 60% of those who responded (response rate 66%) indicated that public health approaches to death, dying and loss were a priority for their organisation; the most common initiatives undertaken were working with schools; engaging community groups and organisations; raising awareness; and using the compassionate communities' framework or using 'Dying Matters' as a focus to raise awareness[152]. The authors concluded that this was an "*under-researched area, and conceptual clarity of what the approach comprises and does not, is essential…. detailed evaluations of these initiatives from various perspectives are needed to underpin future work*".

A recent scoping exercise of Compassionate Community projects in the UK identified 32 diverse projects led by a wide variety of stakeholders including individuals, hospices, health care, the third sector, funeral directors and academia[151]. Stakeholders identified a number of barriers to the health promoting palliative care approach being developed, implemented and evaluated, including social taboos around death, professionals attitudes, lack of resource (including funding), concerns around trust and risks, lack of clarity around definitions of, and approaches to, developing Compassionate Communities and a changing strategic environment. The inherent difficulties in defining and evaluating these projects were identified. Opportunities for sharing learning and networking were extremely limited. The authors of the report concluded that while there was evidence of enthusiasm for these approaches, communities needed support to develop them. There were very few examples of the approach being adopted under a public health framework. It is important to note that the risks associated with this

approach have not yet been fully characterised. There is a danger that the authenticity of the approach is compromised by professional involvement and a push to delivering this approach as a service response. The report also suggested that attempts to formally recognise and regulate informal support networks may be disruptive, preventing these from developing organically, and acting as a barrier to community involvement.

PHE have recently, in association with the National Council for Palliative Care, developed a toolkit that provides an introduction to designing and implementing HPPC approaches to end of life care in their communities[164]. The toolkit explores the academic theory underpinning the approach in some detail providing some practical examples of initiatives already undertaken, and sign-posting to evaluation resources.

A range of practical resources to support asset-based approaches and co-production have been developed in Scotland. Although not specifically developed for the field of PELC, these resources could be applied to this agenda. They include a range of tools and resources developed by the Scottish Community Development Centre (SCDC) that are highly relevant to the Scottish context,[166] and the Scottish Co-production Network[167], co-facilitated by the SCDC, which supports the development of co-production approaches in Scotland through sharing practice and information exchange.

Key challenges for a public health approach to PELC

Public health action is not the sole remit of public health specialists. However, with specific knowledge, skills and attitudes in areas of essential public health function, public health specialists could make a meaningful contribution to the work already underway in this area.

Public health approaches have the potential to inform complementary service-based and wider societal responses to PELC. There is a compelling argument for the service-based response to PELC to be delivered through a public health framework to ensure high quality, equitable care for those with a capacity to benefit from it. It is an anomaly that PELC is often not considered when a life course approach to planning at population and local level is adopted. Public health specialists have expertise in navigating complex service environments and could make a valuable contribution to the strategic planning and delivery of PELC by Integration Authorities and partners in the independent and voluntary sectors. Importantly, public health specialists can effectively advocate for PELC services to be located within a framework of wider actions to address inequalities.

There are avoidable harms associated with a societal reluctance to openly discuss death, dying and loss. The evidence base on how to address this is limited. The approach that has gained most traction is Kellehear's HPPC model; progress translating this model from academic theory into evidence based practice has been slow. In Scotland this approach is being progressed at a national level through the

GLGDGG alliance. While the published literature to date is limited, the absence of evidence is not in itself evidence that this approach does not have the potential to make a significant contribution. Public health action is often taken where the evidence base is limited yet there is a moral and ethical imperative to doing something. Shifting cultural norms is complex, takes time and requires innovation[149]. Research has the potential to inform practice and policy. Lessons can be learned from the growing evidence base around community engagement to, for example, reduce inequalities in health[166]. If current practice is not evidence based then it must be evidence generating. There is a need to apply conceptual frameworks to support robust evaluation of complex community engagement and community development interventions that examine not just process but direct (and indirect) outcomes in the short, medium and long term, costs and resource use[168]. Interventions to raise public awareness and change public attitudes must consider health literacy and equalities sensitive practice.

There is a need to develop a better understanding of the goals of community development work, support communities developing, implementing and evaluating interventions and support exchange of knowledge and best practice. Extension of community development models to inform the design, implementation and delivery of PELC services may currently be aspirational. The evidence base around the use of these models in relation to PELC and in the social and political context of the UK must be developed.

Finally, a narrow perspective on the role of health promotion in relation to PELC may be a barrier to engaging the public health community. A shared language and shared understanding are necessary for effective action. In the context of a wider policy agenda toward early intervention and supported self-management there is scope to develop the role of health promotion specialists in PELC, adapting and applying core health promotion skills, attitudes and knowledge, to support the delivery of PELC and advance practice in this area.

Conclusions and recommendations

In the UK both PELC and public health have grown in parallel from their community origins. Both recognise the need for experiences to be socially framed and are underpinned by an understanding that co-production and asset based approaches support the delivery of holistic, realistic and compassionate care. It is anomalous that PELC has rarely been viewed through a public health paradigm. This report has presented a compelling case for applying a public health approach to PELC. With core skills, knowledge, attitudes and values, public health specialists are well placed to support the PELC agenda. However an inter-sectoral, population-level response is required. The challenges and opportunities in applying a public health approach to PELC are summarised below. As a starting point, a number of high-level national recommendations have been made that could contribute, through co-production, contribute to the valuable work already underway in this area.

PELC as a public health issue
This report has presented the case for the public health workforce renewing their interest in PELC as a public health issue.
Recommendations 13, 14, 15, 16, 17

A shared language and shared understanding
Lack of a shared understanding of the scope and goals of PELC and lack of clarity around the roles and responsibilities of generalists and specialists has been a barrier to effective action. The nuances of these issues are discussed in greater detail in Appendix 6.
Recommendations 3, 4

Health Intelligence and current data deficits
Health intelligence is required to support Integration Authorities and partners in the independent and voluntary sectors design, deliver and quality assure evidence-based services to meet the needs, preferences and priorities of local populations. Scotland is a world leader in the centralised collection and collation of high quality, individual level, electronic health and social care data.
Recommendation 5, 10, 11

Building research capacity and developing the evidence base
There is evidence to support specialist palliative care services, but there are significant evidence gaps around how best to identify and meet PELC needs in different populations and settings, including crucially the needs of informal carers. More broadly, at population level, accurate and detailed epidemiological data to help us understand the period of morbidity prior to death are lacking. For example, we do not know what proportion of people will experience decline and dependence at the end of life, for how long or the nature of this decline and dependence.

Scotland's critical mass of academic and clinical expertise in PELC should be harnessed. Leadership and succession planning is required to support the

development of academic infrastructure across a range of specialties where PELC is of direct interest. Moreover, there are opportunities for knowledge exchange from other fields, for example, anticipatory care planning and supported self-management have been embedded in clinical practice for people with long-term conditions for some time. These are directly applicable to PELC, indeed many people with PELC needs who are living with multiple, complex comorbidity will be familiar with these tools and approaches. Working across disciplines, public health specialists are well placed to identify opportunities for knowledge exchange. As seen from the example of the LCP[118], it is crucial that approaches developed for use in one setting by one group of professionals should be robustly evaluated at implementation and in routine clinical practice if adapted for use in other settings by other professional groups. Public Health specialists should use their skills, knowledge and attitudes to support Integration Authorities and community planning partnerships do this using the Scottish Government's 3 Steps Improvement Framework. The recently established Scottish Research Forum for PELC has the potential to make a significant contribution to this area[39].
Recommendations 6, 7, 8, 9, 15

Establishing meaningful outcomes and indicators
Establishing meaningful outcomes in PELC is challenging but there is emerging consensus on key metrics, and international experience can directly inform developments in Scotland. In particular, there is interest in capturing people's experiences of care as a measure of the quality of services. In localities across Scotland the VOICES study has already been piloted. With investment, it would be possible to extend the VOICES study, or another appropriate survey that is inclusive of the whole population, to provide national data on people's experiences of PELC. Alternatively, it may be feasible and economically viable to utilise existing and emergent tools available through NHS Scotland's Quality Improvement Hub. The current PELC indicators in Scotland are complex to administer which has proven an insurmountable barrier to national data collection.
Recommendations 10, 11

Inequalities and Social Justice
Framed as a social justice issue, the provision of equitable PELC is unequivocally the business of the specialist public health community. The skills, knowledge, attitudes and values of public health specialists in Scotland should be harnessed to provide leadership and advocacy in progressing this agenda. Scotland has deep-rooted social inequalities which impact on health and wellbeing. Our ambition should be to achieve equality of outcome not access, and here public health leadership and advocacy is essential.
Recommendations 13, 16

Developing the role of health promotion
There is scope to develop the role of health promotion specialists in relation to PELC to facilitate and support people, and their carers, to live well until they die. This is

particularly relevant in the context of a wider policy drive toward early intervention and support for self-management and in the face of an ageing, multi-morbid population. **Recommendations 14, 15**

Service Improvement
Across Scotland Integration Authorities are conducting Joint Strategic Needs Assessments, relating the health and social care resource they have available to the needs of their local population, for their Strategic Commissioning Plans. A life course perspective is frequently used in planning at population and local level; it remains anomalous that PELC is not generally considered in this context. Community planning partnerships have a pivotal role to bringing together public, private, community and third sector organisations to inform the development, implementation, delivery and evaluation of PELC services. PELC will feature prominently in Strategic Commissioning Plans given the resource implications of delivering these services. Beyond the requirement for health intelligence to support Strategic Commissioning, Integration Authorities and community planning partnerships will require support interpreting evidence for decision making and using assets-based approaches and co-production to develop, implement and evaluate interventions and services to meet local preferences and priorities for care. Improving services is a core public health function. **Recommendations 5, 7, 8, 9, 10, 13, 14, 15, 16, 17**

Workforce planning and development
The quality of PELC that people experience is directly influenced by the knowledge, skills, attitudes and values of front line staff across the continuum of care. The *Neuberger* report identified significant shortcomings in the skills and attitudes of staff caring for people who were dying in the acute sector in England[118]. It is not clear whether these findings are generalisable to Scotland although evidence from the literature review would suggest that many health and social care professionals feel they lack the skills and confidence to discuss death, dying and loss.

There is evidence from the social care sector in Scotland of poor recruitment and retention and gaps in the skills and values of front line staff[169]. Workforce planning and development is crucial to ensure that all front line staff are competent and confident discussing issues around death, dying and loss, and have the skills and values to deliver high quality PELC in all care settings. Action at a national level is required to create conditions conducive to recruitment and retention of front line staff in health and social care and support their training and professional development. At a local level the need for workforce planning and development should be explicitly recognised in the Strategic Commissioning Plans. A significant proportion of the social care workforce is comprised of staff from the third and independent sectors; workforce development should be inclusive of partner agencies across sectors.

How and where the specialist palliative care workforce is deployed to support sustainable development of the generalist palliative care workforce will need careful consideration and negotiation. Primary care is the backbone of generalist palliative care

provision and has a central role in ensuring continuity and co-ordination of PELC. The future of primary care services in Scotland must be secure.
Recommendations 4, 12

Strategy and Policy
In Scotland, PELC have been embedded in strategy and policy. The recently published '*Strategic Framework for Action*'[39] will build upon the success of '*Living and Dying Well*'[26], the first national strategy dedicated to PELC. The Scottish Government should continue to ensure that PELC is visible in strategy and policy in other relevant areas of health and social care, for example, those relevant to carers, Primary Care and disease specific areas such as dementia. High-level acknowledgement by the Scottish Government that death, dying and loss are inevitable human experiences rather than a failure of modern medicine is important and would shape the public discourse.

It is perhaps time to pause and reflect more widely on the Scottish Government's policy drive to deliver PELC at home, or in a homely setting. Is this the right policy? Does this strategic narrative resonate with the preferences, priorities and needs of people who are dying and their carers?[170] There is no evidence, for example, that dying at home is better than dying in any other care setting, on the contrary, there is some evidence that symptoms control is poorer at home than in other care settings. Just as we must caution against considering death a failure of medical science, we must caution against considering any hospitalisation for symptom control or any death in hospital to be a failure of our systems and services. While few people identify hospital as their PPD, the evidence suggests that this changes as death approaches; of those people who do die in hospital, many relatives believe that despite their expressed preferences otherwise, this was the correct care setting for them at the time of their death. How do we reconcile this with the current overarching policy drive and how do we capture these nuances in indicators that reflect the changing preferences and priorities of people who are dying and their carers?

If this is the correct policy, then a pressing question for integrating health and social care partnerships must be how to deliver care at home or in a homely setting when resources are scare and demand from an ageing, multi-morbid population who have diminishing access to informal carers, is rising. Given the population demographics, it is likely that future demand for in-patient care across all settings will increase, as will deaths in institutional settings. Where are these in-patient beds? What are the key elements of a 'homely' setting and how can we recreate such an environment on, for example, a busy acute hospital ward? The strength of the hospice movement is that it reflects the aspirations for care of the local community that it serves. Hospices must evolve to take a whole system approach, understand the needs of their communities and direct resources to meet these without losing this connection. In turn, the health and social care systems must be reflexive and responsive to the local community. Integration Authorities must listen to the preferences and priorities of people with life-limiting illness and their carers and through co-production develop, implement and evaluate diverse models of care (and thoughcare) in different settings to meet these, strengthening evidence based policy and practice and identifying opportunities to share

learning. Given the increasing importance of care homes as 'homely setting' we must also consider the need to address wider issues such as tenancy rights for people living in care homes. It is also important to recognize that
Recommendations 1, 2, 3, 5, 6, 7, 8, 9, 10, 11, 17

Wider societal approaches
There are avoidable harms associated with a societal reluctance to talk openly about death, dying and loss. Shifting cultural norms requires complex interventions across society; policy and practice must be rigorously evaluated to build an evidence base to inform decision-making. The considerable expertise Scotland has in the design, implementation and evaluation of complex public health interventions, for example, the robust work on interventions in the Early Years, could be applied to this field[171]. Specific to PELC, PHE has developed a toolkit to support communities design, implement and evaluate HPPC approaches. The Scottish Community Development Centre, who co-facilitate the Scottish Co-Production Network, has developed a range of tools and resources to support co-production and asset-based approaches that are relevant to the Scottish context[166,167]. Whilst not specific to PELC, these could be applied to this agenda. Further development of HPPC approaches should be encouraged. These should be subject to robust evaluation to build the evidence base around what works in the socio-political context of the UK.

A strategic approach to framing the public debate around death, dying and loss must include engagement with the media. Opportunities for knowledge exchange from practice in other areas, such as the recent experience in changing Scotland's relationship with alcohol, should not be missed[172]. Importantly, we need to reclaim the narrative. We need to create an accessible, open space through which examples, stories, myths, experiences of death, dying and loss can be shared. What is a good life? What does it mean to live through a period of inevitable physiological decline? How can we ensure that people's well-being is supported as their health declines, giving quality and meaning to their life? Perhaps through this approach, as a society, we will arrive at a shared definition and understanding of PELC.
Recommendations 3, 7, 8, 9, 15

The Scottish Government's [Strategic Framework for Action on Palliative and End of Life Care](link) (SFA) was published on 18 December 2015 as this report was being prepared for publication. The SFA maps the future direction of PELC in Scotland. Encouragingly, the SFA recognised the importance of adopting a public health approach to PELC and the valuable contribution that the public health workforce could make to this agenda. This is a timely opportunity for the Scottish Directors of Public Health to ensure PELC is aligned with public health practice in Scotland.

National Recommendations

As a starting point a number of high-level, national recommendations have been made that could, through co-production between agencies and stakeholders, contribute to the work already underway in this area. Unless otherwise indicated we envisage the implementation of these recommendations being facilitated by the National Advisory Group for Palliative and End of Life Care:

1. Scottish Government should explicitly acknowledge that death is an inevitable, and normal, part of life in its strategic narrative.
2. Scottish Government should ensure that PELC is visible in relevant health and social care strategies and policies.
3. A strategic approach to framing a population debate on the issues around death, dying and loss is required; this should include engagement with the media. This debate should seek to promote more open and meaningful dialogue between the pubic and health and social care professionals, and endeavour to establish a clearer terminology that resonates with the public, and translates from policy into practice, of what PELC is and does.
4. All generalist and specialist health and social care professionals should be supported and empowered to provide high quality PELC care.
5. A PELC intelligence network should be established with a remit to collect, analyse, interpret and disseminate data and evidence relating to PELC need, provision, activity and outcomes in Scotland to support local Integration Authorities develop, implement and evaluate Strategic Commissioning Plans and drive quality improvement. This will require leadership from Scottish Government. Public health specialists should work with partners to support this agenda.
6. A strategic approach should be taken to develop a sustainable and innovative programme of PELC research that directly informs clinical practice, health and social care policy and reduces in inequalities in access to and quality of PELC[e]. Academic leadership and succession planning are required to develop the academic infrastructure across a range of specialities where PELC is of interest.
7. Structures that provide an open platform for stakeholders across Scotland to share emergent examples of good practice and experience of what works, for whom and why, facilitating knowledge exchange, informing evidence-based decision making and driving quality improvement in PELC should be maintained and supported to develop their role further[f]. This requires inter-sectoral capacity and commitment.
8. There is a need to develop HPPC approaches, such as those undertaken by members of the GLGDGG alliance, in Scotland. Formal evaluation of HPPC

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[e] The Scottish Research Forum, established following the recent publication of the Scottish Government's 'Strategic Framework for Action on Palliative and End of Life' has the potential to make a significant contribution to this area.
[f] Examples include local palliative and end of life care networks, existing national structure such as the Scottish Partnership for Palliative Care and emergent national structures such as the newly established Scottish Research Forum.

initiatives should be encouraged and supported to build the evidence base relating to this area. Public Health specialists can contribute to this agenda.

9. The GLDGGG alliance provide practical resources to enable local communities to develop, implement and evaluate local HPPC initiatives; through co-production, these resources should be further developed to meet the emergent needs of local communities adopting HPPC approaches. Learning from asset-based approaches in other fields has the potential to inform and enhance the development of HPPC approaches in Scotland[g].

10. Indicators that can be embedded in routine clinical practice and at local, national and international level to support service design, delivery, monitoring, quality improvement and benchmarking are required. These should be aligned with existing national outcomes. Indictors should be produced through co-production with stakeholders. Public health specialists should support this agenda.

11. Consideration should be given to undertaking a national study of bereaved peoples' views on the quality of care provided to their loved one in Scotland.

12. Workforce planning and development should be considered at a national level but also addressed in local Strategic Commissioning Plans.

Recommendations for Public Health

In addition to the areas of public health support identified in the national recommendations, the Scottish Directors of Public Health and all public health specialists should:

13. renew their interest in PELC as a public health issue.

14. explore how best to develop the existing roles of health promotion specialists in PELC.

15. explore how best to encourage and support the development, implementation and evaluation of HPPC initiatives by local communities.

16. advocate for PELC to be located within the wider framework of actions to address inequalities.

17. provide leadership and strategic support to Integration Authorities and community planning partnerships in planning, delivering and continuously improving PELC services.

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[g] Existing structures such as The Scottish Co-Production Network and The Scottish Community Development Centre provide a range of generic and field specific co-production and asset-based resources as well as a platform to support knowledge exchange.

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Appendix 1. Literature search strategy

Databases were searched using the following search terms:

via the OVID interface	
Medline	**Embase**
Exp Palliative care/	Exp palliative therapy/
Exp Terminal care/	Exp terminal care/
Exp terminally Ill/	Exp terminal disease/
Palliat*.mp.	Exp terminally ill patient/
(terminal* and (care or caring or ill*)).mp.	Palliat*.mp.
End of life.mp.	(terminal* and (care or caring or ill*)).mp.
Public health/	End of life.mp.
Health Promotion/	Public health/
Health promoting palliative caer.mp.	Health Promotion/
((or/1-6) and (or/7-8)) or 9)	Health promoting palliative caer.mp.
	((or/1-7) and (or/8-9)) or 10)

via the EBSco interface	
Cinhal	**Psychinfo**
MH palliative care	DE palliative care
MH Terminal Care	DE Terminally ill patients
MH Terminally ill patients	TX palliate*
TX palliat*	TX terminal* and (care or caring or ill*)
TX terminal* and (care or caring or ill*)	TX end of life
TX end of life	MH Public Health
MH Public Health	MH Health Promotion
MH Health Promotion	TW Health promoting palliative care
TW Health promoting palliative care	((or/1-5) and (or/6-7)) or 8)
((or/1-6) and (or/7-8)) or 9)	

The final search was carried out on 30 June 2015. The search was limited to studies on human subjects in the English language. Titles and abstracts of all articles retrieved were screened for relevance. Where relevant the full text was retrieved for review. Further articles were identified through bibliographic searches.

A supplemental search of the grey literature was carried out using a framework developed by colleagues in Knowledge Service, NHS Health Scotland. Details available on request.

The bibliographic software Mendeley was used to manage retrieved references.

Appendix 2. Key informants interviewed

The following key informants we informally interviewed to inform this project.

Prof Craig White	National Clinical Lead for Palliative Care, Scottish Government
Prof David Clark	Professor End of Life Studies, University of Glasgow
Dr David Gray	Consultant Palliative Medicine, Accord Hospice, Glasgow
Prof Phil Hanlon	Professor Public Health, University of Glasgow
Prof Allan Kellehear	Prof End of Life Care, University of Bradford
Prof Scott Murray	St Columbus Chair of Primary Palliative Care, University of Edinburgh

Appendix 3. Methods for National Mapping Survey of Specialist Palliative Care

A national survey to map specialist provision of PELC in Scotland was undertaken in collaboration with colleagues from the University of Glasgow. The questionnaire used by the European Association for Palliative Care (EAPC) to collect quantitative data on specialist palliative care provision across Europe in the European Atlas of Palliative Care was modified for use in this study[18].

Between August and September 2015 the questionnaire was emailed to the Chief Executive Officers (CEO) of each of the independent hospices in Scotland and to the executive leads for PELC at each National Health Service (NHS) Board and, where available the PELC Managed Clinical Network (MCN) Chairperson for each NHS Board. These individuals were asked to identify a person from their organisation who would be available to discuss their responses to questionnaire in a telephone interview with one of three interviewers (MG, AJW, HA).

It is anticipated that data collection will be completed, responses collated and analysed and reported by late autumn 2015.

Through this process the lead author had an opportunity to speak with a range of people involved in direct service provision of specialist PELC in Scotland. These discussions informed the report.

Appendix 4. Ten essential functions of public health systems as defined by WHO Europe

1. Surveillance of population health and wellbeing
2. Monitoring and response to health hazards and emergencies
3. Health protection, including environmental, occupational food safety and others
4. Health promotion, including action to address the social determinants and health inequity
5. Disease prevention, including early detection of illness
6. Assuring governance for health and wellbeing
7. Assuring sufficient and competent public health workforce
8. Assuring sustainable organisational structures and financing
9. Advocacy, communication and social mobilization for health
10. Advancing public health research to inform policy and practice

Appendix 5. WHO Definition of Palliative Care

Palliative care is 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. Palliative care:

- provides relief from pain and other distressing symptoms.
- affirms life and regards dying as a normal process.
- intends neither to hasten or postpone death.
- integrates the psychological and spiritual aspects of patient care.
- offers a support system to help patients live as actively as possible until death.
- offers a support system to help the family cope during the patients illness and in their own bereavement.
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- will enhance quality of life, and may also positively influence the course of illness.
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

Appendix 6

Reflections on definitions of PELC by Dr Euan Paterson, Macmillan GP Facilitator (Glasgow)

Defining Palliative Care: what is it and how is it for?

Defining palliative care can be somewhat problematic. However, there does appear to be a general belief that, not only do all concerned know what the definition is, but that they all share the same thoughts.

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

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

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

This is understandably the natural default position. But is it really that helpful? The group it encompasses is vast; taken to extremes, possible 'life-threatening illness' includes just about everything. Death is mentioned but almost just in passing and the sort of care it describes seems no different to what all good care should be.

NICE Supportive Care
"Everyone facing life-threatening illness will need some degree of supportive care in addition to treatment for their condition. NICE has defined supportive care for people with cancer. With some modification the definition can be used for people with any life-threatening condition.

Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment. Supportive care should be fully integrated with diagnosis and treatment. It encompasses:
• 		Self help and support

- •   User involvement
- •   Information given
- •   Psychological support
- •   Symptom control
- •   Social support
- •   Rehabilitation
- •   Complementary therapies
- •   Spiritual support
- •   End of life and bereavement care"

This definition seems very helpful and applicable not just to life threatening illness due to cancer but to any other life threatening condition and indeed can be applied to aspects of care that all people with any ill health issue would benefit from. It is seen to run in parallel with diagnosis and treatment; implicitly care, where the goal is life prolongation, perhaps even cure. Importantly the people receiving this aspect of care do not need to be dying.

NICE Palliative care
"Palliative care is part of supportive care. It embraces many elements of supportive care. It has been defined by NICE as follows:
Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Palliative care aims to:
- •   Affirm life and regard dying as a normal process
- •   Provide relief from pain and other distressing symptoms
- •   Integrate the psychological and spiritual aspects of patient care
- •   Offer a support system to help patients live as actively as possible until death
- •   Offer a support system to help the family cope during the patient's illness and in their own bereavement"

The NICE definition of palliative care is perhaps more useful but even here there is some uncertainty. Palliative care is both 'part of' but also seen to 'embrace many elements of' supportive care. However, this definition does seem to accept that in some way it is linked to the distance the patient has travelled on their life/death trajectory by stating that the cohort of patients covered by the definition or those with 'advanced' progressive illness. The other clear difference is that there is a shift of emphasis within the goal of care to quality of life.

What is palliative care?

There are two areas to consider; the goals of care and the type of care.

Goals of care
Though difficult to separate there are two distinct and different goals – recovery/cure/life prolongation and quality of life. These are the essence of what is trying to be achieved and the NICE definition by emphasising 'quality of life', acknowledges this. Although the NICE definition does not explicitly refer to the 'quantity of life', it is implicit; clearly improving the quality of life by extending the life span is one of the goals of disease altering/curative care.

The major difference between these two goals is the need to consider what treatments or interventions are felt to be inappropriate or indeed futile. Assessment in terms of risk is necessary, e.g. what may impact so adversely on the quality of a person's life that the individual would turn it down, or perhaps should not even be offered it; the ceilings of treatment or intervention for each individual person will differ.

Type of care
It is hard to discern any difference between the sort of care people who fall or do not fall into the palliative cohort should receive. All aspects of the type of care in the WHO definition of palliative care and in the NICE definitions of both palliative and supportive care are aspects of care that any person with any health concern should expect to receive. Palliative care is simply good care for people who are 'dying'.

Who is palliative care for?

This is perhaps the more pertinent question.

Palliative care is for the individual who realises that their own inevitable mortality is now of relevance to them such that it merits consideration. This is frequently due to either their perception of death's relative imminence or to the belief that some new disease or combination of diseases will inevitably be the cause of their death – both of these will be hugely variable.

In trying to decide what cohort of people should receive 'palliative care' the crucial distinction in the two NICE definitions is the insertion of 'advanced' that, perhaps more honestly, could be viewed as movement on the life/death trajectory such that death has become more imminent.

Professional attempts attempts at defining this cohort have proved difficult, in part due to the unpredictability of the disease process in different conditions and between different people and, in part due to the hugely different view and opinion of each unique individual – how they feel, how they are and crucially how they wish to be viewed.

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Is part of the problem that those providing health care attempt to label rather than allow, and indeed perhaps sometimes help, people label themselves?

Nothing is more certain than the inevitability of death but for most people the relevance of their own mortality, save at specific times in their life eg buying a home or taking out a life insurance policy, is inconsequential.

However, with some specific diagnoses or with clearly advancing disease most people will gradually realise that their won mortality is now relevant enough that it merits consideration. This process will be unique for every individual and will be hard to predict.

In some cases the individual person may not recognise the relevance of their mortality. If this is recognised by health care professionals then they have a role in helping the patient to consider if they wish to consider their mortality or not.

Clearly there are some problems with this approach. Fundamentally, it is only easily applicable to people with the capacity to recognise the importance and relevance of their own mortality. Problem groups are those with conceptual issues – the very young, those with significant learning disability and those whose cognitive abilities are failing. With each individual, in each of these areas, professionals need to consider the individual conceptual ability, and, that of those non-professional carers involved in their care eg parents, siblings, offspring. It may be that the most practical approach would be to 'transfer' the matter of relevance to the non-professional carer much in the same way that other matters of capacity are dealt with.

ScotPHN report