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Care and support
through terminal illness

Palliative Care in Scotland

Research into Practice

Event report: Thursday 11 May 2017

Contents

1.	Introduction	2
1.1.	About the event	2
1.2.	Scottish Government policy	2
1.3.	Research and the Strategic Framework for Action on Palliative and End of Life Care	5
2.	Palliative care research in Scotland 2006-2015: A scoping review	6
3.	Expert insights	10
3.1.	Identification and care co-ordination of those who can benefit from palliative and end of life care	11
3.2.	Getting services right – care in the community and care homes supporting Integration Authorities with strategic commissioning	15
3.3.	Building an education and training evidence base	17
3.4.	Examining holistic palliative care for the 0-25 years age group	19
3.5.	Support greater public and personal discussion of bereavement, death, dying and care at the end of life	22
4.	Themes from discussion	24
5.	Links	25
6.	References	26
7.	Further information	27

1. Introduction

1.1. About the event

In 2015, the Scottish Government set out its five year vision to improve palliative care in Scotland in its Strategic Framework for Action on Palliative and End of Life Care 2016-2021. This included a commitment to evidence based knowledge exchange across Scotland.

Researchers from Marie Curie, the University of Edinburgh, NHS Lothian and the University of Glasgow, as part of the new Scottish Palliative and End of Life Care Research Forum, have undertaken a comprehensive scoping review of Scottish palliative care research, published between 2006 and 2015. This has mapped key areas that are relevant to clinical practice, service development and policy.

To support the dissemination of the results of this study, and to begin a wider discussion on how this research can inform policy and practice Marie Curie, the Scottish Government and the Research Forum held a seminar in May 2017. This seminar explored what palliative care research exists in Scotland and how this can help inform and improve the reach and quality of palliative care, and decisions on strategy and policy. It also identified gaps in the research and suggested possible future areas of study.

The seminar specifically explored how the scoping review's findings could inform the progress towards meeting some of the ten commitments set out in the Strategic Framework for Action.

This short report highlights the key points raised by each of the speakers at the seminar and concludes with a range of recommendations.

1.2. Scottish Government policy

The Scottish Government recognises that support and care have a vital role to play in ensuring everyone can enjoy the same human rights – dignity, equality of opportunity and access.

Recent policy direction has a common approach grounded in talking to people about what matters to them and involving them in decisions about their own lives. Much of it is intended to help support people to be empowered to make decisions about their own lives, care and support. This empowerment leads to increased confidence and helps people to lead more independent lives. Having greater control of your life and decision making can lead to improved health and wellbeing outcomes and helping people to achieve their aspirations for a happier and more fulfilled life. Some of these key policy areas to support this approach have been highlighted below:

- The Scottish Government's 2020 Vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting. Its aims are to have a healthcare system with integrated health and social care, focusing on prevention, anticipation and supported self-management.
- The integration of health and social care functions from NHS Boards and local authorities came into effect in April 2016. New integration authorities are now responsible for commissioning services to support the needs of their local populations. The Scottish Government believes that integration is about putting people, not services, at the centre of decisions.
- Realistic Medicine is an approach set out by the Scotland's Chief Medical Officer (CMO), which aims to put the person at the centre of decision-making about their health and care. As part of that its aims are to reduce harm and waste, simplify care, improve innovation, and value and support all health and care professionals to help improve outcomes for people, based on their priorities. The CMO has indicated that she wants all healthcare professionals in Scotland to adopt a personalised approach to their care by 2025.

- The vast majority of palliative care is delivered in people's homes and community settings. Last year 87% of a person's last six months of life was spent at home or in a community setting in Scotland¹. Primary care is then often the first point of contact in health care for people, even when palliative. This will also be the case when GP surgeries are closed and people will still need urgent care. A recent Review of Primary Care Out of Hours Services identified a whole system approach to enable a safe, sustainable and person-centred care making sure people are seen by the most appropriate professional to meet their individual needs. It recognised a challenge for palliative care is that patients should have extended access to community nursing and advanced nurse practitioner support, with nurses able to verify expected deaths in the community.
- Anticipatory Care Planning (ACP) is a "thinking ahead" approach to ensure health and care professionals work with people, and their carers, to ensure that the right thing is done at the right time by the right person with the right outcome. It is about having conversations with people about what matters to them, putting people at the centre of the decision-making process about their health and care needs. It helps people make informed choices about how and where they want to be treated and supported and ensures this is communicated to all health and care professionals involved in that care. The Scottish Government has committed to ensuring that everyone who needs an ACP will receive one by 2021, which is set out in its Health and Social Care Delivery Plan.
- New National Health and Care Standards now also set out what people should expect when using health, social care or social work services in Scotland. They seek to provide better outcomes for everyone; to ensure that individuals are treated with respect and dignity, and that the basic human rights we are all entitled to, are upheld. The Standards are underpinned by five principles; dignity and respect, compassion, be included, responsive care, and support and wellbeing.
- Self Directed Support (SDS) allows people, their carers and their families to make informed choices on what their support looks like and how it is delivered, making it possible to meet agreed personal outcomes.

The Strategic Framework for Action on Palliative and End of Life Care is closely aligned with the policy initiatives set out above and aims to bring together acute, secondary and community healthcare, personal and social care to help meet people's needs and improve outcomes.

In doing so, the framework sets out commitments to help achieve this. These commitments are to:

1. Support Healthcare Improvement Scotland in providing Health and Social Care Partnerships with expertise on testing and implementing improvements in the identification and care co-ordination of those who can benefit from palliative and end of life care.
2. Provide strategic commissioning guidance on palliative and end of life care to Health and Social Care Partnerships.
3. Support the development of a new palliative and end of life care educational framework.
4. Support and promote the further development of holistic palliative care for the 0-25 years age group.
5. Support the establishment of the Scottish Research Forum for Palliative and End of Life Care.
6. Support greater public and personal discussion of bereavement, death, dying and care at the end of life, partly through commissioning work to facilitate this.
7. Seek to ensure that future requirements of e-Health systems support the effective sharing of individual end of life/Anticipatory Care Planning conversations.
8. Support clinical and health economic evaluations of palliative and end of life care models.

¹ ISD, Percentage of End of Life Spent at Home or in a Community Setting, May 2017

9. Support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care.
10. Establish a new National Implementation Support Group to support the implementation of improvement actions.

In terms of palliative and end of life care, it is hoped that the framework can help achieve a common cross-sectoral approach, linking the above policy drivers, to ensure that health and care services are commissioned around a person's needs and the focus is on a person-centred approach that leads to better outcomes for people.

1.3. Research and the Strategic Framework for Action on Palliative and End of Life Care

Shona Robison MSP, Cabinet Secretary for Health and Sport



The cabinet secretary set out the Scottish Government's vision for palliative and end of life care set out in the Strategic Framework for Action that everyone who needs palliative care in Scotland will receive it by 2021.

Commitment five of the framework was to support the establishment of the Scottish Research Forum for Palliative and End of Life Care. The Forum, established in 2016, is co-chaired by Professor Scott Murray and Professor Bridget Johnston.

The cabinet secretary commended the efforts of the Forum and how it has grown and developed into a valuable resource in Scotland since its establishment. She particularly highlighted that the forum has become a place where people can come to learn, collaborate and influence the direction of efforts to improve palliative and end of life care across Scotland. She reiterated that the Forum is integral to sharing research to support meeting the commitments set out in the Framework as well as achieving the overarching vision of the Framework.

The cabinet secretary praised the Forum's scoping review, led by Dr Anne Finucane, Marie Curie Research Lead, as a significant milestone in examining palliative care research in Scotland.

"Palliative and end of life care will affect every single person here at some stage in our lives. Be it through the experience of witnessing the passing of a friend or loved one, or our own mortality, it really matters – either now or at some point in the future - to everyone... I look forward to our continued collaboration with the Research Forum and the further progress I am certain we will witness over the coming months and years."

She also went on to highlight the important role she sees research playing in informing policy and practice:

"Research can be an end in itself - though my interest is in how it can assist us to support people in living the lives they want to live, right up to their death."

Shona Robison MSP

2. Palliative care research in Scotland 2006-2015: A scoping review

Anne Finucane, Marie Curie



In 2016 the Scottish Government and Marie Curie co-funded a scoping review of all Scottish palliative care research published over a 10 year period from 2006 – 2015. This work was based on a similar review of palliative care research in the Republic of Ireland (McIlfatrick & Murphy, 2013) and was considered an important exercise to carry out in order to establish the current palliative care evidence base in Scotland.

The scoping review was conducted between May 2016 and January 2017. It resulted in the identification of 308 palliative care research papers published by researchers based in Scotland. Each paper was reviewed by the research team, and categorised in terms of the key areas it addressed, for example, services and settings, experiences and/or needs, co-ordination, bereavement, physical or psychological symptom management, education and training and so on. The review looked at what types of studies were undertaken during this time, the focus of these studies and identified strengths and gaps.

The Research Team

Marie Curie

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Results

Palliative care research in Scotland 2006-2015: A scoping review

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Background

The Scottish Government set out its 5 year vision to improve palliative care in its Strategic Framework for Action 2016-2021. This includes a commitment to evidence based knowledge exchange across Scotland. A comprehensive scoping review of Scottish palliative care research was considered an important first step.

Aims

- To identify all Scottish palliative care research published from 2006 to 2015;
- To map key thematic areas relevant to clinical practice, service development and policy.

Methods

Palliative care research involving at least one co-author from a Scottish institution was eligible for inclusion. Five databases were searched with relevant MeSH terms and keywords; additional papers authored by members of the Scottish Research Forum for palliative and end of life care were added. 496 papers underwent full text review; 308 were retained in the final set.

Results

- There has been a steady increase in publications over time. (*Figure 1*)
- Research output was strong compared with that reported in a similar Scottish review in 2006 and a review of Irish palliative care research in 2013.^{1,2} (*Figure 2*)
- In terms of methodology, 33% were quantitative, 29% were qualitative, 14% were reviews and 25% had other designs including mixed methods.
- Just over 70% were descriptive studies, and 9% were interventions or feasibility studies (29 papers). Twelve studies were randomized controlled trials.

Figure 1: Publications by year.

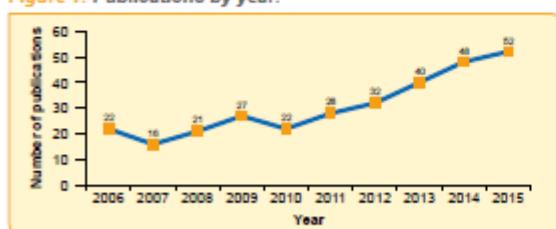
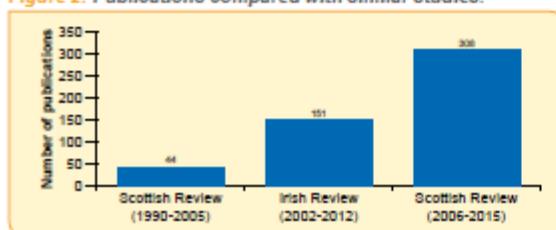


Figure 2: Publications compared with similar studies.



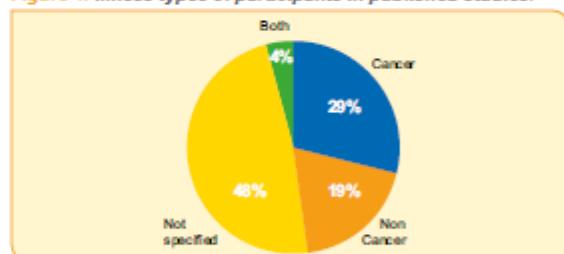
- The top 3 areas of research focus were experiences and/or needs; services and settings; and physical symptom management. (*Figure 3*)
- 58 papers (19%) were specifically concerned with palliative care for people with conditions other than cancer. (*Figure 4*)
- Few studies focused on ehealth, health economics, out-of-hours and public health approaches.
- Relatively few papers focused on palliative care for children and young people (18 papers), and one-third of those papers were related to bereavement.

Figure 3: Top 15 areas of research by number of publications.*



*Note: Publications can have up to three associated themes so may appear more than once.

Figure 4: Illness types of participants in published studies.



Conclusion

There was a considerable increase in palliative care research output over the last decade, with many studies identifying early palliative care needs, and needs in conditions other than cancer.

The new Scottish Research Forum for palliative and end of life care is now engaging with clinicians, service managers and policy-makers to facilitate understanding, use and further dissemination of key implications for education, service innovation, policy and practice.



University
of Glasgow

Health Research
Board of Scotland

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NHS
Lothian

References: 1) Johnston B et al. (2006). A scoping review of palliative care in Scotland. Final Report. Cancer Care Research Centre. Available at: https://www.jisc.ac.uk/images/edukit/resource-repository/documents/147299403_A_Scoping_Review_of_Palliative_Care.pdf. 2) McHaleck S & Murphy T (2013). Palliative care research on the island of Ireland over the last decade: a systematic review and thematic analysis of peer-reviewed publications. BMC Palliative Care 12: 23-33.

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The 308 research papers identified highlight the growth of palliative care research in Scotland when compared to a former Scottish review between 1990-2005, which identified 44 papers (Johnston, Nimmo, Baughan, & Kearney, 2006). A similar review in Ireland between 2002-2012 resulted in 151 papers. This suggests that there is a strong and healthy palliative care research output in Scotland. The review also highlighted a large amount of collaboration between Scottish researchers and those elsewhere in the UK and further afield. Scotland has also made a large contribution to international research on palliative care, particularly in developing countries.

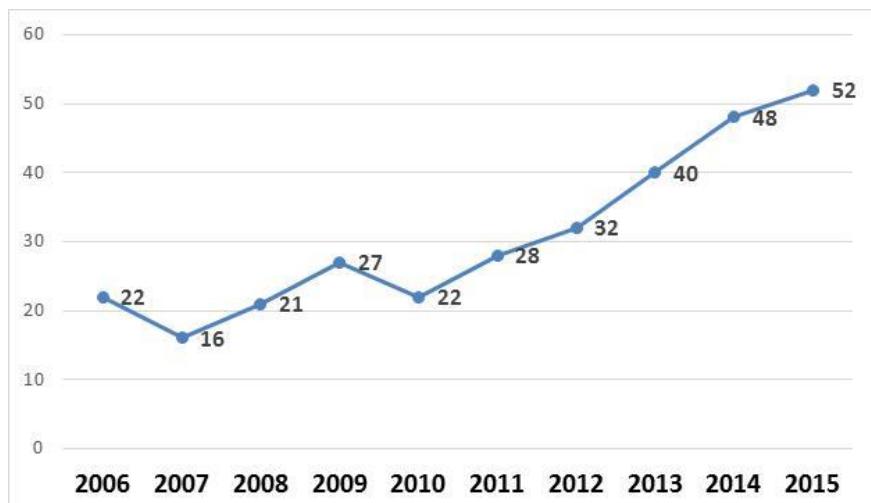


Figure 1. Number of palliative care research papers published by Scotland based researchers by year (n=308)

30% of all papers recruited participants with a cancer diagnosis. However, the review also highlighted that 19% (58 papers) were specifically focused on palliative care for people with non-malignant conditions.

The review highlighted the top 15 areas of research:

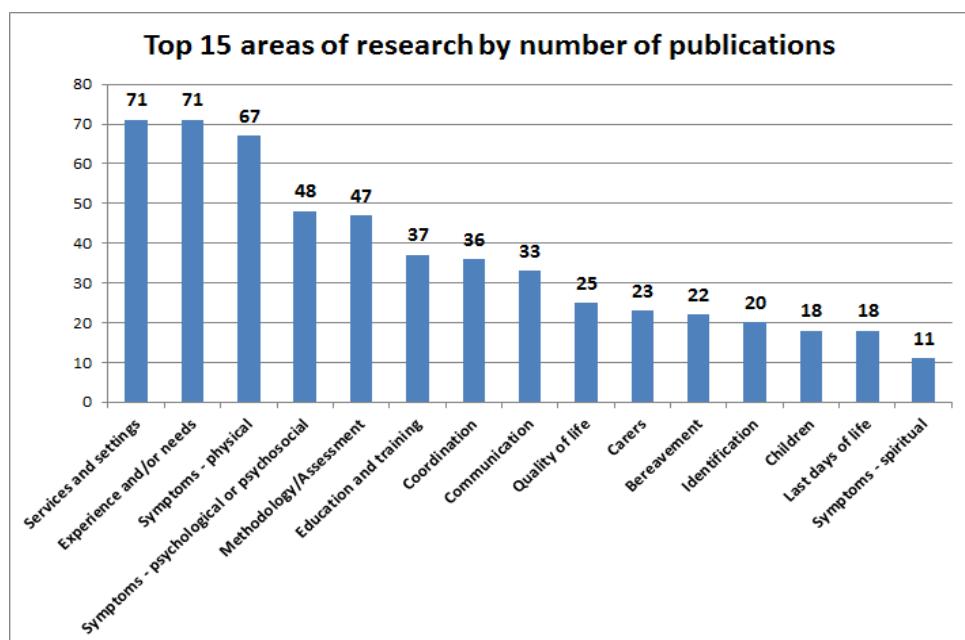


Figure 2. Top 15 areas of research by number of publications

The research identified in the scoping review showed the following strengths:

1. Substantial evidence based on the experiences and palliative care needs of people with advanced progressive illness, including those with a non-cancer diagnosis.
2. Growth in the design and testing of palliative care interventions.
3. Rigorous symptom control studies and randomised controlled trials.
4. Methodological expertise in qualitative methods.
5. Stable growth in research output.
6. High level of collaboration with other UK and international research groups.

The research identified in the scoping review showed the following research gaps:

1. Intervention studies.
2. Cost-effectiveness studies.
3. Care homes / frail older people with dementia.
4. Non-cancer and multi-morbidity.
5. eHealth
6. Public health approaches.
7. Out-of-hours
8. Building resilience, promoting autonomy.

e-Health, health economics, public health and out of hours services were represented in the scoping review, but these areas were not identified as significant themes in Scottish research. Work on these themes is currently underway, but also represent areas for future focus.

Key recommendations:

- Collaborative research between health care providers and academics to rigorously evaluate new palliative care interventions.
- Provide opportunities for engagement between research users and research producers so that research and evaluation can be considered from an early stage, and co-funded.
- Develop funding opportunities for palliative care practitioners to engage in research so that research continues to become embedded in practice and is focused on clinical priorities.
- Through the research forum, use the findings as a basis for identifying palliative care research priorities in Scotland in context of broader UK research priorities.

3. Expert insights

The research team identified five themes for wider discussion that align to commitments within the Strategic Framework for Action:

1. **Identification and care co-ordination** of those who can benefit from palliative and end of life care (Commitment one)
2. Getting services right – **care in the community and care homes** (Commitment two)
3. Building an **education and training** evidence base (Commitment three)
4. Examining **holistic palliative care for the 0-25 years age group** (Commitment four)
5. Support greater **public and personal discussion of bereavement, death, dying** and care at the end of life – exploring bereavement research (Commitment six)

To facilitate knowledge exchange relating to each of the five areas to be discussed at this event, the research team established small evidence review groups composed of both researchers and non-researchers to consider the key research findings to date in relation to each area. Expert speakers from these evidence review groups were asked to speak on their findings at the event.



3.1. Identification and care co-ordination of those who can benefit from palliative and end of life care

Stuart Cumming, NHS Forth Valley



Stewart spoke about the challenge of identifying people who need palliative care and then co-ordinating that care, as well as highlighting the importance of understanding recent changes, trends and informing future research.

Stewart posed three key questions around identification and co-ordination of palliative care:

1. How do we identify people who would benefit from palliative care? Including those who have cancer, long term conditions, organ failure, frailty and dementia.
2. When does palliative care currently start?
3. When should it start?

Too often, palliative care needs are not identified by professionals and if they are identified it is very late. However, there have been improvements in this area over the last few years. There is a range of ways that a person may be identified for palliative care in both general or specialist settings and in both primary and acute settings. This can be supported through the use of risk predictive tools, for example, the Supportive & Palliative Care Indicators Tool (SPICT) (Hightet, Crawford, Murray, & Boyd, 2014). An indication that someone has been identified for palliative care can be highlighted by them being placed on the GP palliative care register or receiving a Key Information Summary (KIS).

However, the recording of palliative care needs is variable. These needs are much more likely to be recorded for people with terminal cancer than other conditions, particularly those with organ failure or frailty and dementia. A study carried out in 2013 highlighted the gap of care between groups of diseases, but also showed the gap between when people received the care they need from the point at which they needed that care to start (Zheng et al., 2013).

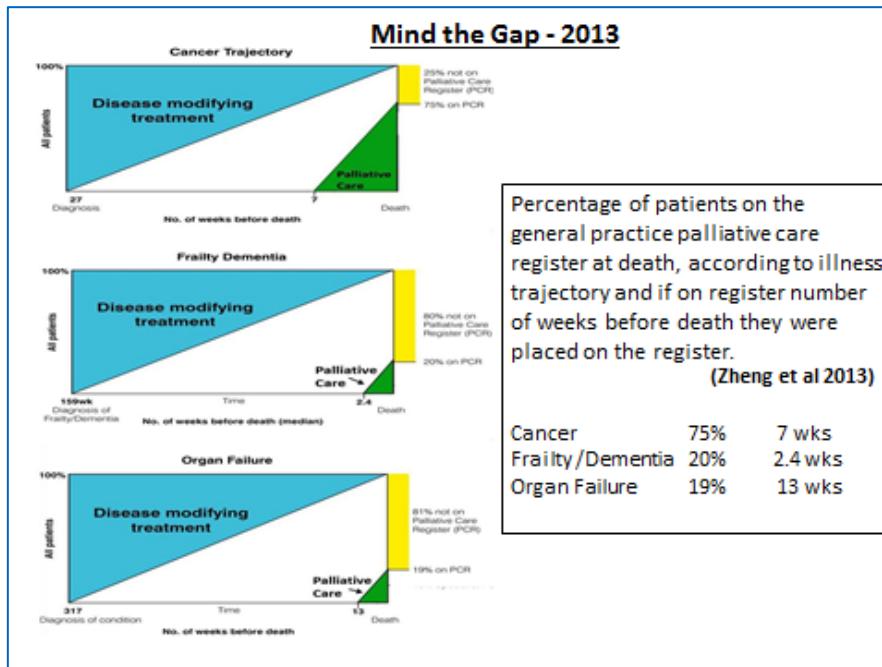


Figure 3. Mind the Gap 2013

Research carried out in 2016 has highlighted that the gap identified in 2013 is beginning to close (Tapsfield et al., 2016). The research points to more people receiving anticipatory care planning earlier in their disease trajectory and so increasing their chances of getting palliative care when they need it. This has coincided with a greater national focus on anticipatory care planning for people with long term, chronic and terminal conditions. However, gaps between those with terminal malignant conditions and those with non-malignant terminal conditions continue to exist. Those with organ failure are still considerably less likely to get palliative care.

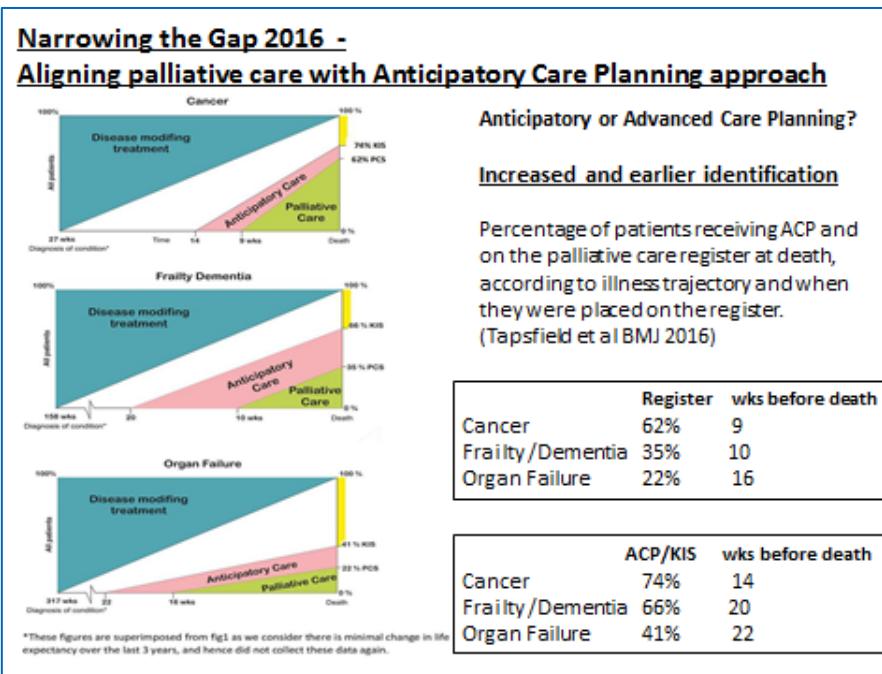


Figure 4. Narrowing the Gap 2016

What is Anticipatory Care Planning?

Anticipatory care planning (ACP) helps people make informed choices about how and where they want to be treated and supported in the future. It requires health and care practitioners to work with

people and their carers to ensure the right thing is done at the right time by the right person to achieve the best outcome.

The ACP approach adds the following elements to someone's care:

- Person centred care and ownership – working with individuals and those close to them.
- Having the right conversations at the right time.
- Having an understanding of the medical condition, what services are available, and understanding deterioration and avoiding crisis interventions.

There are a range of factors that can affect early intervention of palliative care and ACP. These include human factors, such as struggling to deal with prognostic uncertainty, the need to maintain hope and feeling uncomfortable talking about issues relating to end of life. There is a real need for a cultural shift, as well as a whole system change to address these issues, such as earlier and more open conversations, and training and support for staff. System issues can also affect early intervention.

Identification can be significantly increased using agreed risk predictive tools, such as the SPICT. These tools can act as triggers for professional prompts and are intended to support rather than replace clinical judgement.

However, wider work also needs to be done in co-ordinating palliative care. There is a real need to recognise all stakeholders, including health, social care, the third and independent sectors, carers and individuals. 24/7 planning is needed and agreements in the ways people communicate and work together.

The Key Information Summary (KIS) is a collection of information about a patient extracted from the patient's general practice record and is a way of sharing information between professionals. It is a record of someone's current situation, individual preferences, anticipated outcomes and decisions, including resuscitation wishes. The Scottish Government states that everyone who needs a KIS should have one. 60% of those who died in 2014 in Scotland had a KIS (Tapsfield et al., 2016) showing a 40% gap.

While there is a variation in the use of and the quality of information in KIS, those people who have a KIS have improved outcomes.

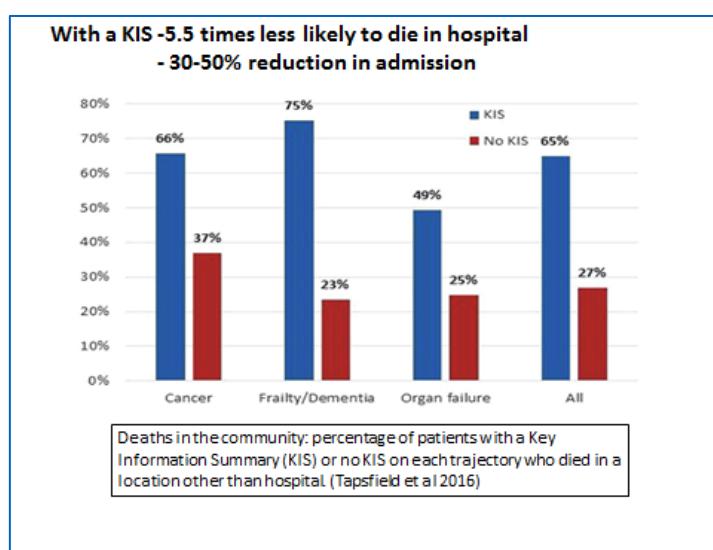


Figure 5. Use of KIS and likelihood of death in hospital²

² <http://spcare.bmjjournals.org/content/bmjspcare/early/2016/04/13/bmjspcare-2015-001014.full.pdf>

Key recommendations:

- There is positive movement in Scotland towards identifying people at an earlier stage in their journey for both anticipatory and palliative care. This should continue to be prioritised.
- The KIS can be an effective tool in communicating anticipatory care planning and palliative care needs, wishes and the current situation. More focus is required to optimise the potential of KIS and encourage professionals to complete and provide the appropriate quality of information to support informed decision making, person-centred care and whole system working.
- There is a need to focus on identifying people at an early stage of their journey for anticipatory care planning and for this to link seamlessly with palliative care provision when appropriate. There is a particular need for greater recognition of this for individuals with long term conditions and multiple morbidities.

Future work and research is needed on:

- The impact of the Strategic Framework for Action on Palliative and End of Life Care on the identification and co-ordination of palliative care for people living with a terminal illness.
- The impact of the integration of health and social care on the availability and accessibility of palliative care.
- The impact on carers of caring for a person with terminal illness and how/if they are identified for support.
- The quality of information in KIS and the effect of having a KIS on patient outcomes.
- The impact of inequalities on access to palliative care.
- Sustainability and capacity in communities.

3.2. Getting services right – care in the community and care homes supporting Integration Authorities with strategic commissioning

Diana Hekerem, Healthcare Improvement Scotland



Diana spoke about the need to identify and discuss key research findings relating to the needs and experiences of people who would benefit from a palliative approach and to highlight the implications for palliative care service commissioning. From the research, 71 papers on experiences or needs were identified.

Palliative care, in recent years, has moved from a marginal issue to being at the centre of health and social care planning. Integration Authorities, those responsible for commissioning palliative care services for their areas, must plan for the delivery of palliative care in their local areas and even more importantly highlight how strategic commissioning can be used to make change happen.

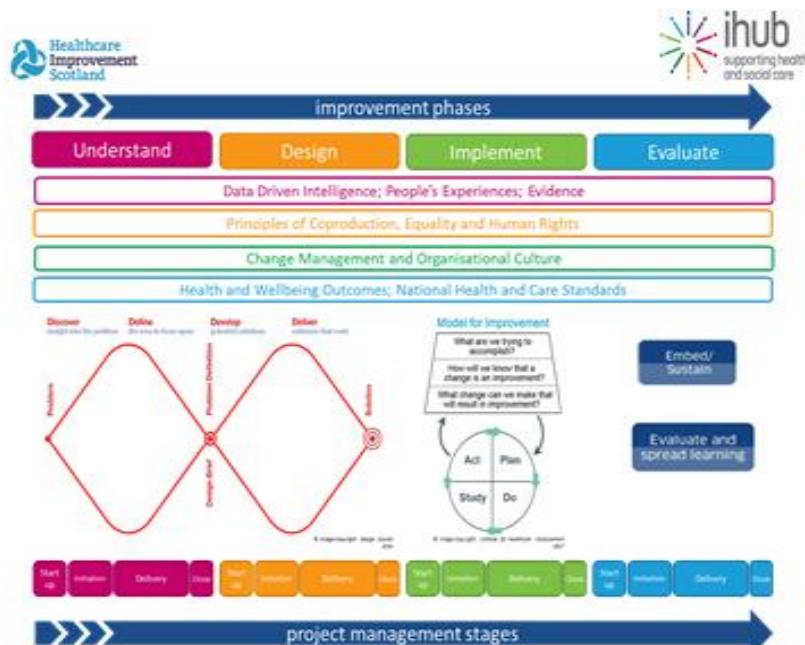


Figure 6. Improvement phases

There is now access to much more and wider data, alongside an understanding of what palliative care looks and feels like for people.

The following need to be considered in planning and commissioning services:

- Trajectories of dying are valid in pathway planning.
- Service pathways in general meeting needs of cancer patients.
- Service users prioritise independence, dignity and aim to minimise service use.
- Introduction of social care improves perception of quality of life of people receiving care.
- Participation in research improves perception of quality of services.
- Identification of points to support anticipatory care planning.

It is vital that evidence is used to inform planning. Approaches need to bring in the voice of people in the last stages of life and the recognition that people's experiences vary depending on their disease/diagnosis. Carer's experiences are also extremely important, especially as they often don't identify themselves as carers. Professionals need to consider the language used and how they talk to carers. There is also a need to engage with people in non-NHS settings.

Deteriorating health is experienced differently by patients with different advanced conditions (Kendall et al., 2015)

There is a degree of uncertainty on issues for those planning palliative care services – and services need to be designed which understand that. They need to be flexible, require coordination and there needs to be identifiable trigger points which can recognise that uncertainty. In short, a whole system fully integrated approach is needed.

Key recommendations:

To support better service design, delivery and commissioning of palliative care services the following recommendations should be considered:

- Better evaluation of interventions such as anticipatory care planning.
- Health literacy needs on death and dying need to be improved and there needs to be better conversations with people around this.
- Build an evidence base on self-directed support, self-management and building resilience for those with palliative care needs, as well as carry out more research in these areas.
- Improved knowledge and understanding of social care experiences must be available to support commissioning decisions.
- Increase the amount of health economic assessments carried out on palliative care interventions to support service design and commissioning.
- An increased level of knowledge of experiences for people with mental health and learning disabilities with palliative care needs.
- Develop and test approaches to multi-morbidity and co-designing with people who would benefit from palliative care.
- Develop and test community enabling initiatives.
- Foster expert patient and carers to shape research questions and interventions.

3.3. Building an education and training evidence base

Sarah Doyle, NHS Education for Scotland



Sarah spoke about the need to ensure that staff are supported and appropriately trained to deliver palliative and end of life care. From the research, a total of 37 papers focused on education and training – the sixth most popular subject area. The papers were predominantly descriptive, with a small number of intervention studies and service evaluations. The literature encompassed a broad range of populations, health conditions, healthcare settings and education and training approaches. Much of the research was very detailed and led to context-specific findings. Papers on education were typically published in healthcare journals.

A key finding to emerge from the studies was that healthcare staff have unmet education needs relating to end of life care – some felt they lacked clinical exposure to patients at end of life, others felt unsupported or isolated when providing palliative care. However, the papers suggest that there is an abundance of opportunities for staff (in all specialties and settings) to gain the required experience.

The review highlighted that feeling isolated when providing end of life care is a finding that emerged from several different studies and in several different settings. It also highlighted that while issues of and opportunities for education and learning can be found in a variety of contexts, translating education into practice is highly complex.

Implications:

Clinical practice – It's clear that there are many opportunities for education and learning in clinical practice, but that practitioners in different sectors and services have varying access to these opportunities. The papers reviewed suggest that clinical practice in this field has a powerful emotional impact on practitioners.

Policy – The tendency towards smaller scale studies and a more local focus creates challenges for those seeking opportunities to intervene at scale. Policy can however play a role in making education a more visible part of initiatives in order to help support workforce development; the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care is a good example of this, with commitment 3 explicitly highlighting these issues.

Service development – the research available suggested there is scope to make use of information about unmet learning needs. The detailed nature of these studies is difficult for scaling up but it is ideal if the population and subject area match as issues services are struggling to address. For example, observational studies can be richly descriptive of both the challenges and the solutions explored. Another recurring finding was the difficulty of accessing educational opportunities: digital literacy, competing work priorities, funding, time, and work commitments.

Education – there is a need to make educational opportunities accessible for practitioners, and to further develop the scope for enabling and supporting learners to gain experience in palliative and end of life care. There is also a need to better organise and coordinate opportunities to make best use of limited resources.

In terms of suggestions for what might be progressed, there is scope to amplify and use educational opportunities that arise in everyday work. There are strong papers examining palliative care education and training in key settings and there is scope to undertake further studies in settings not yet well represented, such as general practice and acute settings perhaps not conventionally associated with palliative care. A third area of interest is the recognition of educational opportunities as a way of containing the emotional impact of palliative care work – thinking and learning about emotional responses to clinical practice in this field.

Key recommendations:

- There is a need to know more about education and learning for carers and care at home workers because these groups were not well-represented in the papers reviewed.
- Most studies were descriptive and so more work focusing on educational interventions is needed.
- Palliative care and palliative care education are part of a wider context of health and social care integration and so it is important to draw on findings from social care research and engage in interdisciplinary work.
- There is scope to use education journals to draw on conceptual and theoretical understandings of education, knowledge, learning and practice and especially to bring these together with palliative care expertise in order to inform workforce development.

3.4. Examining holistic palliative care for the 0-25 years age group

Fariel Rahman



Fariel spoke about ways to support and promote the further development of holistic palliative care for the 0-25 year age group, highlighting that children and young people are often not on the agenda. Children and young people need their own level of care and planning. The timescales for this group varies and services lag behind the adult equivalent. Scotland is also behind other UK regions in this area. There are also no dedicated transition services between child and adult services.

The scoping review found relatively few papers on palliative care for children despite increased prevalence. Where there was research it was primarily descriptive, with a retrospective methodology and evaluated practice implications.

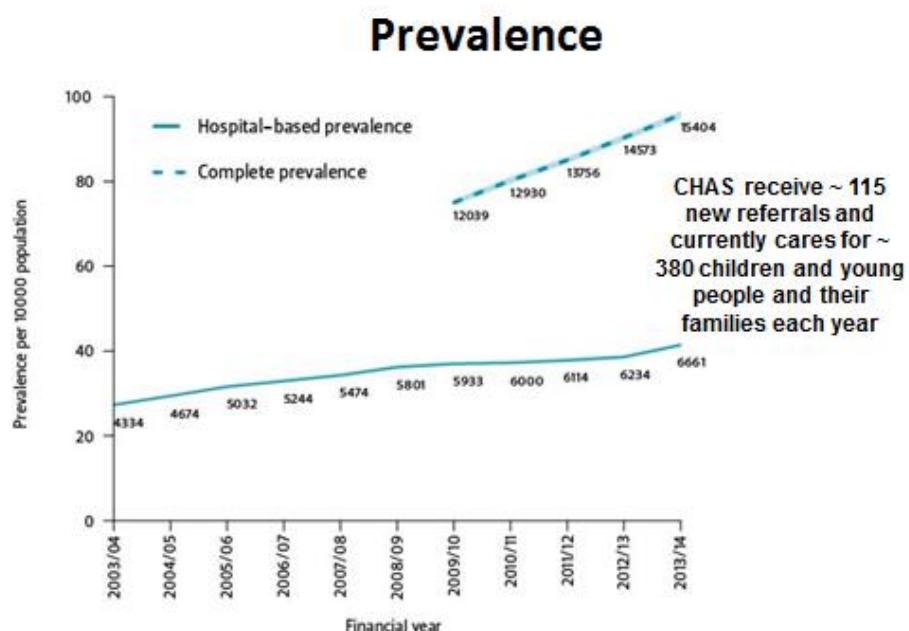
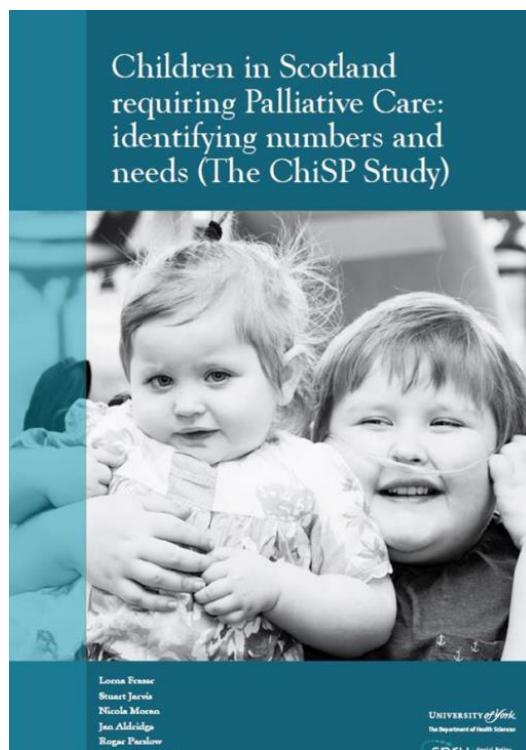


Figure 7. Prevalence per 10,000 population of palliative care need for children

However, more recently valuable work has been undertaken in this area, led by Children's Hospices Across Scotland (CHAS). Children in Scotland requiring Palliative Care: identifying numbers and needs (The ChiSP Study)



The ChiSP study highlights that the needs of children and young people are under-estimated and that children under one year were a priority (Fraser et al., 2015). It also highlighted that Scotland is unable to provide and sustain the services needed for children. Among other things, the study calls for age specific services for 16-25 year olds, ensuring services in areas of higher deprivation are culturally sensitive and improving psychological, emotional and domestic support.

The study also reported that the needs of children with non-malignant diseases are substantial and are not being met and goes on to highlight that adolescents with life-limiting conditions face many different challenges explaining that the patterns for this group are very different from adult experiences.

Learning

- Transition is a key area.
- There is value in more symptom profiling.
- There needs to be more focus on non-malignant diseases.
- Local pockets of research should be explored.

However there are also numerous on-going challenges:

- There is a struggle to provide out of hours care for children.
- How to adapt services for young people?
- How to address clinical skills?
- Paediatrics provides a very small evidence base.
- Where to direct limited money to get the best outcomes?

Key Recommendations

There is a paucity of research on Children and Young People, in particular coordinated research. The prevalence of many of the conditions are low and the heterogeneity of grouping conditions together make it a challenge to extrapolate useful evidence if this is not appropriately addressed at the outset to ensure the research output is clinically relevant.

- Priorities for palliative care research involving children and young people should be co-ordinated at a national level.
- There are local pockets of data that are often seen as service evaluation as opposed to specific research. Their purpose is often used to define and support service need, however, these can be used to pilot ideas and promote future collaborative working partnerships. This is relevant for all services, not just children's services.
- Children and young people are an under-represented group. There should be a defined programme of research to address this. Children's Hospices Across Scotland (CHAS) are ideally placed to take forward this work.
- The disease trajectory and natural history of many conditions have changed and this has implications on transition services. We do not have up to date information on this and therefore this should be part of any future programme of research.
- Given the specific challenges of conducting research with terminally ill children and their families, continued collaborative work across the UK and internationally is recommended.

3.5. Support greater public and personal discussion of bereavement, death, dying and care at the end of life

Stewart Wilson, Cruse Scotland



Stewart spoke about exploring bereavement research and ways to support greater public and personal discussion of bereavement, death, dying and care at the end of life.

The research included papers exploring issues for children, carers, parents and older people, as well as hard to reach groups, such as ethnic minorities, prisoners and people with learning disabilities. The majority of the research focused on preparation for death and bereavement, and socio-economic impacts such as healthcare costs, delayed return to employment and delayed discharges.

NHS Education for Scotland has undertaken work to enhance professionals' confidence, capability and preparedness of talking about death and bereavement.

NHS Education for Scotland: Supporting Scottish Grief and Bereavement Care

Aim:
Enhancing health and social care professionals' confidence, capability and preparedness in handling and initiating death / bereavement related discussion

Building the Evidence Base:

- 4 literature reviews
 - bereavement education
 - post death team based reflective practice
 - staff wellbeing
 - review of bereavement care standards and guidelines
- Surveys of Scottish medical trainees and UK undergraduate and foundation medical schools
- Extensive stakeholder consultation
- Scoping / mapping of current medical training and curricula
- Understand what is taught / assessed and how – identification of gaps
- Learning and working in an international context

Papers / surveys available / published 2017
For more information contact:
✉ supportarounddeath@nes.scot.nhs.uk [@NES_Bereavement](#) Web www.sad.scot.nhs.uk

Figure 8. NHS Education for Scotland's work supporting grief and bereavement care

It is very important to promote greater discussion around death, dying and bereavement. Stewart highlighted the role of Cruse bereavement Care Scotland (CBCS), who are committed to research based practice and looking at how to improve the quality of services delivered in Scotland.

At CBCS, each person is offered an initial/assessment interview where a skilled volunteer will discuss their needs in more detail. This tool looks to treat each person as an individual and providing tailored support.

Key Recommendations

- More targeted support is needed. Particularly, research and policy need to reflect how bereavement changes throughout the life course and the experiences of hard to reach and marginalised groups, including older people, kinship carers, prisoners, ethnic minorities and those living with dementia.
- Support needs to go beyond one-to-one support and group work to be innovative, individualised, targeted and 'light touch' interventions. There is a recognition that support needs to be delivered at the right time and outcomes measured.
- There also needs to be a focus on enabling approaches and co-production that involves schools and communities in bereavement support, a greater cultural conversation around bereavement and building people's natural resilience. This would have positive impacts on people's mental health, returning to work, sustained recovery and by reducing GP appointments.

4. Themes from discussion

The seminar focused on early intervention, commissioning of services, education, children and young people, and bereavement.

The discussion that followed the presentations highlighted that there are further planned studies and activity being undertaken across Scotland in each of the areas. However, a common concern across all areas was around reaching hard to reach groups and ensuing that the existing gaps are not widened. There was also significant discussion around identification of carers and the need for long-term support.

There was extensive discussion around how evidence can inform practice. In order for policy decisions to be made the evidence needs to be accessible for both professionals and the public. Discussion was focused on how to access research and recent moves towards open access journals. Funding issues in research were also highlighted, particularly around evaluating and funding of interventions.

The Scottish Research Forum was highlighted as an arena for ensuring palliative care research is available, promoted and used to help build relationships between research producers and research users. It could also be an opportunity to build up a group of patients and carers to share their expertise and experiences.

It was agreed that a summary of the papers from the scoping review will be made available online.



5. Links

Strategic Framework for Action on Palliative and End of Life Care
www.gov.scot/Publications/2015/12/4053

Marie Curie
www.mariecurie.org.uk

Living Well in Communities
www.livingwellincommunities.com

ACP in Scotland
www.myacp.scot

SPICT
www.spict.org.uk

The Improvement Hub
www.ihub.scot

Enriching and Improving Experience
Palliative and End of Life Care A framework to support the learning and development needs of the health and social service workforce in Scotland
http://elearning.scot.nhs.uk:8080/intralibrary/open_virtual_file_path/i2564n4083939t/Palliative%20framework%20interactive_p2.pdf

CHAS
www.chas.org.uk

The ChiSP Study
www.chas.org.uk/assets/0001/5573/ChiSP_report.pdf

Cruse Bereavement Support Scotland
www.crusescotland.org.uk

NHS Education for Scotland, Support around Death
www.sad.scot.nhs.uk

Other useful links

Scottish Atlas of Palliative Care
www.gla.ac.uk/media/media_486122_en.pdf

Hospice UK
The role of hospice care in Scotland

Good Life, Good Death, Good Grief
www.goodlifedeathgrief.org.uk

Scottish Partnership for Palliative Care
www.palliativecarescotland

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7. Further information

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