

CÙRAM IS SLÀINTE NAN EILEAN SIAR
WESTERN ISLES HEALTH AND SOCIAL CARE PARTNERSHIP



PALLIATIVE AND END OF LIFE CARE COMMISSIONING PLAN
2019-2021

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1. Introduction

The development of effective palliative and end of life care is an essential part of any health and care system and a central priority of the Western Isles Health and Social Care Partnership.

Palliative care is about providing good care to people who have a life limiting illness or who are dying. Its function is to enhance quality of life, to support a person's goals and to ensure that they are able to live during the time they have left in accordance with what matters to them.

This document sets out our ambition to deliver proactive, planned and supportive palliative and end of life care across the Western Isles. It considers the national and local legislative and policy context, our current service provision, what we want to achieve and how we will deliver an improved service.

Its focus is on how we support **adults** with palliative needs. There are very few children in the Outer Hebrides who have a life limiting illness and through the NHS Board and Comhairle nan Eilean Siar we will use, where appropriate, the support of highly specialist children's hospices and hospitals to provide support

This document also considers the needs of patients with different diagnoses and conditions. It is not limited to patients with a particular diagnosis or condition and indeed we bring into consideration some diseases like dementia that have not historically been considered to be life limiting.

More than anything else, this document provides a framework for professionals, carers and service users to use in the identification of effective and appropriate care and support.

2. Our Mission

Our vision for palliative and end of life care is that all people who have life-limiting and life-threatening illnesses live as well as possible and have access to the best palliative and end of life care when they are dying.

To achieve this we will:

- Put the individual, their carers and families at the centre of everything we do;
- Ensure that we look beyond people's disease(s) to focus on what is important to them;
- Embrace multidisciplinary working;
- Be innovative in supporting people's needs and wishes;
- Work across organisational boundaries so we deliver as a single team;
- Support as many people as possible to die at home or in a homely setting;

There are already good examples of high quality care being provided in the Western Isles; our mission is to further improve to ensure that we deliver high quality support across all communities.

What is Palliative and End of Life Care?

While there is no single definition for either Palliative or End of Life Care, the World Health Organisation defines it as follows:

Palliative care is an approach that improves the quality of life of patients 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.

Specialist Palliative Care can help people with more complex palliative care needs. It is provided by specially trained multi-professional specialist palliative care teams, who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital. Specialist palliative care has a particular role in providing support, advice, education to the rest of the health and care system without which generalist care would not be sustainable.

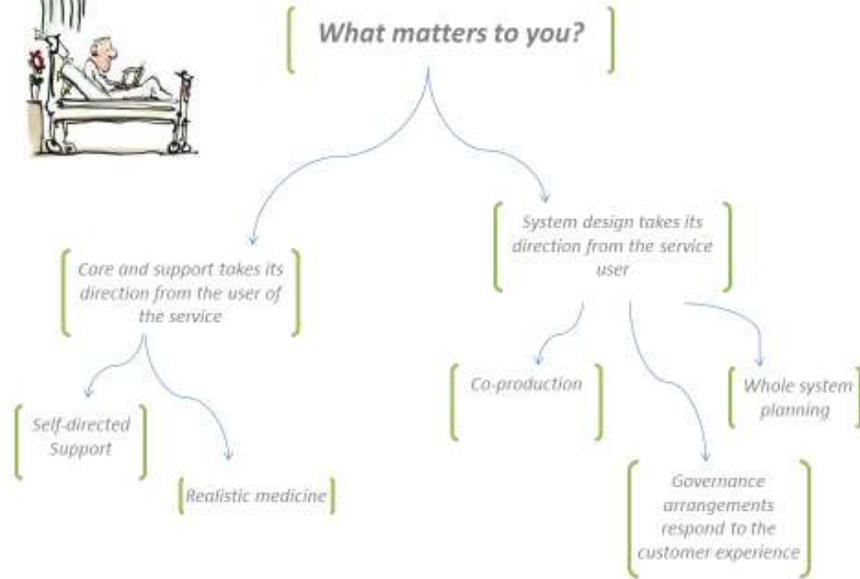
Most professionals also distinguish end of life care from general palliative care. End of life care – or care of the person living through the dying phase of life - is that part of palliative care which should follow from the recognition that a person is entering the process of dying, and there is a high likelihood of them dying over the next few hours, days or weeks, whether or not he or she is already in receipt of palliative care. A person's need for palliative care can be identified using a range of tools such as the Supportive & Palliative Care Indicators Tool. However, when a person will reach their last days of life can be unpredictable so planning to meet their needs can be challenging.

Understanding what matters to people

In the last few years, we have seen two landmark developments in the form of realistic medicine and self-directed support. Both of these approaches take their point of departure not just from an assessment of a person's needs, but what it is that matters to them as an individual.

This philosophy has implications that reach far beyond that immediate relationship between the professionals and the user of the service. It implies that as we develop new service arrangements, we need to do so *with* the people who will ultimately use those services; otherwise, we're unable to understand what it is that people want. That does not mean we are always able to respond to individual preference - but it is nonetheless crucial to take our direction from that question: 'what matters to you?'

This approach is particularly important in respect of palliative and end of life care. We want to ensure, protect and enhance people's autonomy and agency throughout their lives, including as they approach death.



Our approach to supporting people with palliative care needs will be expressly based on a human rights model. Human rights are the fundamental freedoms and rights to which everyone is entitled. They are built on universal values such as dignity, equality, freedom, autonomy and respect, first set down in the Universal Declaration of Human Rights and now grounded in international laws.

Within a Scottish context, the Scottish National Action Plan (published by the Scottish Human Rights Commission in 2013) promotes a “human rights based approach” which emphasises participation, accountability, non-discrimination, empowerment and legality (PANEL). This has several benefits: supporting person centred services, helping good decision making, improving institutional culture and relationships and, finally, ensuring legal compliance and promoting best practice.

Our approach therefore recognises individuals receiving care as being active citizens with rights and entitlements. Chief amongst this collection of human rights is the right to shape their own care and be at the heart of the decision making process, to ensure they can live fulfilled and independent lives, and not just be looked after. As part of this approach a key onus is placed on all service providers to promote awareness and understanding of rights.

A human Rights approach also underpins the national [Health and Social Care Standards](#), which set out what we 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 be upheld. The headline outcomes are:

1. I experience high quality care and support that is right for me.
2. I am fully involved in all decisions about my care and support.
3. I have confidence in the people who support and care for me.
4. I have confidence in the organisation providing my care and support.
5. I experience a high quality environment if the organisation provides the premises

Why Palliative and End of Life Care Matters

There are many reasons for having a focus on palliative and end of life care services and support.

- Getting health and social care right for people is a vital aspect of Health and Social Care Partnerships' role in planning, commissioning and delivery, and this is especially important at the end of life. When we do get it right, it is typically by working with everyone involved to provide holistic, multi-disciplinary and personalised care and support.
- There is good evidence that people provided with early palliative care and support in all settings have better outcomes, with a better quality of life, fewer depressive symptoms, and on average live longer, despite opting for less curative treatment. Effective support at end of life and investment in supporting people in all settings, but especially at home, can have a beneficial impact on maintaining support at home, the quality of care, and achieving the desired place of death for the person.

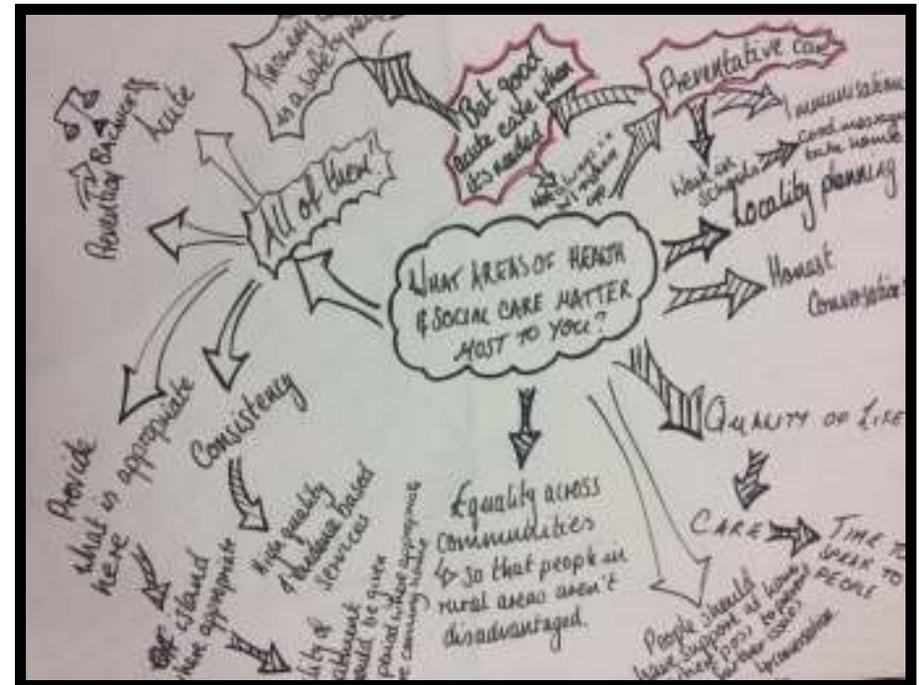
3. Developing the Commissioning Plan

This plan was developed by the Palliative and End of Life Care Strategy Group. This group is chaired by the Chief Officer, Health and Social Care and encompasses representatives from statutory and third sector agencies who provide support to people at the end of their lives. The group is supported by data intelligence and improvement staff.

The group considered the needs analysis and data that we currently hold about our service provision and their own perspectives about the services that we provide. A detailed analysis is set out in Annex 1. The group also considered detail from other Health Boards in respect of innovative and different ways that they are delivering palliative and end of life care.

In order to properly recognise the voice of users and carers, the main themes of the work will be discussed

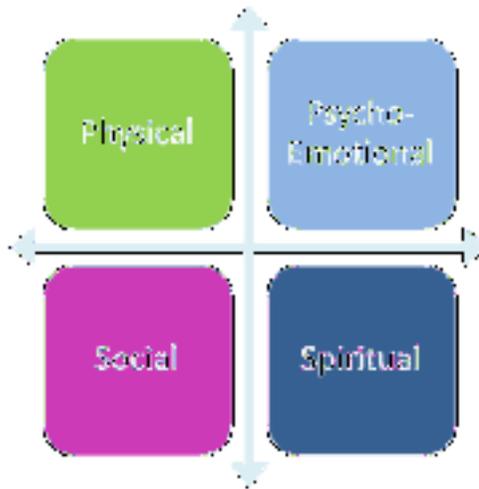
with a range of community-led and service user-led groups, including Locality Planning Groups.



In particular, we want to explore the rationale for supporting people to die at home. We find this is a commonly expressed desire, although some people have fears in respect of pain management and managing emergency situations.

4. Operating Context

In assessing needs, and planning how the full breadth of those needs will best be met sustainably, the four dimensions of palliative care should always be considered. Attending to the spiritual, social and psycho-emotional are not optional extras, and doing so may impact positively on the support a person needs.



Palliative care involves all these dimensions.

Legislative and Policy Context

The integration of health and social care is predicated on the ambition to integrate services around the needs of individuals, their carers and other family members. It seeks to achieve this by bringing responsibility for planning and resourcing integrated health and social care services under a Health and Social Care Partnership.

This arrangement allows Partnerships to take a joined-up approach to planning supports and services, in partnership with people, carers, communities and the third and independent sector. It allows Partnerships to better balance hospital and community provision, invest in preventative measures to minimise hospital admissions and ensure that people receive the care that they need, as and when they require it.

The Scottish Government published a Health and Social Care Delivery Plan in December 2016. This plan identifies Palliative and End of Life Care as a priority area for Health and Social Care Partnerships. The plan sets out the

significant body of evidence that shows that people would prefer to die at home, or in a homely setting, rather than in a hospital and it estimates that 8 out of every 10 people who die have needs that could be met through the provision of palliative and end of life care.

The delivery plan sets out some national ambitions to ensure that the right support and services are in place for people at the end of life. By 2021 the Scottish Government aims to ensure that:

- Everyone who needs palliative care will get hospice, palliative or end of life care;
- All who would benefit from a 'Key Information Summary' will have access to it - these are plans that bring together important information to support people, including future care plans and end of life preferences;
- The availability of care options will be improved by doubling palliative end of life provision in the community, which will result in fewer people dying in a hospital setting.

In December 2015, the Scottish Government published a strategic framework for action and an associated advisory group and action plan. The Scottish Government has since published updated guidance for commissioners in May 2018 in respect of the aims set out in the National Delivery Plan. We have considered our local strategy in light of this guidance and defined national priorities.

Local policy has also been developed to support palliative and end of life care, including the recently published policy and procedure for Adults and Older People in a Residential Setting.

Other important legislative agendas are relevant to our work on palliative and end of life care, including the Carers (Scotland) Act (2016). This legislation ensures that unpaid carers have the right to a plan and to have their support needs assessed. It is being implemented from April 2018.

Services and Support in the Western Isles

Palliative and end of life care is delivered via a variety of services that are provided by both statutory and non-statutory partners:

Most palliative and end of life care is delivered in the community. We have teams of primary care practitioners (including community nurses, GPs, OTs, speech therapists, social care workers and social workers) who provide general palliative and end of life care to people in their own homes or in care homes.

These core statutory services are augmented by third sector provision, which is commissioned on a spot purchase basis from a range of organisations, such as Marie Curie and Crossroads, which provide support, services and respite for people. Third sector organisations are very much at the heart of this commissioning strategy and have actively shaped its development as equal partners.

There are two nursing homes and two residential homes on the Isle of Lewis. Harris has two residential homes, Uist has two residential homes, and Barra has a single residential home attached to the hospital. These facilities provide care to people who require more intensive support than can be provided in their own homes. Palliative and end of life care is provided across all of these venues. A number of people are also supported in facilities on the mainland where their needs can be better met, e.g. to be closer to family who are resident on the mainland.

The Isle of Lewis has a local hospice – Bethesda – which operates four beds, which offers specialist palliative care.

We also have specialist palliative care professionals, with a well-established Macmillan team, a range of specialist nurses who provide leadership and advice in areas such as dementia and heart failure, and two physicians who lead the palliative care work of Bethesda. Our local health professionals can also access specialist consultant advice at Roxburgh House in Aberdeen, Grampian.

The Western Isles Hospital is a Rural General Hospital with 98 beds, capable of supporting people with acute care needs. Although not set up to support palliative and end of life care, it often fulfils that function in the absence of alternative options being available or because of medical need.

The Uist and Barra Hospital in Balivanich (16 beds) and St Brendan's Hospital in Castlebay (4 beds) are, by contrast, smaller community hospitals which will support people with palliative and at end of life care needs.

With regards to the Bereavement services, we offer a range of support arrangements beyond that offered by the health and social care professionals named above.

We offer a pack entitled 'When Someone has Died' which is available to all bereaved families. It includes all the necessary information nationally and locally such as death registration, contact details of funeral directors, therapeutic services available locally and nationally. This is an important practical guide to families as they work through their grief.

Our Community Chaplaincy Listening (CCL) service is also available across the Island. This service can be accessed either via GP surgeries or directly by families in need of spiritual support. We also have a peer support Bereavement Group which meets every month in the Western Isles Hospital Chapel. Outreach services are in development.

Not all people who are affected by bereavement will seek support from health and social care professionals. Other types of support may better suit their needs such as the church or other spiritual groups, private counselling, family, community and other peer groups.

All of these services play a significant part in supporting people, their families and carers in the run up to death and in respect of bereavement support. We have strong communities and churches which play a significant role in supporting people across the Western Isles. Indeed, it is often these community assets that do most to support people in times of need and this plan actively acknowledges the contribution they make.

Our Resources

The Integration Joint Board has a budget of circa £58m to provide health and social care across a range of secondary, primary and community care services. Within that budget, specific sums are set aside to support palliative and end of life care, including:

- £186k from the IJB to support the annual operating cost of the Bethesda Hospice. This means the hospice brings to the table significant charitable income of its own (£631,053 in 2017/18).
- £6k from the IJB to Marie Curie to support families at home to support a family member at end of life. This sum is also match-funded another £6k by Marie Curie.
- £14k from NHSWI to Roxburghe House to provide expert medical advice and support in respect of palliative care

In addition to the above, we have a number of specialist nursing teams, which, although not focused entirely on

palliative and end of life care, have significant regard to this area of work:

- Specialist cancer (Macmillan) team
- Specialist cardiac nursing team
- Specialist neurology nursing team
- Specialist dementia nursing team
- Specialist respiratory nurses

Finally, we have a range of generic services which provide palliative and end of life care when required. These include:

- Community Nursing
- General Practice
- Residential and nursing homes
- Homecare

It is also possible to quantify the secondary care activity associated with care at end of life.

5. Understanding Our Local Health and Social Care System

In 2016 we published a strategic needs assessment that looked at a wide range of information for the Western Isles. Part of this analysis looked at the changing population over the next two decades. These projections provide an indication of the scope and scale of palliative and end of life care we will require in future years.

Our projections show that the proportion of the population who are older than 65 is projected to rise by 14.7% by 2037, compared with an 8% rise for the rest of Scotland. This will mean that almost 40% of the population will be over the age of 65 by 2037.

The strategic needs assessment also notes that there has been a trend in recent years in the number of people of pensionable age who are living alone. In 2011, the Western Isles recorded the highest percentage of all the Scottish Health Boards at around 17% as compared to the

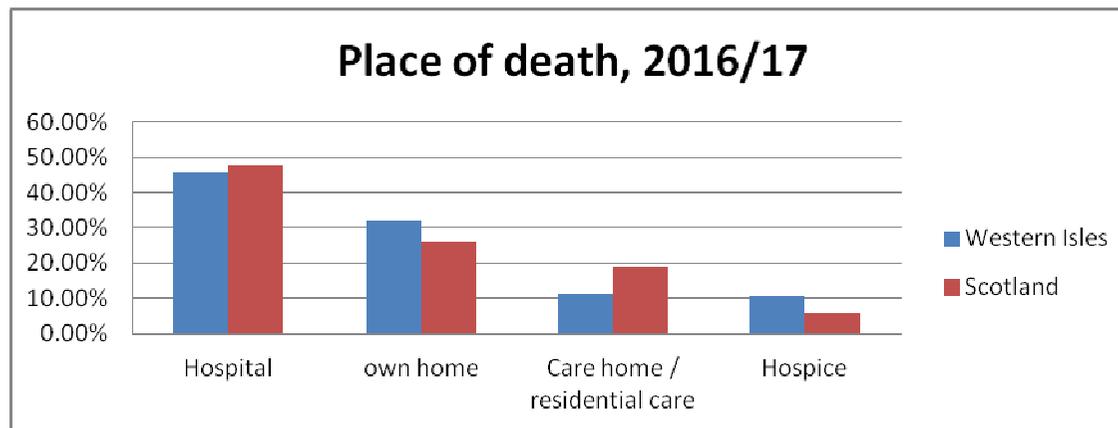
Scottish average at 13%. We can therefore expect that as the years go by, we will have more people who are naturally reaching the end of their life who are living alone and may therefore require more statutory support.

Over the last decade there has been a considerable amount of research that looks at the prevalence of long term conditions, or multimorbidity as it relates to age. The research demonstrates that multi-morbidity increases with age, with older people having more long-term conditions than those who are younger than them. The support and services that we plan will need to cope with this increase in complexity.

Over the coming two decades, palliative and end of life care services will have to deal with an increase in the number of people they support, an increase in the proportion of those people who have multiple and complex needs and an increase in the proportion of those people who live alone. The model of service provision we put in place will need to be able to respond to all these demographic changes.

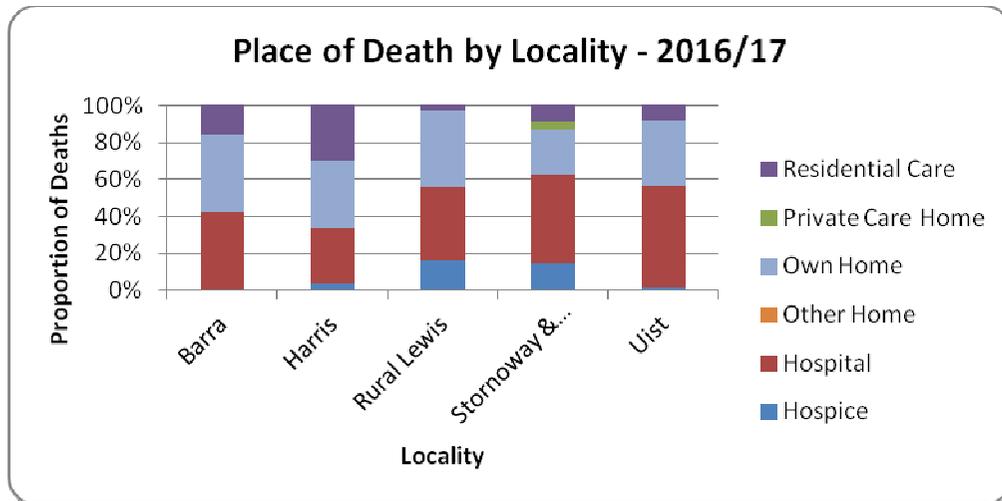
Current Patterns of Consumption

Each year around 350 people die in the Western Isles and as such we estimate that over 1,400 people are significantly affected by the death of a loved one. A key measure at both a national and a local level is the proportion of people who die in different settings. This information helps us to see how well we support people at the end of life and is comparable across all Health Board areas. This information for the Western Isles compared with the figures for Scotland as a whole.



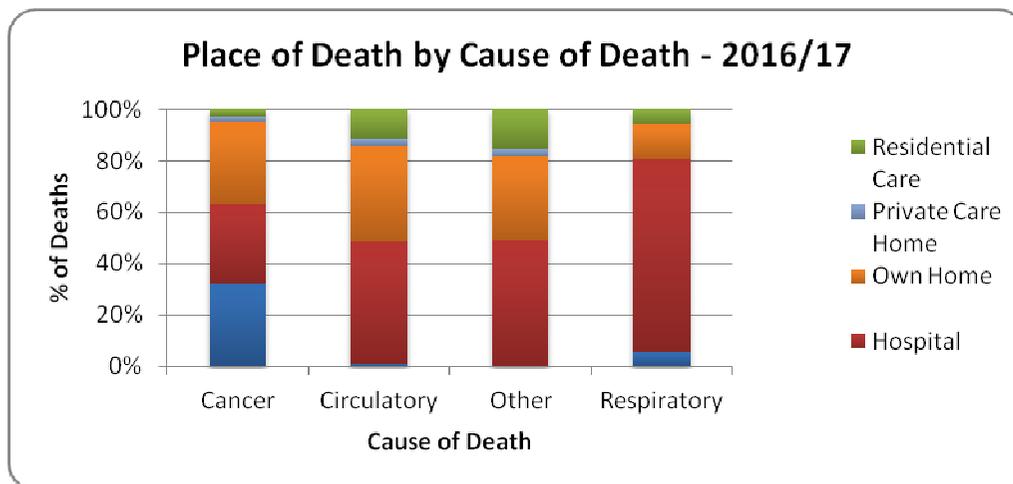
It shows that a greater proportion of people die in their own homes and in a hospice than the rest of Scotland, and fewer people within a residential care or hospital setting. However, we are unable to measure this against people's preferred place of death at this stage.

When we consider the same information by locality, we can see that there is a significant variation between our localities. While this highlights that there is expertise in all our localities in delivering last days of life care, it also suggests that some localities deliver palliative and end of life care in different ways, making better use of resources in the community and avoiding hospital admission to a greater degree. This is important because of what we mentioned earlier - effective support at end of life and investment in supporting people in all settings, but especially at home, can have a beneficial impact on the quality of care received.



This data shows us that the cause of death has a material effect on where people die. People who die of cancer are more likely to receive hospice care than others, and those with respiratory conditions are more likely to die in hospital than those with other causes of death.

We also see significant variation across the different causes of death.



As part of the needs analysis, we also looked at people who had hospital bed days within the last two weeks of life, including both patients who were hospitalised for the whole of that period, and those that were admitted during the last two weeks of life. Again, Harris residents have fewer hospital admissions in the last two weeks of life than the residents of any other locality.

6. Service Development

The data suggests that a number of service development opportunities exist and in particular, we should seek to better understand why the Harris locality is better at supporting people to remain at home at end of life.

Harris Case Study

The data shows that the Harris locality is more successful at supporting people to remain at home or in a homely setting at the end of their lives. The key features of how they manage their service are:

- Multidisciplinary working co-ordinated around the needs of individual people through weekly team meetings;
- A lead professional for each person they are supporting, usually a Community Nurse or the GP;
- Up-to-date Palliative care register and Key Information Summaries;

- Flexible home support that can be provided at short notice when people require it. Crossroads Harris plays a key role in providing this support;
- Access to specialist support and knowledge from the Bethesda hospice as and when required;
- Working with families and carers so they are supported to provide support to the person at the end of their life.

In this way, professionals in Harris are providing flexible support to those people who are under their care when they need it most and could provide the basis for a new model of care.

The team in Harris are unequivocal that at the heart of their success in supporting people at the end of their lives is multidisciplinary team work. This mirrors the evidence and advice from national sources that also point to a team approach to providing care at the end of life as a determinate in improving people's outcomes.

In addition to better understanding what works well in Harris, consideration was also given to the barriers to good practice that can emerge day-to-day. Three broad themes were identified:

1. The primary care team working with patients, especially at end of life, are often unable to secure or commission care and support at short notice to allow a person remain safely at home. This can lead to the breakdown of care arrangements and lead to hospital admission;
2. The primary care team managing a palliative patient at home does not always have access to specialist medical advice. In consequence, it can become difficult to support that person at home;
3. The team managing day-to-day care are not always able to provide the desired level of care and respite to unpaid carers – often family members – and as such, the burden of care can become too great for them.

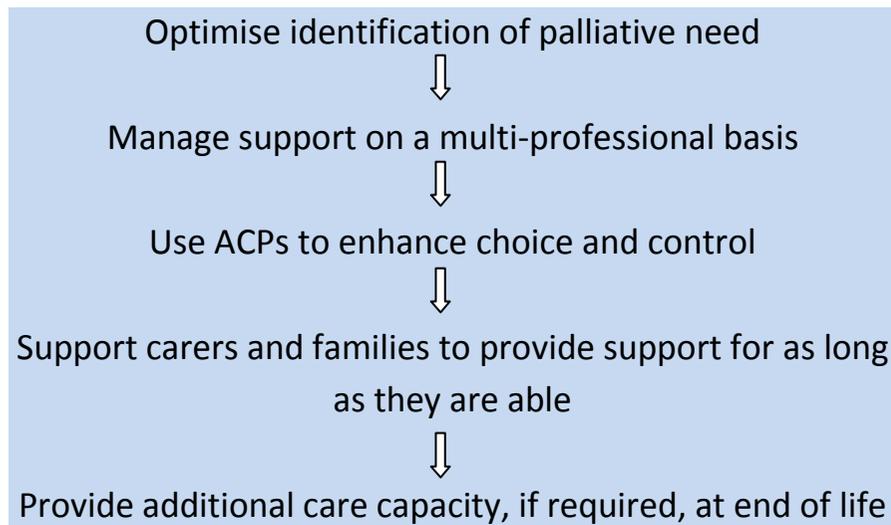
Service development arrangements and models of care will therefore be commissioned to address these barriers.

In addition to the service design arrangements, it is also evident that the provision of education and training to all partners, including unpaid carers, is essential for delivering high quality palliative and end of life care. NHS Education for Scotland (NES) in partnership with the Scottish Social Services Council (SSSC) has developed a framework to support the learning and development of the health and social care workforce in Scotland. This commission plan relies on the educational framework being implemented across our statutory and non-statutory partners to ensure that we have the right skills and knowledge within the workforce to support the delivery of Palliative and End of life Care.

It is important that carers and families are considered in this context. Often, unpaid carers can lack confidence in how they are approaching the care of a loved one but reassurance and guidance can make the difference of whether they ask for admission to hospital or not.

Developing a Model of Care

To improve the way that we deliver palliative and end of life care in the Western Isles we will support localities to build multidisciplinary models. This will be based on the learning that we have from Harris, but with effective local leadership allowing for arrangements to be tailored to local service arrangements. The following general model is proposed:

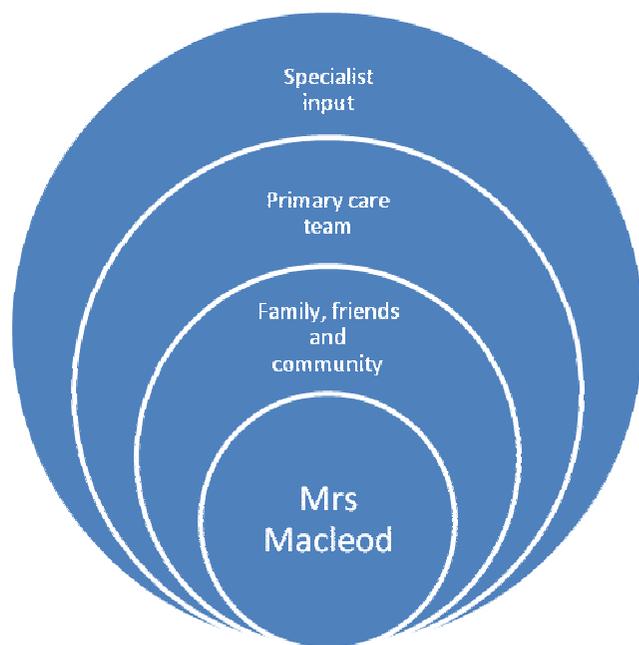


Our proposed model of care places the individual – in this instance we refer to Mrs Macleod - their carers and their family at the centre of everything we do. We also

recognise that people will be able to draw on assets and support from the wider community - from churches and voluntary groups for example – and often times these civic institutions will provide the spiritual and social support which keep people embedded in their communities.

In terms of the coordination of care and support, we anticipate that a lead professional, normally a community nurse, will co-ordinate a multidisciplinary approach to providing care and support to people within their locality at the end of their lives. This is an important function which supports effective care management and will include liaising with the GP or specialist nurse in respect of symptom management and general medical care; liaising with social work and care professionals to ensure that the requisite home support is in place – or where that’s not possible placement within residential or hospice care; liaising with the family and friends of the person being supported to ensure that they are capable of sustaining their caring roles and understand the prognosis and how needs may change with time; using tools like Anticipatory Care Plans to ensure that a

person's preferences and principles are fully considered and inform their care and support arrangements; and ensuring that the wider spiritual and emotional needs of patients are met through direct care or referral, as appropriate.



The family GP will normally be heavily involved in support arrangements as well. Under the terms of the new GP

contract in Scotland, we would expect the GP to provide the local clinical oversight and function as an 'expert generalist'. This will mean providing clinical direction and advice to other health and care professionals involved, which may include Advanced Nurse Practitioners, AHPs, community nurses and social workers. It may also mean liaising with specialists in palliative medicine to ensure that expertise is brought to bear on symptom management and other clinical care considerations. Where the patient has been under the care of a specialist nurse, her expertise will be utilised as much as possible. The Health and Social Care Partnership will ensure that specialists in palliative medicine are available to support GPs in their work.

Effective coordination and communication will be supported through multidisciplinary teams, which will normally involve the lead community nurse, the GP and the social worker, with social care professionals, AHPs and others as required. Each multidisciplinary team would meet regularly to discuss individuals on palliative care registers. At these meetings consideration would be given to the care requirements, coordination, and plans for

response to crisis. Ideally, all people on the register would have a Key Information Summary in place.

Arrangements should be put in place to ensure that the team can respond quickly and effectively at times of crisis to support individuals, their carers and their families and access to specialist advice and knowledge from specialist nurses and from the staff at Bethesda Hospice. This will include arrangements for supporting people during the out of hours period.

While recognising that this model has been loosely drawn, that will allow local professionals to establish the precise arrangements that work for that locality. It may be that the MDTs are organised around GP practices – which is how it works in Harris – and which would be in keeping with the direction of travel set out in the new GP contract.

Identification

The early identification of people with palliative care needs is important if we are to embed effective care and support. Many GP practices hold a register of people with

palliative care needs and it is important that these are maintained and regularly updated.

The University of Edinburgh has developed an internationally recognised and free tool to support prognosis. The Supportive Palliative Care Indicators Tool (SPICT) is used by health and care professionals to help them identify people at risk of deteriorating and dying with one or more advanced, progressive conditions or a new life-limiting illness.

Many of these people (particularly if they don't have cancer) are identified too late to benefit from well-coordinated, supportive and palliative care integrated with appropriate treatment of their underlying illnesses.

SPICT helps clinicians decide when it is time to look for unmet holistic care needs. We can then start talking with people and their families about what is important to them and the available treatment and care options.

Anticipatory Care Plans

Anticipatory Care Planning is about individual people thinking ahead and understanding their health. It's about knowing how to use services better and it helps people make choices about their future care – including what support they want as they near death. Planning ahead can help the individual be more in control and able to manage any changes in their health and wellbeing.

An Anticipatory Care Plan (ACP) is a dynamic record that should be developed over time through an evolving conversation, collaborative working and shared decision-making. It should be reviewed and updated as the individual's condition or personal circumstances change and different things take priority. It is a summary of the "thinking ahead" discussions between the person, those close to them and health and care professionals supporting them. It is a record of the preferred actions, interventions and responses that care providers should make following a deterioration in health or a crisis in the person's care or support. It should highlight the person's personal goals, preferences, views and concerns.

As care becomes more complex, it may be helpful to discuss legal and practical issues as well as care and support preferences. As the needs and dependency of the person increase, it may become appropriate to talk about care towards the end of life within these conversations.

ACPs will include additional information about the person's understanding about their illness and prognosis, and wishes and views about end of life care, including preferred place of care, as well as their views about any interventions, treatments and whether or not cardiopulmonary resuscitation is appropriate or wanted. For ACPs to work we need to build on existing good practice. This requires a cultural shift and change in the way we work to develop a robust community infrastructure that has the capacity and capability to provide 24/7 care, improve quality of life and manage more people more independently out of hospital.

There is increasing evidence that appropriate access to community services and good anticipatory care, supported by the development of a Key Information Summary (KIS) that contains the right information, can

reduce the risk of hospital admission by 30–50%. While the KIS is commonly used by all our GP practices, we see variation in the degree to which they are applied in practice. We also know that in Harris, where less people die in hospital, there is a greater proportion of the practice list with an active KIS in place. Further work is underway to roll-out wide ACPs and we anticipate that this will be actively used by the care coordinators (community nurses) as we roll-out the reforms highlighted in this plan.

Education and Training

Our model of care will only be effective if statutory and third and independent partner staff have the right training, skills and knowledge. As part of the implementation of Hospice at Home we shall roll out a Partnership-wide education and training programme for all professional staff involved in the delivery of palliative and end of life care.

In the first instance, that will be in the form of a train the trainer education programme for key staff, both statutory and non-statutory, across our five localities. This will be

delivered in partnership with Macmillan Cancer Support in line with the NHS Education for Scotland and Scottish Social Services Council's framework. Education will then be rolled out to all staff within our localities who play an active role in providing end of life care and support. We will also further develop training for the family and carers, to ensure they are better equipped to support and manage the person's care needs at home, outside of the specialist services provisions. This will be detailed in our new carers strategy and will also be monitored through the palliative care workstream.

Improving our qualitative understanding of the service

There is a lack of patient, carer and family feedback in respect of the services we provide. Whilst some information exists, through annual GP surveys and the health and wellbeing information gathered nationally, there are no specific end-of-life care surveys that we can draw upon to guide service development.

Establishing a baseline of information in respect of feedback and opinion of people who experience our services is essential in understanding whether we are delivering the outcomes that people seek. We shall

develop a questionnaire for recently bereaved families and carers asking for feedback and information on how well we delivered support prior to the death of the individual. Just as important are the reflections from the staff involved in delivering care at the end of life. As part of the multidisciplinary team approach, localities will be asked to ensure time is given over to reflect on the positives and negatives of the care delivered to people. This currently happens within the Care Homes as part of the 'traffic light' system. Localities and multidisciplinary groups will be asked to share this information with the working group in the first instance to provide better oversight and assurance of how the new arrangements are bedding in.

Equity of Access across Diagnostic Groups

As noted within our needs analysis, there is significant variation in the place of death dependent on the cause of death. To consider if this variation is due to clinical necessity, or if improvements to the support that we offer can be made, we shall establish a clinical review group. This group, containing professionals from both the community and the acute sector will consider how care is

currently provided and if adjustments can be made to better support people to die at home or in a homely setting, particularly in respect of respiratory conditions. Our aim would be to produce bespoke guidance on the latter, given that people with respiratory illnesses can have particular challenges around symptom management. We will examine the practical criteria used to determine how and when someone accesses care, across different conditions. This will also consider the limits of providing palliative care at home.

Support for Carers

Recognising that we are seeking to grow the overall provision of respite care in the Western Isles, we will increase our investment in respite targeted at families caring for someone with palliative or end of life needs. This will help manage the caring role for those supporting loved ones. We will also work towards introducing the Carer Support Needs Assessment Tool, which is an evidence-based tool that facilitates support for family members and friends.

6. Implementation Plan

To ensure that the changes we make to the way that we provide palliative and end of life care deliver better outcomes, we aspire to the following high-level objectives:

1. We shall work with community health teams to ensure that we are identifying all people with palliative care needs and actively managing support on a multi-disciplinary team basis;
2. We shall improve our recording and performance in respect of people at the end of their lives having a Key Information Summary/Anticipatory Care Plan in place – and enhance the choice and control of people over their support arrangements;
3. We shall seek to increase the proportion of time spent at home or in a homely setting in the last six months of life by building on the good multi-disciplinary practice we see across all our localities, especially in Harris.
4. We shall seek to provide more equitable access to end of life care and symptom control across all diagnostic categories by:
 - a) Working with our local providers of palliative and end of life care to consider who accesses hospice support and in what circumstances;
 - b) Developing bespoke guidance and training for members of staff and carers to reduce the proportion of people with respiratory diseases who die in hospital;
5. We shall seek to ensure that all relevant staff, both within the statutory and non-statutory sectors, have received training in PEOLC;
7. We shall double the amount of respite available to families supporting a person in the last days of life, to further reduce the likelihood of care arrangements breaking down.

| | AMBITION | ACTION | IMPACT | LEAD | TIMESCALE |
|---|--|--|--|----------------------------|------------------|
| 1 | The identification of people with palliative care needs is further developed | Work with GP practices to optimise palliative care registers and to promote early identification of need | The number of late presentations is reduced by 5% by 2021 | Associate Medical Director | April 2021 |
| 2 | Improve the choice and control of people with palliative care needs | Undertake further data analysis to establish a baseline for Key Information Summaries for each locality | Our understanding improves of how KIS/ACP are used across localities | LIST | January 2020 |
| | | ACPs are used to support people with palliative care needs and these are implemented to cross-refer to a corresponding KIS | By 2020, we increase the proportion of people with a KIS by 10% across all GP practices | Lead Nurse | June 2020 |
| 3 | Implement the hospice at home model in each locality | Identify multidisciplinary teams in each locality and confirm arrangements to working groups | By 2021, the percentage of people who die at home or in a homely setting will have increased from 89.4% to 92% | Lead Nurse/Chief Officer | July 2020 |
| | | Establish the scope of specialist support available from Bethesda | | Chief Officer | July 2019 |
| 4 | Ensure that our teams have the right skills and training | Arrange PEOLC training through Macmillan. Roll out training to all appropriate community staff, both statutory and non-statutory | Members of staff feel more confident in supporting people with palliative care needs | Macmillan Lead Nurse | Ongoing |
| | | Develop resources that help carers and families continue their support | Unpaid Carers feel more confident in supporting people with palliative care needs | Macmillan Lead Nurse | June 2019 |
| 5 | We improve the tailored support we provide by engaging patients | Develop a questionnaire for people, carers and their families about the support and services we provide | Our understanding of what matters to people improves | LIST | June 2020 |
| 6 | Improve equity across diagnostic categories | Clinical lead to develop respiratory palliative care sub group to identify possible redesign options | By 2021, the percentage of people with respiratory conditions who die in a hospital will have decreased by 2% | Associate Medical Director | June 2020 |
| 7 | Families and carers are better supported to continue in their caring role at end of life | The amount of respite care is doubled and can be access across all diagnostic categories and localities | By 2021, the percentage of people who die at home or in a homely setting will have increased from 89.4% to 92% | Chief Officer | Aug 2020 |

Annex 1 - Needs Analysis

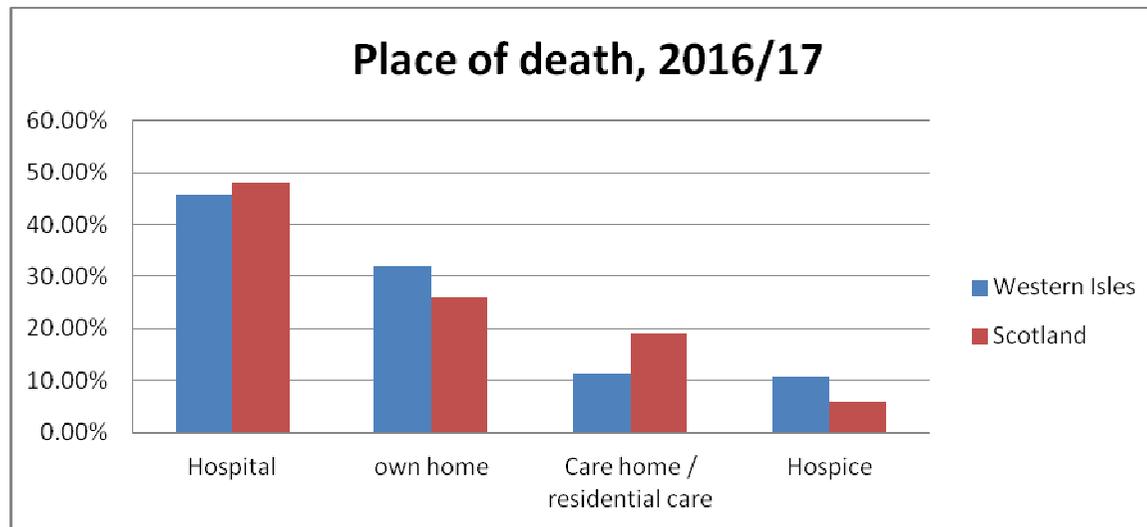
1. To provide the basis for this strategy we have looked across a wide range of data that we collect to see how our system is operating and performing.
2. We have little qualitative information, particularly from patients, their families and their carers. Developing this qualitative information is a core aim of this strategy to ensure that our assumptions about service delivery are correct, and that the changes we make improve services in the eyes of the people who receive them.
3. The Scottish Government sets out in the National Health and Social Care Delivery Plan¹ and the subsequent advice on the strategic commissioning of Palliative and End of Life Care several aims and observations about service delivery in Scotland. They note the significant body of evidence that shows that people would prefer to die at home, or in a homely setting rather than in a hospital and they estimate that 8 out of every 10 people who die have needs that could be met through the provision of palliative and end of live care.
4. To underpin the analysis of how we are delivering palliative and end of life care in the Western isles we have considered a wide range of data that highlights how well we are doing to provide and personalise care, focusing on supporting people to die where they choose to do so. We have looked to see if there is variation between our localities and the conditions that people present with.

¹ [Health and Social Care Delivery Plan, December 2016, page 8](#)

Place of death

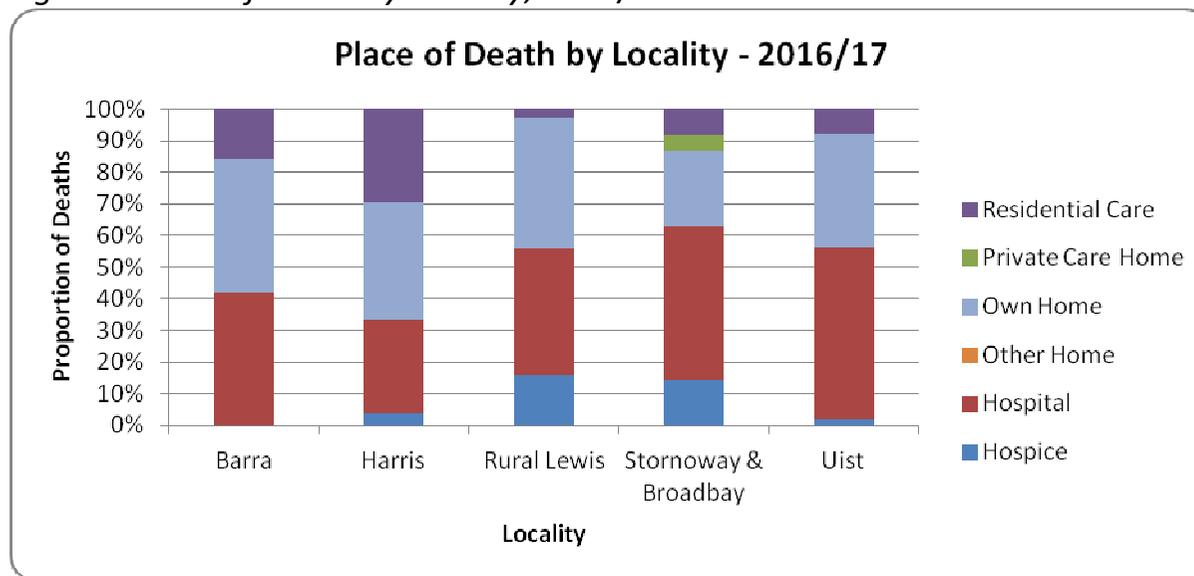
5. Figure 1 describes where people die and compares this with the rest of Scotland. The data shows that a greater proportion of people die in their own homes and in a hospice within the Western Isles than the rest of Scotland, and fewer people within a residential care or hospital setting.

Figure 1 Place of death, 2016/17



6. When we consider place of death by locality (Figure 2) we can see that there is a significant variation between where people die in the different localities across the Western Isles. It is difficult to ascribe causality for this variance other than it relates to the facilities that each locality has. What this does highlight, is that there is expertise in all of our localities in delivering end of life care across the full range of facilities. Harnessing and sharing how this is coordinated and delivered is likely to be of benefit across all localities.

Figure 2 Place of Death by Locality, 2016/17



Understanding people's choices

7. This data would indicate that the Western Isles is doing better at supporting people to die at home or in a homely setting than in Scotland more generally. However, whilst this data shows us where people died, it does not compare it to where they wanted to die.

8. The Scottish Government has promoted the use of Anticipatory Care Plans and Key Information Summaries as places that this information should be recorded. The number of people who have these plans and summaries in place differs from month to month and are also in place for people who are not near their end of life, for example, those receiving chemotherapy, previous transplant patients or those with drug seeking behaviours. These people cannot be disaggregated from the data to show only those at the end of life in receipt of a Key Information Summary.

9. The data we have on Key Information Summaries (Figure 3) does show that there is variation between localities with Harris having a much greater rate per population than the other localities.

Figure 3 – The rate per 1000 population of people with an active KIS

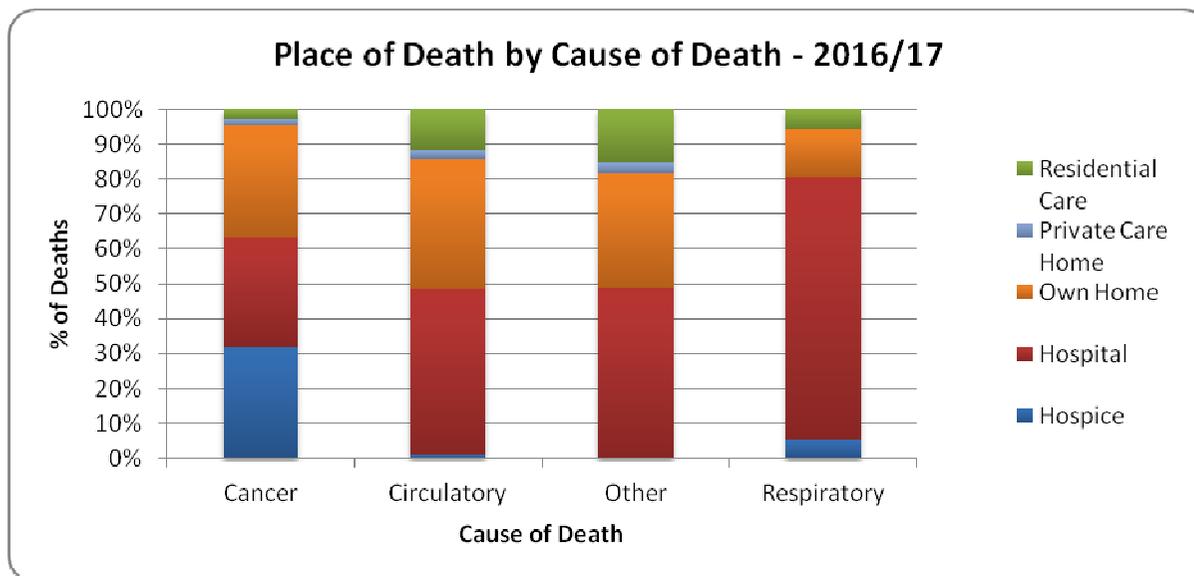
| Locality | Rate per 1000 population |
|---------------------|---------------------------------|
| Stonoway & Broadbay | 32.6 |
| Rural Lewis | 28.8 |
| Harris | 57.0 |
| Uist | 19.9 |
| Barra | 13.9 |
| WI Overall | 30.3 |

10. The working group considered the data that we have and there is a recognition that we could improve our use of both Anticipatory Care Plans and Key Information Summaries. This work will be a key part of taking forward the redesign of our palliative and end of life care services including better baseline information for how these are currently used for those people who are known to the service and are expected to die within the next six months.

Causes of death

11. As part of the needs analysis we compared the major causes of death against the place of death.

Figure 4 – Place of Death by cause of Death 2016/17

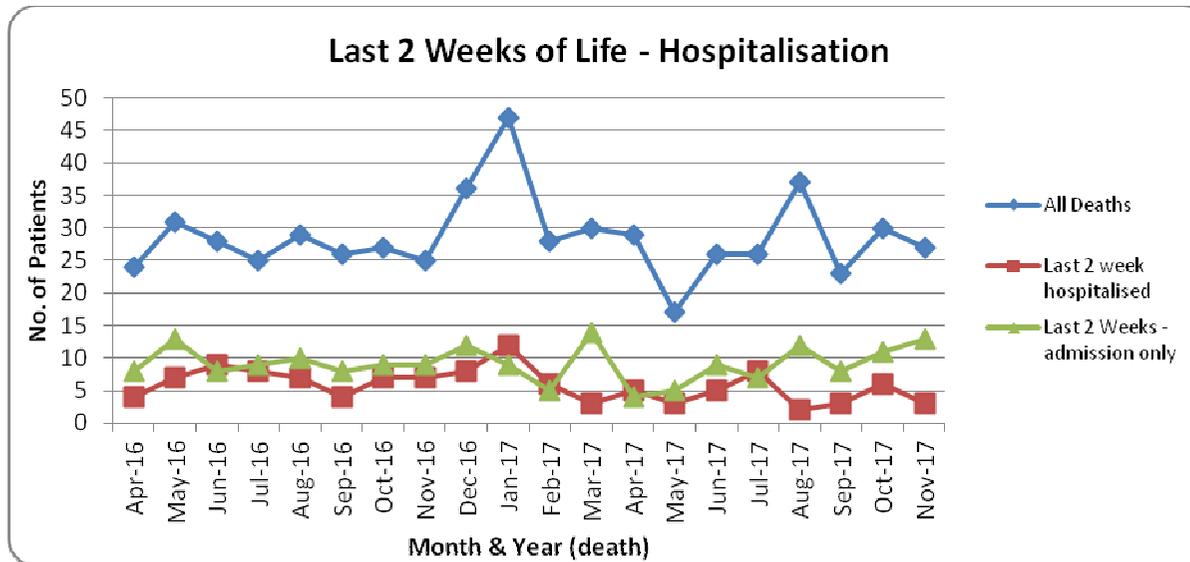


12. This data shows us that the cause of death of someone has a material effect on where they die. People who die of cancer are more likely to receive hospice care than others, and those with respiratory conditions are more likely to die in hospital than those with other causes of death. Historical and clinical reasons do explain some of this variation, but it is likely that with further investigation and consideration we might be able to reduce the variation that people encounter, especially in respect of respiratory conditions and hospice use.

Last two weeks of life

13. As part of the needs analysis we looked at people who had hospital bed days within the last two weeks of life, including both patients who were hospitalised for the whole of that period, and those that were admitted during the last two weeks of life.

Figure 4 – last two weeks of life



14. This can also be broken down by our localities and Figures 5 and 6 respectively show those who were hospitalised for the entire two weeks and those who were admitted in the last two weeks of life by locality. Both graphs demonstrate that Harris performs well in respect of reducing admissions to hospital in the last two weeks of life. This will contribute to the lower levels of deaths that occur in hospital for Harris as noted in Figure 2 above.

Figure 5 – Last two weeks of life – Hospitalised

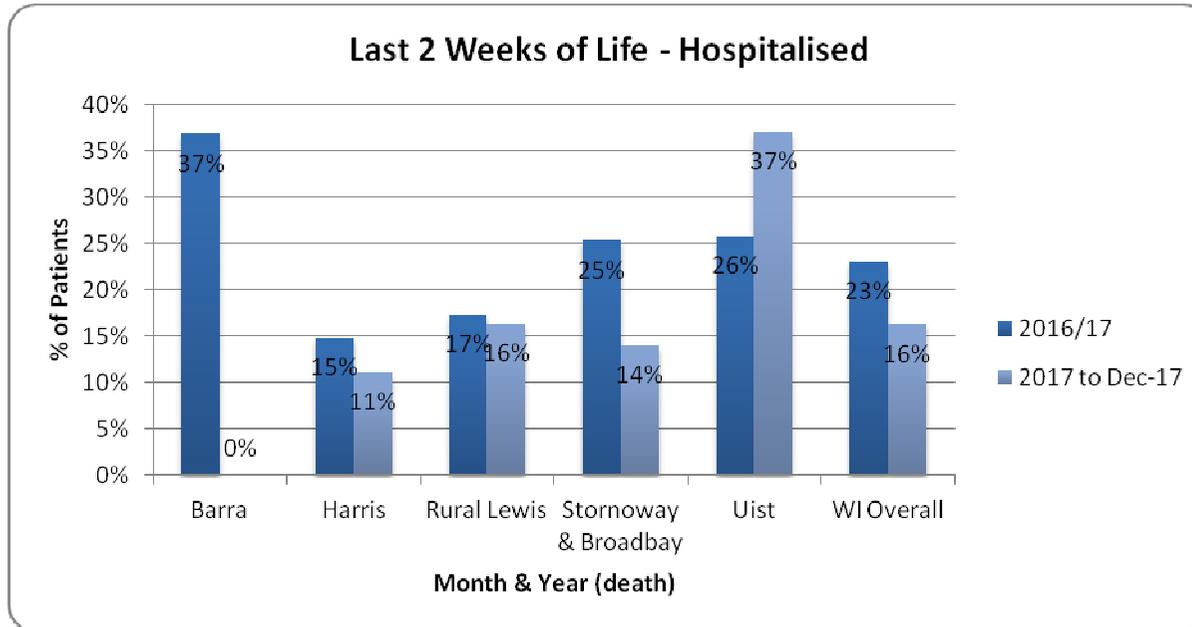
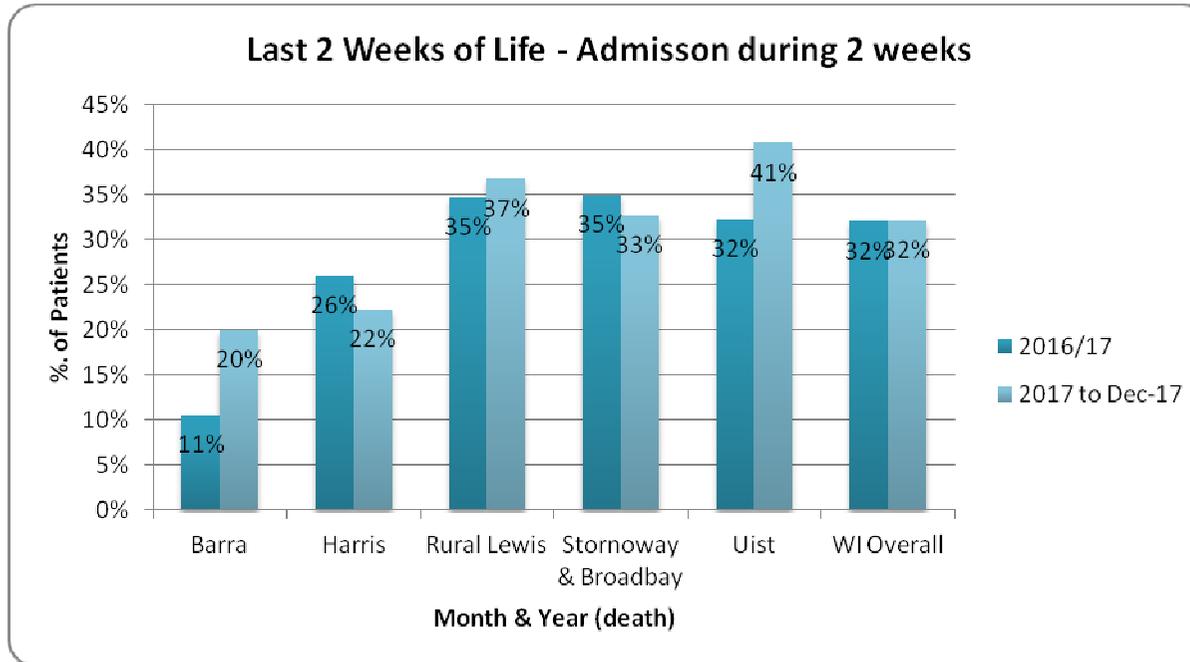
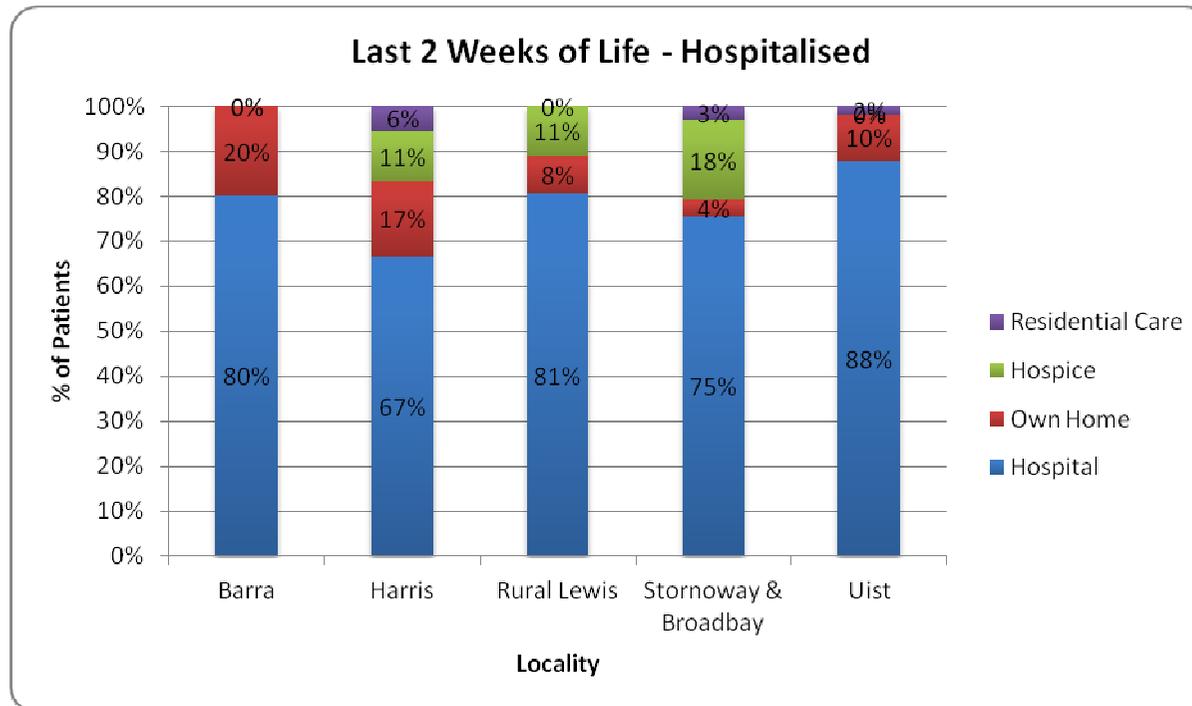


Figure 6 – Last two weeks of life - admitted



15. We reviewed the place of death for those who had a hospital stay within the last two weeks of life and found that a high proportion of those admitted to hospital within the last two weeks of life, go on to die in hospital

Figure 7 – Place of death for those admitted to hospital in the last two weeks of life



16. Finally, we looked at when in that two week period most people were admitted and found that the highest number of admissions were within the last 72 hours of life

Figure 8 – Number of days before death patient admitted

