Needs Assessment:

Integrated Palliative and End of Life Care for the Isle of Man

2020

Workstream 1
From Vision to Reality
Island Plan for Integrated Palliative and End of Life Care

Foreword Hospice Isle of Man

Anne Mills
Chief Executive Officer
Hospice Isle of Man
Director Scholl Academic Centre

The completion of the Needs Assessment is a significant milestone and achievement of the work set out in *From Vision to Reality: The Island Plan for Integrated Palliative and End of Life Care 2018-2023.* A Strategic Partnership Steering Group, led by Hospice Isle of Man, the Department of Health and Social Care, and the Council of Voluntary Organisations developed the Island Plan and set out an ambitious five year strategy. The aim of the plan is to deliver excellent and sustainable palliative and end of life care for all who need it by working together to support more people to remain in community settings.

The Independent Review of the Isle of Man Health and Social Care System by Sir Jonathan Michael highlighted the need for better data across the system in order to support system transformation. This Needs Assessment, brings together data from multiple sources in order to answer fundamental questions such as what is the need for, and provision of, integrated palliative and end of life care on the Island and predict how needs will change in the near future. The findings from the work conducted for this Needs Assessment are the evidence base for the Island Plan work streams based on local data to help us understand and meet our *local* needs on Island.

We are extremely grateful for the generosity of the Manx Lottery Trust who funded the Scholl Academic Centre to carry out this Needs Assessment.

Anne Mills

Foreword Manx Lottery Trust

Sarah Kelly
Chairman
Manx Lottery Trust

This programme is funded by the Manx Lottery Trust as a delegated partner of the National Lottery Community Fund.

Our aim is to fund projects which address the issues, needs and aspirations of local communities and people and fund a wide range of community projects aimed at developing skills, improving health, revitalising the local environment and enabling people to become more active citizens.

We were pleased to be able to support the Needs Assessment work undertaken by The Scholl Academic Centre's Research Team which aims to help improve our community and the lives of people most in need, something we feel aligns with our aspirations.

Working with the Strategic Partnership Steering Group - Hospice Isle of Man, the Department of Health and Social Care (DHSC) and CVO Isle of Man has allowed the Needs Assessment to examine the current and near future needs of the Isle of Man as an evidence base for an Island Plan for Integrated Palliative and End of Life Care.

At the time the grant was awarded, the Trustees were aware that this would be a long piece of work which required meticulous gathering of data. We were keen to be kept up to date as the information was being compiled, and the final results and analysis give a clear indication of the way forward across the Island.

The report makes very interesting reading and highlights the need for collaboration in various areas. We are pleased that this evidence is now in place to be built upon in coming years.

Executive summary

From Vision to Reality

Island Plan for Integrated Palliative and End of Life Care

2018 -2023

Caring for people in the last phase of life is challenging for families, carers and service providers. As the population of the Isle of Man ages and people live longer, we will have a greater proportion of older, relative to younger, people. This will result in more deaths per year and these will be of older people. Since 2016, when Hospice Isle of Man extended its services to those without cancer, referrals to Hospice have increased by 24%. This rise will continue and we also do not know how many more people might benefit from specialist palliative or end of life care and are not receiving it.

We report here a needs assessment which aims to examine the current and near future needs of the Isle of Man as an evidence base for an Island Plan for Integrated Palliative and End of Life Care. This needs assessment is Workstream 1 of the Island Plan for Integrated Palliative and End of life Care "*From Vision to Reality*" developed by of the Strategic Partnership Steering Group (SPSG) led by Hospice Isle of Man with the Department of Health and Social Care (DHSC) and CVO Isle of Man. The SPSG was set up in 2018 to deliver this Plan.

The needs assessment was funded by the Manx Lottery Trust (as delegated partner of Big Lottery Fund UK), the Gough Ritchie Charitable Trust, the Masonic Charitable Foundation and the Elizabeth Clucas Charitable Trust. Data sources included Government published and unpublished data, interviews with professionals from all relevant services and Third Sector groups and views of members of the public, schoolchildren and students from University College Isle of Man. Data were collected between May 2018 and August 2019. All methods and detailed results are to be found in the full report and its associated appendices available at: **www.hospice.org.im/NeedsAssessment.**

Questions to be answered by the needs assessment were:

1. What services are currently available for palliative and end of life care?
2. How many people on the Island could benefit from palliative and end of life care?
3. Who and how many is Hospice helping?
4. What do people want from these services?
5. What is currently working well and not so well?
6. How close are we to delivering appropriate care and what remains to be done?

What services are currently available for palliative and end of life care?

Hospice Isle of Man is the only specialist provider of palliative and end of life care on the Island but many other services deliver general palliative and end of life care in the community. These include general practitioners (GPs), district nurses, long-term conditions coordinators, specialist nurses and social care services. Third Sector organisations are also involved in patient, family and carer support.

How many people on the Island could benefit from palliative and end of life care?

Between 2013 and 2018, there were an average of 834 deaths per year but this number is expected to rise to over 1,100 a year by 2036, an increase of over 30%. Using data from registered deaths we estimated that 64% of those who died had a condition which could have benefited from palliative care; however only around 30% of those who died were known to Hospice leaving a further 34% who might have benefited from referral. The fastest growing conditions among those who might benefit from palliative care is dementia (21% growth from 2013 to 2018), followed by neurodegenerative conditions at 12%. Cancer growth rates are flat but, given that more and more non-cancer cases are being referred to Hospice, the implications for workload and capacity are serious.

These concerns have prompted SPSG Workstream 4 which focuses on Hospice services to develop its Community Plan through which resources will be invested in community-based care to ensure as many as possible who can benefit from Hospice-influenced care will receive it.

Who and how many is Hospice helping?

More people (41%) died in hospital, between 2013 and 2018, than in any other setting. However, increasing numbers of people were dying at home (including Nursing and Residential Homes). The majority of people with cancer still die in Hospice. Most people with dementia or neurodegenerative disease die in their Nursing Home, often with Hospice involvement. Those with organ failure tend to die in hospital, sometimes because of reluctance to engage with Hospice or fast deterioration. The time that someone is under Hospice care tends to be much shorter for those who have a condition other than cancer. Many of the non-cancer cases spend only a few days with Hospice and this is not optimal in terms of the benefit they might have received through earlier referral.

What do people want from palliative and end of life services?

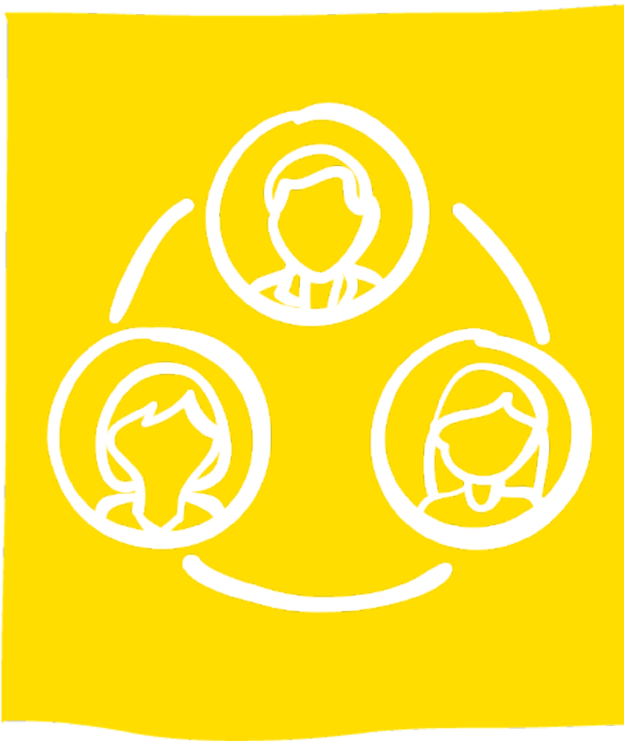
Most people, and the professionals who care for them, prefer that end of life care is delivered as far as possible at home. Major areas of need to achieve this are 24-hour support and an urgent response service which could avoid unnecessary admissions to hospital. More availability of respite care would avoid carer burnout and people being transferred to long-term care. Integration of care across services and with the Third Sector is desired but difficult to achieve at present due to staffing issues, challenges in communication, access to care records and a general lack of information on services available.

Those who know of Hospice tend to be happy with its care but more information about the services available is needed by professionals as well as the community. All sectors of the community, as well as Third Sector interviewees, would like to see more discussion about death and care at the end of life; young people thought this might reduce stigma. Advance Care Plans (ACPs) were considered useful by most professionals but there was also uncertainty about who should be responsible for their completion; more training and encouragement of professionals might enhance their use and result in better adherence to patient’s wishes. All age groups were keen that Hospice services be sustainable in the longer term.

What is currently working well and not so well?

All staff involved in end of life care go 'above and beyond' in their attempts to deliver an integrated service but the extra work this involves is not sustainable. The current system is complex with navigation and coordination difficult for patients and families; they would benefit from a designated keyworker. Carers feel that the essential role they play in coordination of care is not recognised by the services while Third Sector groups also believe that their complementary role is not always acknowledged. Patients and carers face challenges, including off-Island care, and feel the need for more physical and emotional support. Carer assessments are not always carried out as they should, partly because providers or Third Sector groups are concerned that the needed services are not available.

Communication between professionals and patients/families could be improved, in hospital wards but also between all professionals in the different services. The computer-based record systems were identified by every respondent as a particular problem due to non-connectivity and resulting delays, confusion and inefficiencies. Concerns about paying for off-Island care and on-Island 24-hour support were expressed. It was felt that appropriate triggers for referral to Hospice which were agreed with community providers would help ensure fairness and timeliness of Hospice involvement.



How close are we to delivering appropriate care and what remains to be done?

The evidence collected during the needs assessment has been used by the SPSG Workstreams to design and deliver improved services. In October 2019, the UK National Institute of Health and Care Excellence (NICE) released an evidence-based guideline for adult end of life care (End of life care for adults: service delivery, NICE Guideline ng142 16th October 2019).

The recommendations are:

1. Identifying adults who may be approaching the end of their life, their carers and other people important to them
2. Assessing holistic needs
3. Supporting carers
4. Providing information
5. Reviewing current treatment
6. Advance care planning
7. Reviewing needs
8. Communicating and sharing information between services
9. Providing multipractitioner care
10. Providing end of life care coordination
11. Transferring people between care settings
12. Providing out-of-hours care

While the actions of the SPSG Workstreams will go a long way to meeting the NICE recommendations, there are some actions still needed to ensure that the NICE guidelines can be met, partly because the system on the Island is different to that in UK. The table below shows how the SPSG Workstreams will ensure we meet many of the guidelines and the following table shows the work remaining to be done.

SPSG Workstream no. and theme	Workstream Actions	Guideline 142 Recommendation	Island Plan Outcomes
2. Compassionate Isle of Man	Compassionate citizens are involved in and supported to care for people nearing the end of life.	3	*Compassionate citizens come together to offer each other support at the end of life.*
3. Person centred and coordinated care	Ensure multidisciplinary agreement on holistic assessment, care plans and provision of information to support individuals and families.	2, 4, 5, 7, 8 and 9	*My physical, emotional, spiritual and practical needs are met.*
	Consider appointing a keyworker for those receiving end of life care.	9, 10 and 11	*I am at the centre*

SPSG Workstream no. and theme	Workstream Actions	Guideline 142 Recommendation	Island Plan Outcomes
4. Much More than a Building	Enhance information to GPs and other practitioners about specialist Hospice services, who is eligible for them and how to refer.	4 and 11	*Health and care professionals and carers are more knowledgeable about palliative and end of life care.*
	Increase use of the Gold Standard Framework in general practice, hospital and care homes.	1, 5 and 7	*We work for my goals and the quality of my life and death.*
	Ensure the Community Model is available 24-hours, 7 day a week so Hospice or Hospice-influenced care is experienced by all Island residents who need it.	3, 5, 7, 10 and 12	*I have responsive, timely support day and night.*

SPSG Workstream no. and theme	Workstream Actions	Guideline 142 Recommendation	Island Plan Outcomes
5. Developing our Workforce Together	Continue to expand the upskilling of those delivering palliative and end of life care in care homes, hospital and community settings.	1, 2, 3, 5, 9 and 10	*Health and care professionals and carers are more knowledgeable and confident about palliative care and work together for the individual's goals and the quality of their life and death.*

SPSG Workstream no. and theme	Workstream Actions	Guideline 142 Recommendation	Island Plan Outcomes
5. Developing our Workforce Together	Ensure carers and others who are important to people at the end of life are identified and recorded.	1 and 3	*The people who are important to me are at the centre of my support.*
	Ensure all professionals who manage people at the end of life are prepared to discuss treatment and care preferences with individuals and their chosen family members and encourage completion of an ACP.	5, 6 and 7	*I have honest discussions and the chance to plan.*
	Improve timely discussion of palliative care support and review of treatment options with patients in hospital and their families.	1, 3, 4, 5 and 6	*Care is provided in the place of my choice.*
6. Monitoring Progress and Measuring Impact	Monitor information on the demand, capacity and quality of palliative and end of life care services.		
	The services delivered are based on predicted population needs, informed by evidence and lived experience and prioritise what is important to local people, professionals and organisations.		

Action required		Guideline 142 Recommendation
Discuss further with Hospice partners	Fully implement the **Isle of Man Carers' Charter** to support carers for all who have palliative or end of life care needs, regardless of their condition, and consider the availability of respite services to support carers and avoid premature admissions to long-term care.	3
	Ensure **data-sharing agreements and improvements to electronic information-sharing** continue so that care plans and treatment plans can be shared and reviewed and ACPs bridge hospital and community services.	6, 8 and 10
	Improve communication and information transfer between **off-island providers** and islands services, residents and family members.	10 and 11

As further data becomes available on the Island, it is important to look in more detail at e.g. case mix at the different levels of the system to monitor access to specialist end of life care to ensure equity of access for the whole population. Better data would also enable us to assess our services against the NICE Quality Standards QS13, QS14 and QS15 for End of life care, Care of dying adults in the last days of life and Patient experience in adult NHS services, respectively.

**Hospice Isle of Man is also known as Hospice Care,
a registered charity in the Isle of Man Number 317.**

hospice.org.im