Appendix 1: The local and international context

Integration of palliative care into health systems

The World Health Assembly (WHA), the forum through which the WHO is governed, published a resolution on palliative care in 2014 calling on member states to integrate it into national health care systems (1). Their adopted resolution was “Strengthening of palliative care as a component of comprehensive care throughout the life course”. The resolution recognises that palliative care is:

- fundamental to improving the quality of life of patients and families facing life-threatening conditions
- an ethical responsibility of health systems
- needed across disease groups and age groups

The resolution urges member states to “develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes.” Other elements mentioned include adequate funding, multi-sectoral partnerships, education and training and assessment of population needs.

Population changes

According to the last interim census information (2) in 2016, the population on the Isle of Man was 83,314 with an increase in the average age of just over a year in the last 5 years and more predicted. Figure A1.1 shows the predicted ageing of the population in a population pyramid. The coloured horizontal bars represent the number of people in each age group for males and females. The black outline represents the change in these numbers which were expected by 2021. As shown, there are greater increases in numbers expected in the older age groups.

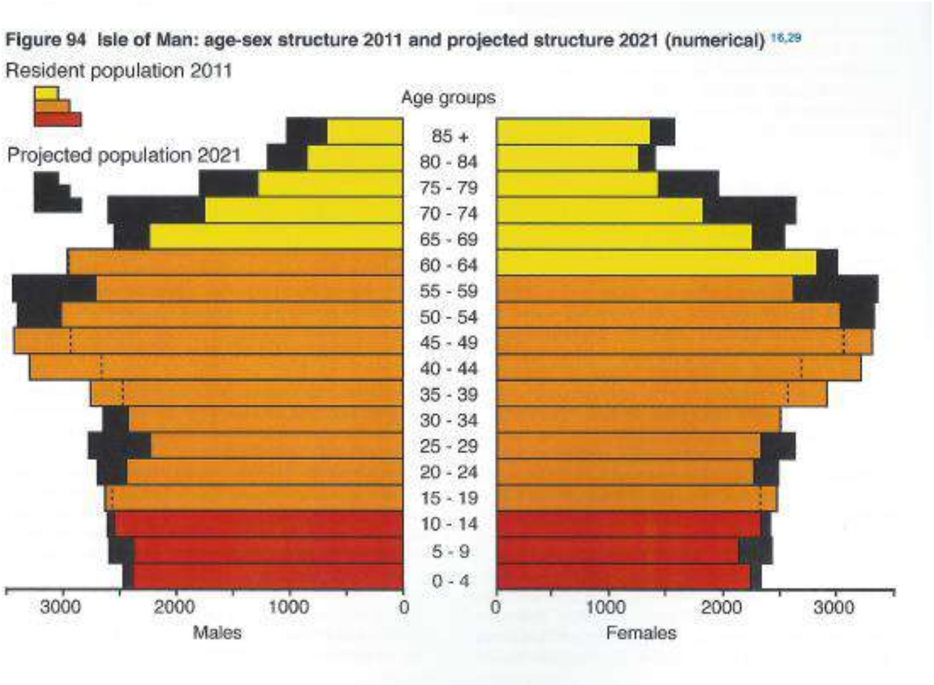

Figure A1.1 From Paul Craine. The Population Atlas of the Isle of Man (3)

Annual deaths are predicted to increase by 1.5% in each future year (Personal correspondence with the Department of Economic Affairs, July 2018) and we will be dealing with more frail and complex cases of illness. This may impact workloads of all the relevant services and require new ways of working.

End of Life Care Framework and Implementation Plan for Adults 2012-2015

A partnership between the former Department of Health, now incorporated into the Department of Health and Social Care (DHSC), and Third Sector organisations resulted in the End of Life Care Framework and Implementation Plan for Adults 2012-2015 (4), which gathered information from 1,215 residents. Key findings were that the location of death was less important here than in the UK and more than half of respondents had not discussed their wishes for end of life care. Support for carers and the bereaved were identified as areas that needed to be improved.

The End of Life Care Framework set out the following objectives:

1. A change in society's recognition, understanding and acceptance of death as relevant to everyone, appropriate for discussion, and something we can all plan for
2. Identification of people approaching end of life and initiating discussions about preferences for end of life care

3. Care planning that assesses the needs and preferences of patients, before agreeing a care plan which reflects these and is reviewed regularly
4. Coordination of care
5. Delivery of high quality care provision in all locations
6. Improving care in the last few days of life
7. Care after death

Almost every objective in this Framework includes ‘assessing needs of carers’.

In 2012, the End of Life Matters (ELM) initiative (5) was formed with the aim of bringing about a change in society’s recognition, understanding and acceptance of death as being relevant to everyone. This initiative is now based at Cruse Bereavement and has a range of printed resources that support these aims.

Situation of carers

The Isle of Man Carers’ Charter (6) was launched in 2013. This was signed by Ministers and Chief Executives from the Departments of Health, Social Care and Education and Children and by the Chief Executives of Crossroads Care, Manx Cancer Help and Live at Home. It acknowledged carers’ contributions and stated that it would consolidate their rights and principles for carer support. There were many commitments including identifying carers, developing a carer assessment process and providing information, advice and training.

In 2016, according to the Social Attitudes Survey (7), around 13% of people considered themselves to be carers with 28% of the rest having a caring role (Figure A1.2) i.e. nearly 11,000 people were looking after someone else. Of these caring groups, around 90% said they had no support in this role from Government or charities and so they may not be known to support organisations.

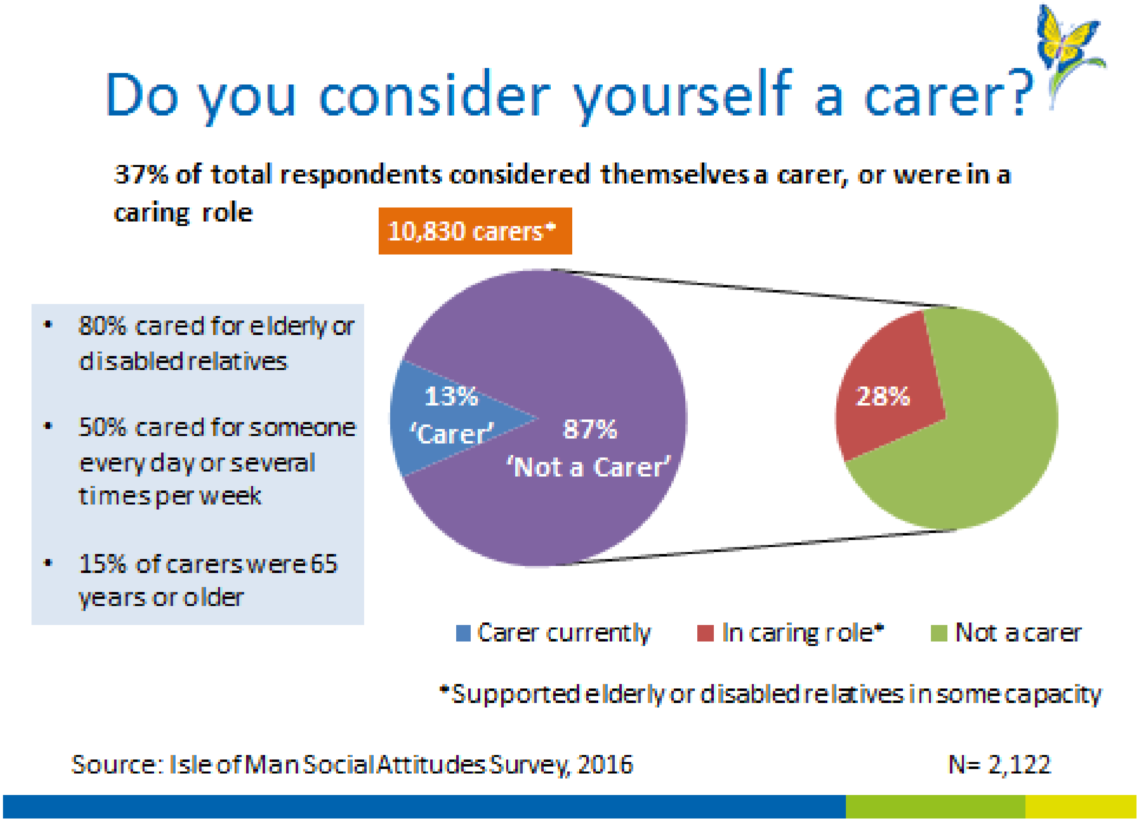

Figure A1.2 Whether respondents to the Social Attitudes Survey 2016 (7), considered themselves as carers

References

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Appendix 2: Methods

The needs assessment was conducted using a mixed methods approach overall but each section had a specific methodology that is described below.

Service review

The service review was conducted using available leaflets, internet searches, email, and interviews with service providers and users. As a result, the information may not be comprehensive.

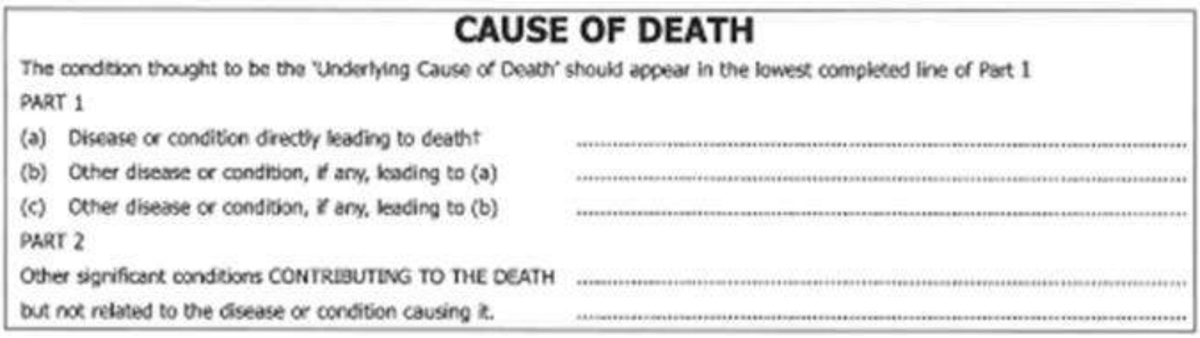
Population data

Mortality data

Hospice obtained weekly death certificate data from the Isle of Man Registry, dated 2013 until 2018. The following variables were extracted and cleaned for analysis: age, sex, marital status, date of death, date of death registration, place of death (home, nursing home, residential home, Hospice, Noble's Hospital, Ramsey District & Cottage Hospital, other), usual place of residence (nursing home, residential home, home) and cause of death as written in the Medical Certificate of Cause of Death (MCCD) or the coroner's report. Figure A2.1 illustrates the content of the cause of death field containing the entirety of the entry for this section, or the 'raw' data.

Cause of death

Following the guidance in the MCCD for selecting the "underlying cause of death", a new variable (*causeofdeath)* was created using the categorisation framework in Table A2.1. Underlying cause of death was categorised into one of five categories if it appeared in the last line of Part I of the MCCD: Alzheimer's / dementia / frailty; cancer; neurodegenerative; organ failure; and other for anything that did not fall into one of the above categories. The categories are based on conditions known to be likely to benefit from palliative care. Regardless of whether a person died *of* (i.e. underlying cause of death) or died *with* (i.e. contributing to death) one of the conditions they would likely benefit from Hospice care. A second variable, *palliative,* was created from the cause of death field. This variable categorised a death into one of the five categories regardless of where the disease appeared in the death certificate (i.e. Part 1 or Part 2 of the MCCD) which counts persons who had the condition regardless of whether it was considered to be the cause of death or not.



CAUSE OF DEATH

The condition thought to be the 'Underlying Cause of Death' should appear in the lowest completed line of Part 1

PART 1

(a) Disease or condition directly leading to death†

(b) Other disease or condition, if any, leading to (a)

(c) Other disease or condition, if any, leading to (b)

PART 2

Other significant conditions CONTRIBUTING TO THE DEATH

but not related to the disease or condition causing it.

Figure A2.1 Medical Certificate of Cause of Death

Table A2.1 Cause of death conditions likely to benefit from Hospice services

Category	Sub-category	Including
Alzheimer's / dementia / frailty	Alzheimer's/Dementia	any type of dementia, Alzheimer's
	Frailty	“old age” “senility”
Cancer	Cancer	any type
Neurodegenerative	Neurodegenerative	motor neurone disease, Parkinson's disease, progressive supranuclear palsy, multiple system atrophy, multiple sclerosis, cerebellar atrophy, cerebral atrophy, chronic demyelinating disease
Organ failure	Chronic lower respiratory diseases	chronic obstructive pulmonary disease, pulmonary fibrosis, chronic bronchitis, emphysema
	Diseases of the liver	cirrhosis, alcoholic cirrhosis, decompensated liver disease, cryptogenic liver cirrhosis
	Organ failure	renal failure, heart failure, liver failure, chronic kidney disease, chronic renal failure, congestive cardiac failure, multi-organ failure, chronic liver disease

Mortality projections

Projected number of deaths were provided by personal correspondence with the Isle of Man Government’s Department of Economic Affairs, Cabinet Office (31 July 2018). These are the same number of deaths used to estimate population size to 2036 published in *Meeting our Population Challenges* (1). There are three scenarios applied to the population projections that vary according to the net inward migration to the Isle of Man. The first scenario is the "zero" variant and assumes net migration per year sums to zero. The "moderate" variant assumes the population adds 500 persons, distributed according to age and sex of migration patterns from 2006-2016. The "high" variant assumes the population adds 1000 persons distributed according to age and sex of migration patterns from 2006-2016. Percent increase and the compound annual growth rate in number of deaths were estimated for each scenario.

Hospice service user data

Hospice care

Hospice paper records were searched to identify persons who died between 2013-2018. A new variable was added to the mortality dataset to indicate that a person had been under Hospice care. Persons who died and had received Hospice care but did not die on the Island are not included in the dataset.

Referrals and length of care

Number of referrals from 2015 to 2018 were obtained from the Hospice *Clinical Governance and Quality Report, April 2019* (2).

The electronic record keeping system EMIS was introduced on 17 October 2017. In May 2019, data were extracted for every person who was in the system and died up to the date of data extraction (n=449). The date of referral ranged from 17 January 2008 to 4 May 2019. The data included the date of referral, the date of death, the cause and source of the referral. Length of care was calculated in days by subtracting the referral date from the date of death. Length of care in days was used as a continuous variable in some analyses and categorised as follows for others: < 2 days, 3 to 7 days, 8 to 14 days, 15 to 30 days, 1 to 3 months, 4 to 12 months, 1 to 2 years, 2 years or more.

Other data

Population figures and forecasts were obtained from published reports and surveys and are cited where relevant.

Analyses

Mortality

All analyses using death certificate data are based on *year of death* as opposed to year of registration. Published mortality statistics report deaths according to year of registration, as did the Isle of Man Government's *Mortality Report 2017* (3). Numbers may differ slightly due to a small percentage of deaths that for various reasons are registered in a different year to the year of death. Year of death was chosen for consistency with analyses that include Hospice records. The following associations were examined:

- Mean and range of deaths for the period of 2013 to 2018
- Comparison of the mean age at death by sex
- Proportion of deaths by place of death by year of death
- Comparison of place of death by sex, age (continuous and categorical) and marital status
- Percentage of people who died in their usual place of residence
- Place of death for each of the four cause of death categories (cancer, neurodegenerative, dementia/frailty, organ failure)

Palliative care need

Persons with one or more conditions from the four categories were considered to have been able to benefit (though perhaps did not) from palliative care and were categorised as *palliative*. Need for palliative care was estimated using the *palliative* variable from the death certificate dataset and the Hospice care variable to create four categories:

- Palliative and Hospice
- Not palliative but Hospice
- Not palliative not Hospice
- Palliative but not Hospice

The percent of deaths in each palliative condition category (cancer, neurodegenerative, dementia/frailty, organ failure) that had received Hospice care was calculated to identify met need by disease category. Trends in cause of death due to the four palliative disease categories were analysed by calculating the compound annual growth rate for deaths from 2013 to 2018. Analysis of trends for when a disease was recorded as the cause of death, as well as for any mention of the disease in the death certificate, were conducted.

‘Expected’ and ‘unexpected’ causes of death

Another way to estimate how many people could potentially benefit from palliative care is to categorise deaths depending on whether they died unexpectedly or not. Using key words in the raw cause of death field, a categorization of expected or unexpected death was made. An unexpected death was one resulting from suicide, accident, misadventure or catastrophic event or which included the term myocardial, viral, bacterial, sepsis or acute (except for acute leukaemia). This allocated coding was verified by a senior clinician on a random sample of 100 cases. The remaining deaths not in these categories were coded as ‘expected’.

Statistical tests

Statistical significance was tested using Student's t-tests when comparing two group means and Analysis of Variance (ANOVA) where there were more than two groups. Proportions were tested using a Pearson's Chi-squared test. Logistic regression was used to calculate odds ratios (ORs) and 95% confidence intervals (CIs). A *p*-value of <0.05 was considered to be statistically significant. Descriptive analyses were conducted using Microsoft Excel or STATA statistical software (StataCorp LLC. College Station, Texas; Release 15, 2017).

Views of the public

"Listening Events" were set up at five supermarkets and two community events around the Island, facilitated by a minimum of two research staff each time (Table A2.2). Posters were displayed quoting "What matters to you matters to us…" and staff engaged with members of the public to collect their responses to 3 broad questions:

1. What do you know about Hospice?
2. If you or your family had to use Hospice services, what would matter to you?
3. How do you think Hospice can best serve the community over the next 5 years?

Conversations were generally 5 minutes or less. Responses were written down by the interviewer and basic demographic information (age and sex) on each participant was recorded.

Table A2.2 Consultation details

Data source	Detail	Number of participants
Community Roadshow Listening Events	7 locations: Supermarkets/ church/community event	278
Young People's Listening Events	31 Classes – 418 UCM, 203 High School	621
Total		**899**

Listening Events - Schoolchildren

A series of Listening Events were carried out across three secondary schools in the Isle of Man. The lesson plan was discussed with two Isle of Man secondary school teachers, who judged the plan as feasible and appropriate for Personal Social Health Education (PSHE) / citizenship lessons. Schools were contacted in advance to seek their approval of the lesson content.

The lesson was slightly under one hour and was designed as a mix of presentation and workshop features. Hospice staff recorded class demographics and any influencing factors. Students were asked to consider and discuss the following three questions among small groups, facilitated by prompt questions. The first question preceded a presentation with information about Hospice. Students wrote their responses on post-it notes, which were placed on an A1 sheet of paper for each question and collected by Hospice staff.

1. What do you know about Hospice?
2. If you or a member of your family became seriously unwell and needed to use one of Hospice's services, what would be most important to you?
3. Thinking about the future, what could we do to make Hospice a better service?

Student responses and field notes were collated and identifying information was removed. Analysis was conducted using the framework of thematic analysis described in Braun & Clarke, 2006 (4). The section **Thematic analysis of qualitative data** of this document describes the process in detail.

Engagement with college students

Listening events were planned in collaboration with University College Man (UCM) staff and held during the students' induction week, as part of the citizenship and wellbeing agenda of the college. The objective of the sessions was for students to learn about Hospice and palliative care; to understand students' attitudes towards death, dying and bereavement; and for students to consider ways in which Hospice's services could be improved.

Each session was led by a team of researchers and clinicians from Hospice. After setting out the agenda and expectations for the session, students were given a short "true or false" exercise to engage them in thinking about hospice and palliative care. This was followed by a short presentation about hospice and palliative care. Students then gathered into small groups to discuss one of three questions (listed below, including prompts, which were written on prompt cards provided to the students).

1. What comes to mind when you think about death and dying?
2. Is there such a thing as a 'good' death?
3. If you were designing a Hospice, what would it include/look like/offer?

The students were asked to note down their key discussion points on post-it notes, which were collected at the end of the session. Students fed back to the wider class and noted down key points and comments on post-it notes were transcribed verbatim and then coded by members of the research team. Themes and sub-themes were then extrapolated from the data using thematic analysis (4).

Views of patients and carers

There were two main methods of engagement with carers. The first was interviews and the second was a novel methodology using patient and carer diaries supplemented by interviews. A further set of focus groups in nursing homes included residents, carers and staff. These are described below.

Interviews with patients and carers

Twelve persons, who were patients with a life-limiting condition, carers or in some cases both, were interviewed. Ten had involvement with Hospice. Persons who were not involved with Hospice were identified by Hospice research staff during the course of the needs assessment and invited to an interview. One person shared their experience in an email.

Patient Diaries Project

Judy's case study was constructed using a mixed methods approach. It includes data extracted from hospital and medical records kept by the patient, the patient's personal appointment diaries, emails written by the patient and her husband (and carer) to family and interviews with the patient's carer. For the last 18 months of life, all entries from the appointment diary pertaining to care were entered into a Microsoft Excel worksheet. Each care provider was represented in a 'care map' graphic to enumerate the total number of services and professionals involved in Judy's care. The number of contacts were plotted by month and by sector (DHSC, private, Third Sector) as well as by purpose of care. To understand the amount of care undertaken by the carer, the hours of care that were for respite purposes were subtracted from the total number of hours in each given month to estimate the amount of care provided by the carer. The total hours of possible care were 24 hours per day.

Additional Hospice patients and carers identified as willing and able by Hospice clinicians were invited to keep a diary listing daily encounters that contributed to their care. These encounters could include health professionals, professional carers, volunteers and/or family and friends. Patients and their carers were also invited to an interview. The purpose of the interview was to understand the experience of care from the perspective of the patient and their carer; to identify what is working well and what needs improvement; to understand the degree of integration of care; and to what extent care is person-centred. The interviews were recorded, transcribed and coded for thematic analysis using NVivo software (QSR International, Version 12, 2018).

Focus groups with Nursing Homes

Two focus group sessions were held in nursing homes in April and May 2018. In total, 21 patients, relatives and staff attended. Attendees at the first home were asked to choose from a list of positive and negative emotions followed by the question, “What matters to you about your life?” and subsequent discussion. The session was recorded and comments were extracted from the discussion.

At the second home, attendees were invited to choose an image from a range selected by the research team from a pack of Evoke Cards (www.evokecards.com) to illustrate what life on the Isle of Man meant to them, and to discuss their choice with the group. Evoke Cards contain 72 cards with a photograph and an emotion word on the opposite side. The cards were displayed for participants. The participant then chose a card or a set of cards to help them answer the question. This session was recorded and transcribed for analysis.

Thematic analysis of qualitative data

Thematic analysis of the responses was carried out according to phases outlined in Braun and Clarke (4) summarised in Figure A2.2. Coding was conducted using NVivo qualitative data analysis software.

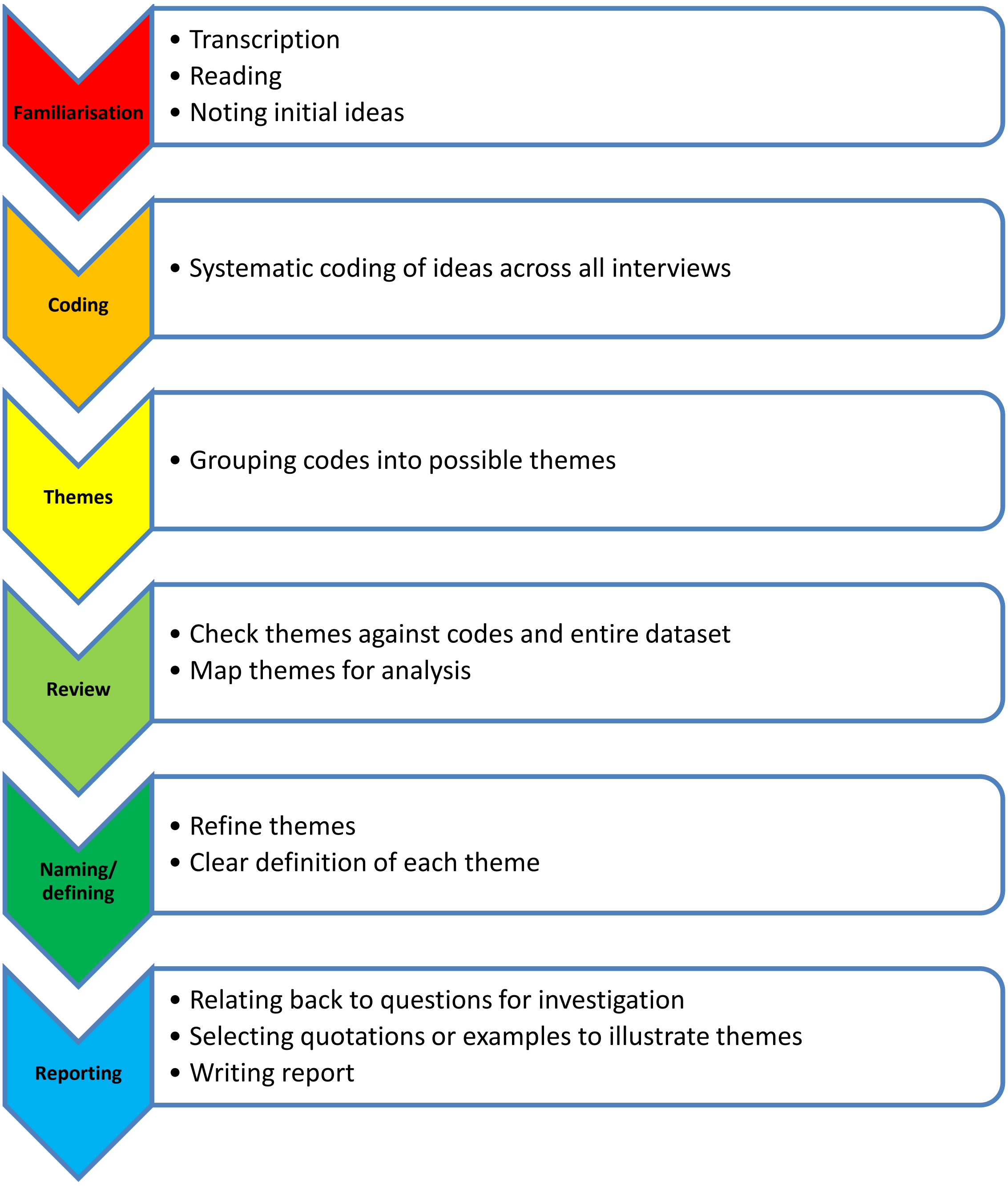


Figure A2.2 Process of analysis of qualitative data

Views of professionals and the Third Sector

Workshop on Integrated Care

Hospice held a multi-disciplinary workshop in December 2017, facilitated by the International Centre for Integrated Care (IC4IC) and including colleagues from DHSC and the Third Sector, represented by members of the Council of Voluntary Organisations (CVO). Judy's case study was presented at the workshop as a basis for discussion on palliative and end of life care on the Island. Participants were asked to identify gaps and issues relating to care and areas of need in three different time periods: 1) pre-diagnosis to diagnosis 2) increasing complexity and disability and 3) last year of life. Challenges were also identified.

Hospice volunteers

All Hospice volunteers were invited, by an email from the Hospice Volunteer Manager, to attend a focus group session in April 2018 and 9 volunteers attended. The session was facilitated by two members of the research team and a visiting professional from the International Centre for Integrated Care (IC4IC) based in the University of the West of Scotland.

Volunteers were invited to choose an image from the Evoke Cards as an aid to help them talk about what Hospice meant to them. A discussion followed where they were invited to speak of something they were proud of in relation to Hospice. Finally, they were invited to answer the question, “How can Hospice be improved?” The discussion was recorded and comments were extracted and analysed.

Professionals and volunteers working in palliative and end of life care

Clinicians (DHSC community-based, private sector and specialist nursing staff) and non-clinicians (DHSC and Third Sector staff in service management and administration roles) who were believed to have a role in end of life care, were identified through consultation with Hospice and DHSC staff and CVO members. Interviewees also identified persons who they considered to be stakeholders. Those identified were invited to attend a one-hour interview with two members of the research team. Interviews were conducted between March 2018 and June 2019. Anonymity was guaranteed and open-ended questions, “what works well”, “what isn’t working well and what are the gaps”, formed the basis of the interview. Automatic transcription using NVivo software was followed by checking and the final transcription was analysed using a thematic analysis (4), as already described.

General practitioners

A short survey was designed and sent out via email to all general practitioners on the Island using SurveyMonkey software (Note: the number on this email list was 91 and included all locum general practitioners). The questions asked about their current referral practices and their opinion of the current services for palliative and end of life care on the Island. Results received were summarised.

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Appendix 3: Population and medical record data analyses

Isle of Man Demographics

According to the 2016 census (1), persons aged 65 or over accounted for 21% of all residents. Moderate population projections to 2036 (2) predict the population 65 and over to increase by an average of 1.2% per year, an increase of 32% from 2016. In 2036, persons 65 years and older are expected to make up one-quarter of the population, compared to 21% in 2016. Residents over 85 are expected to increase by 2% a year, an increase of 49% from 2016. Persons 85 and over were 3% of the population in 2016 and they are expected to make up 4% of the population by 2036.

Mortality

Between 2013 and 2018, there were 5,005 deaths (average 834 per year; range 784-875) on the Island (Table A3.1).

Table A3.1 Number of deaths by sex, 2013-2018

Sex, n (%)	2013	2014	2015	2016	2017	2018
Females	376 (48)	428 (53)	422 (51)	434 (50)	430 (51)	442 (51)
Males	408 (52)	385 (47)	404 (49)	427 (50)	416 (49)	433 (49)
Total	**784**	**813**	**826**	**861**	**846**	**875**

On average, women died at an older age than men ($p < 0.0001$); 81.0 years (SD ± 13.7) compared to 75.0 years (SD ± 14.9). Figure A3.1 below shows the distribution of deaths by age categories for all deaths during this period. The *Mortality Report 2017* (3) lists the top three causes of death as cancer, circulatory disease and respiratory disease.

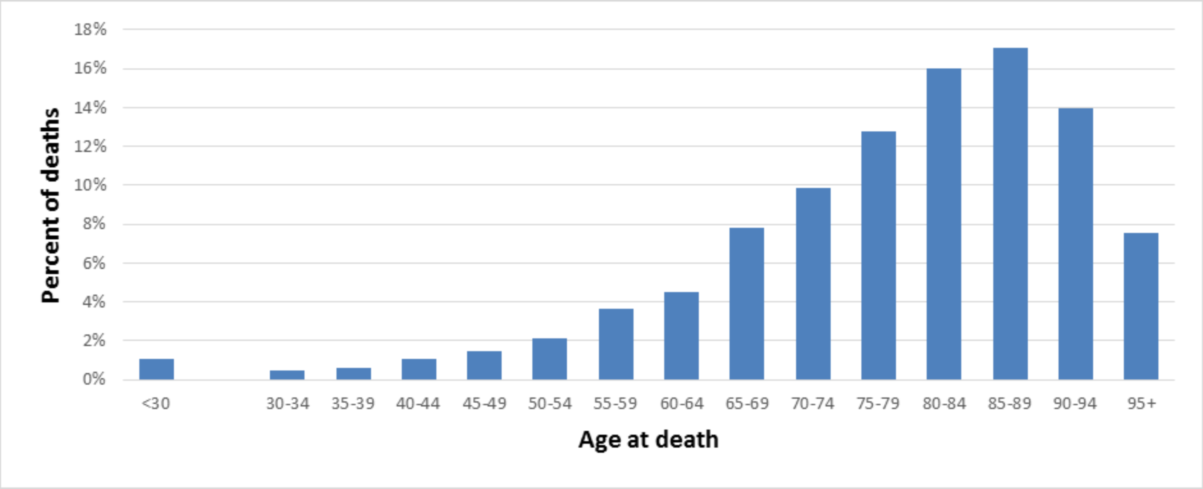


Figure A3.1 Distribution of deaths by age, 2013-2018

Place of death

Between 2013-2018, 41% of people died at Noble's Hospital; 18% at a nursing home; 16% each at both Hospice and home; and 5% in a residential home (Figure A3. 2). Yearly detail can be found in Table A3.2.

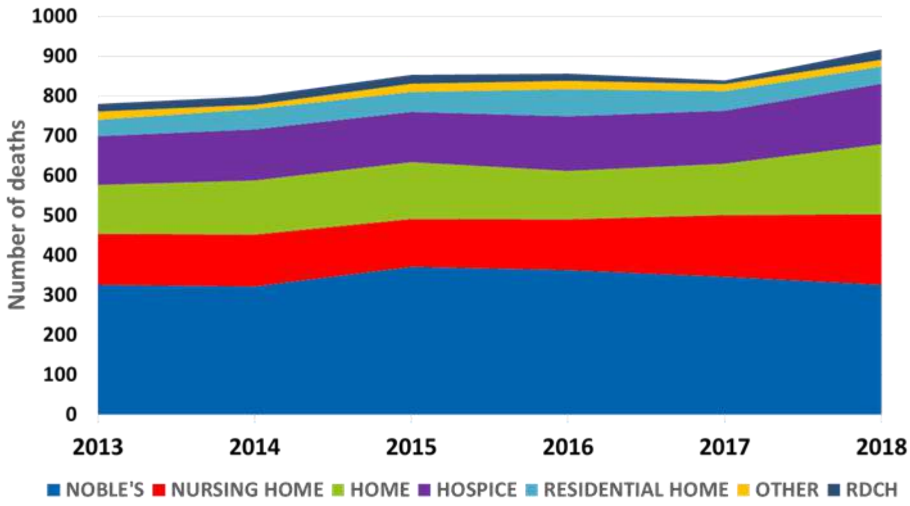


Figure A3.2 Place of death, 2013-2018

Table A3.2 Place of death, 2013-2018

Place of death	2013		2014		2015		2016		2017		2018	
	n	*%*	n	*%*	n	*%*	n	*%*	n	*%*	n	*%*
Noble's Hospital	327	*42*	331	*41*	358	*43*	367	*43*	340	*40*	315	*36*
Nursing Home	137	*17*	139	*17*	132	*16*	138	*16*	171	*20*	181	*21*
Home	123	*16*	134	*16*	135	*16*	121	*14*	142	*17*	158	*18*
Hospice	125	*16*	125	*15*	126	*15*	138	*16*	135	*16*	148	*17*
Residential Home	32	*4*	42	*5*	38	*5*	60	*7*	32	*4*	35	*4*
Other	20	*3*	21	*3*	14	*2*	19	*2*	17	*2*	12	*1*
RDCH*	18	*2*	21	*3*	22	*3*	18	*2*	9	*1*	26	*3*
Unknown	2	*0*	0	*0*	1	*0*	0	*0*	0	*0*	0	*0*
Total	**784**		**813**		**826**		**861**		**846**		**875**	

*RDCH is Ramsey & District Cottage Hospital

There was a statistically significant difference in place of death by sex (Chi-squared= 150.2, $p < 0.0001$) and age (*F*-statistic=173.6, $p < 0.0001$). Women were more likely to die in a nursing home than men (24% vs 12%). Overall, women were more likely than men to die in their usual place of residence (home, nursing home, residential home); 42% vs 33% (Chi-squared=41.1, $p < 0.0001$). Mean age at death was higher when a person died in a nursing home or a residential home (87 years) compared to Noble's Hospital (78 years), home (73 years), or Hospice (72 years).

Marital status was associated with place of death (Chi-squared 417.7, $p < 0.0001$). Fifty-two percent of persons who died in Hospice were married compared to 20% for those who died in a nursing home and 17% in a residential home. Over half of persons who died in a residential home or a nursing home were widowed (56% and 58%, respectively), compared to 26% of persons who died at home.

Ninety percent of nursing home residents died at their nursing home between 2013 and 2018. In this time, the number of deaths in nursing homes increased 37% or an average of 6% per year (Table A3.3).

Table A3.3 Place of death of nursing home residents

Place of death	**2013**		**2014**		**2015**		**2016**		**2017**		**2018**	
	n	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***
Hospice	0	*0*	1	*1*	2	*1*	0	*0*	2	*1*	0	*0*
Noble's Hospital	10	*7*	11	*8*	16	*12*	17	*12*	13	*8*	17	*9*
Nursing home	129	*93*	130	*90*	118	*87*	129	*88*	156	*91*	174	*91*
RDCH	0	*0*	3	*2*	0	*0*	0	*0*	0	*0*	0	*0*
Total	**139**		**145**		**136**		**146**		**171**		**191**	

Forty-nine percent of residential home residents died at their residential home over this same period; however, this proportion increased an average of 2% per year. In 2018, 56% of residential home residents died at their residential home (Table A3.4). The total number of deaths occurring at residential homes has declined by 21% since 2013.

Table A3.4 Place of death of residential home residents

Place of death	**2013**		**2014**		**2015**		**2016**		**2017**		**2018**	
	n	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***	**n**	***%***
Hospice	4	*5*	2	*2*	2	*2*	3	*3*	2	*3*	1	*2*
Noble's Hospital	33	*41*	28	*33*	26	*32*	38	*34*	22	*31*	19	*30*
Nursing Home	8	*10*	9	*11*	14	*17*	9	*8*	15	*21*	7	*11*
RDCH	3	*4*	4	*5*	2	*2*	1	*1*	0	*0*	1	*2*
Residential Home	32	*40*	42	*49*	38	*46*	60	*54*	32	*45*	35	*56*
Total	**80**		**85**		**82**		**111**		**71**		**63**	

Between 2013 and 2018, cause of death was associated with place of death. Persons who died of dementia were more likely to die in a nursing home compared to persons dying of cancer (odds ratio (OR) 17.2; 95% confidence interval (CI), 13.0-22.7) and organ failure (OR 7.7; 95% CI, 5.6-10.8). Cancer patients were more likely to die in Hospice compared to all other conditions (Figure A3.3). Hospice changed its referral criteria to include patients with conditions other than cancer in 2016. From 2016 to 2018, 51% of cancer cases died in Hospice, compared to 12% of patients who died of a neurodegenerative condition, 7% of organ failure, and 3% of dementia in the same time period. Fifty-seven percent of organ failure patients died in Noble's Hospital.

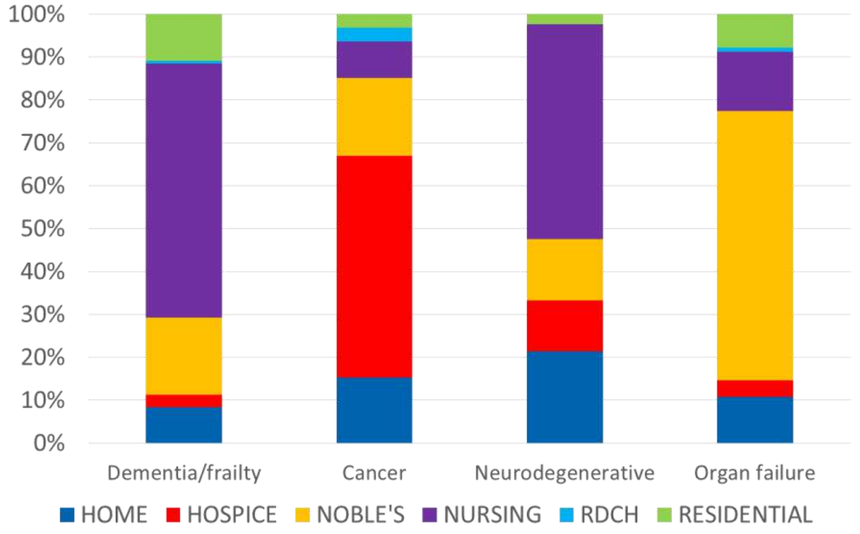


Figure A3.3 Cause of death and place of death, 2013-2018

Mortality projections

According to moderate population projections (Personal correspondence with the Department of Economic Affairs), there will be a 30% increase in the absolute number of deaths from 2018 to 2036, at a rate 1.5% per year.

Palliative care need

Various approaches estimate that approximately 75% of all deaths in high income countries could benefit from palliative care (4, 5). Using key words found in the Cause of Death field, we created a rough categorization of expected and unexpected deaths. An analysis of deaths on the Island between 2013 and 2018 shows that between 20 and 29% each year (mean = 25%) could be considered "unexpected", that is, they could not easily be predicted and therefore less likely to have benefitted from palliative or end of life care (Table A3.5). This means that over two-thirds of all deaths each year might benefit from palliative or end of life care.

Table A3.5 Expected and unexpected deaths between 2013 and 2018

	2013		2014		2015		2016		2017		2018	
	n	%	n	%	n	%	n	%	n	%	n	%
Expected	580	*74*	605	*74*	588	*71*	630	*73*	641	*76*	698	*80*
Unexpected	206	*26*	208	*26*	238	*29*	231	*27*	205	*24*	177	*20*
Total	**784**		**813**		**826**		**861**		**846**		**875**	

Further analysis of data from death certificates of persons who died in the Isle of Man between 2013 and 2018 suggest that 64% had at least one condition (cancer, neurodegenerative, organ failure or dementia/frailty) likely to benefit from palliative care, based on what is recorded in the death certificate; this could be considered a conservative, or minimum estimate because some relevant conditions might not have been recorded. For a full description of all methods, see Appendix 2. Figure A3.4 illustrates the projection of change in number of deaths along with the two estimates of increase in numbers of those who could benefit from palliative care.

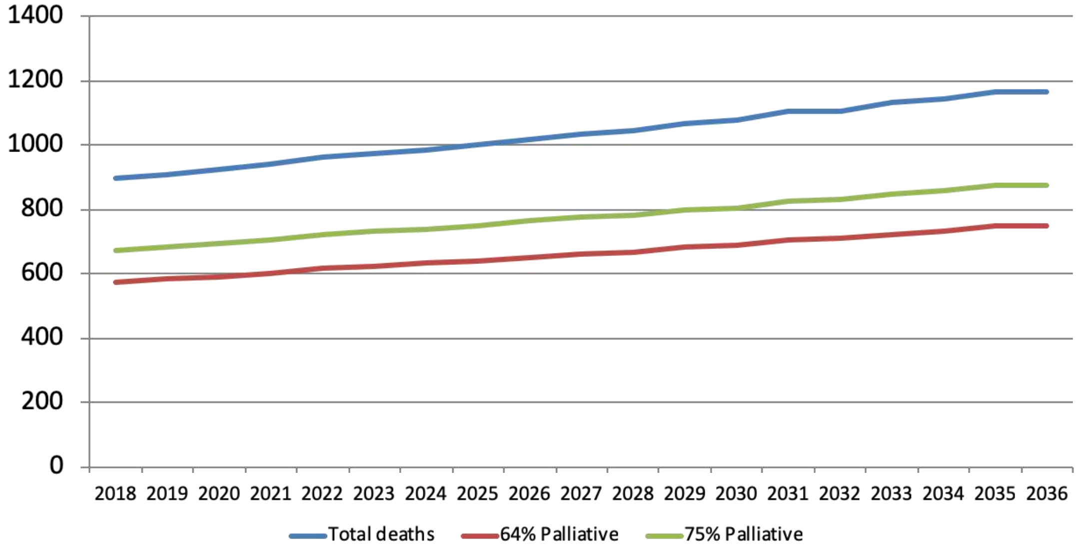


Figure A3.4 Mortality projections assuming moderate population growth and two estimates of palliative care need from 2018 to 2036

Those who died in Noble's Hospital were half as likely to have died with a palliative condition relative to persons who died in any other place; OR 0.46 (95% CI 0.41-0.52, $p < 0.0001$) adjusted for age, sex and marital status. Of those who had a palliative condition, Hospice provided care for 30%; leaving 34% who could have benefited from palliative care (Figure A3.5). Overall, Hospice provided care for 33% of all persons who died in the Isle of Man. Ninety-six percent of persons who died at Hospice had one or more palliative conditions mentioned in the death certificate.

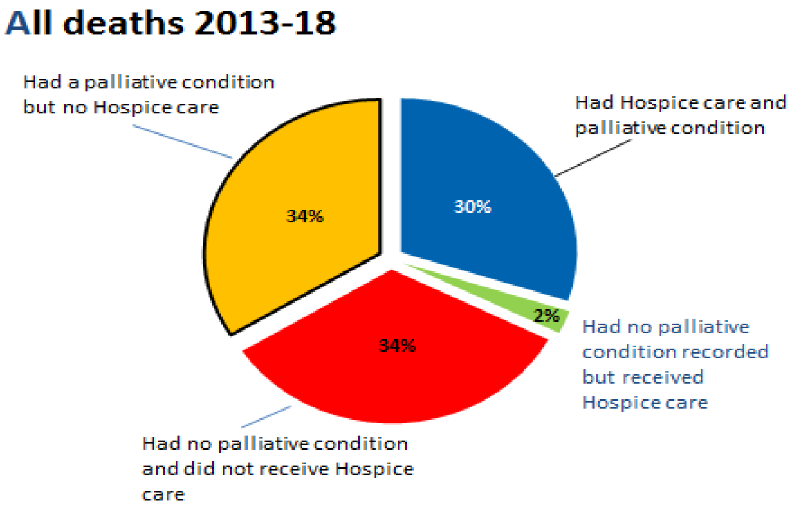


Figure A3.5 Estimated need for palliative care and whether Hospice care was provided

In 2016, Hospice opened up its referral criteria to include life-limiting illnesses other than cancer. From 2016, Hospice cared for 88% of patients who died of cancer; 28% of organ failure; 26% of neurodegenerative diseases; and 16% of persons who died of dementia/frailty. The compound annual growth rate from 2013 to 2018 in deaths due to dementia/frailty was 21%, 12% for neurodegenerative conditions, 7% for organ failure and 0% for cancer (Figure A3.6). Absolute numbers for any mention of the four conditions were higher than those for deaths from the conditions but the annual growth rates were very similar (20% dementia/frailty, 8% neurodegenerative, 5% organ failure, and 2% cancer for deaths).

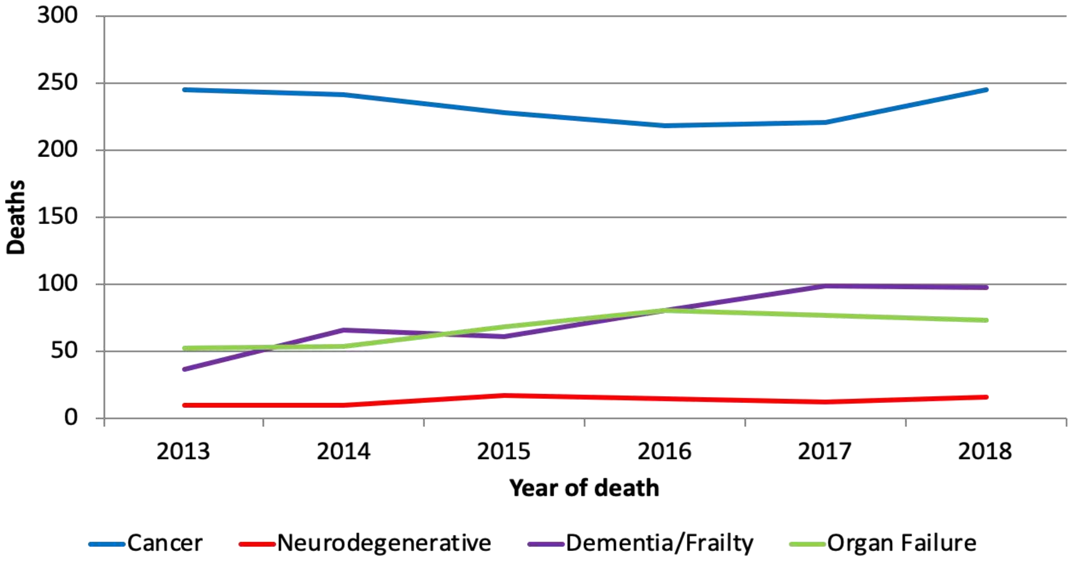
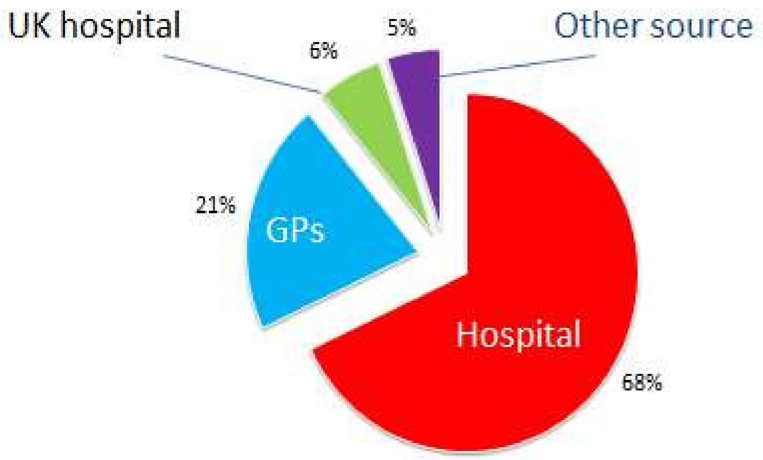


Figure A3.6 Trends in palliative conditions as a cause of death, 2013 to 2018

Hospice medical record data

Hospice referrals

In 2018, Hospice received 527 new referrals; an increase of 24% from 2016. Since the change in referral criteria, non-cancer referrals have increased 131% from 2015 while cancer referrals have increased 22% during the same period. The majority of referrals to Hospice originate in Noble's Hospital (Figure A3.7). An analysis of 449 Hospice EMIS records of patients who died between October 2017 and May 2019 showed that 68% of patients were referred to Hospice by a medical professional from Noble's Hospital (i.e. consultant or a specialist nurse); 21% by a GP; 6% by a hospital in the UK. Thirty-five percent were non-cancer patients.



Source: Hospice EMIS, May 2019

Figure A3.7 Source of referrals to Hospice

Hospice length of care

The length of care provided by Hospice ranged from less than 1 day to nearly 11 years. The median length of care was 38 days and the mean 163 days (SD ± 353 days), indicative of a skewed distribution, i.e. half were under Hospice care for up to 38 days but some for much longer. Eighty-eight percent received care for a year or less and 43% for a month or less (Figure A3.8).

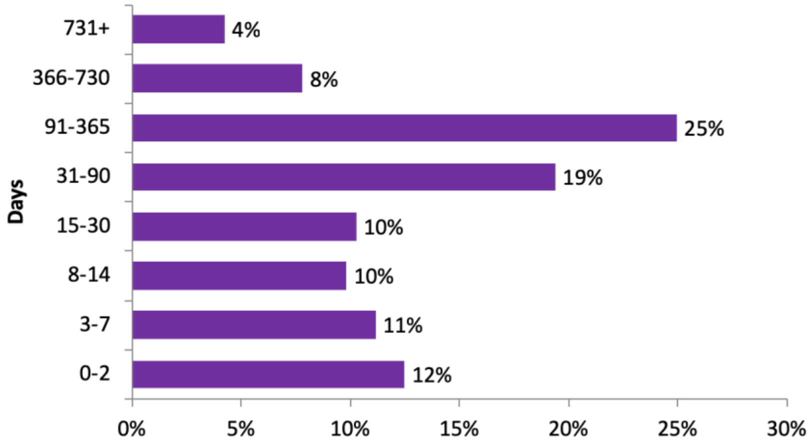
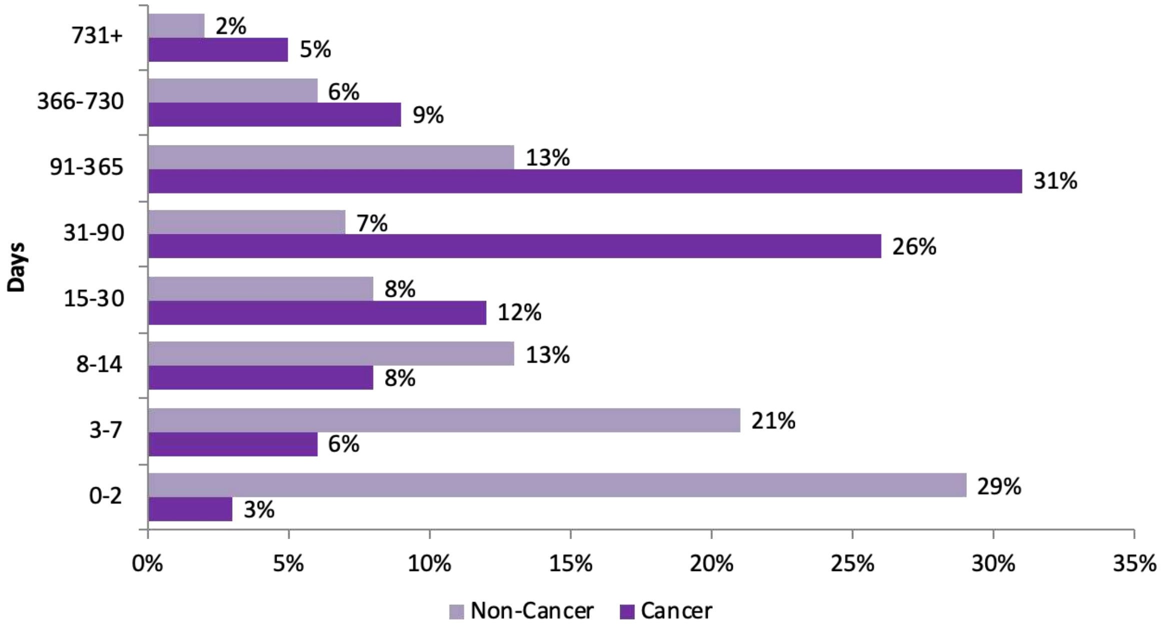


Figure A3.8 Hospice length of care for patients who died between October 2017 and May 2019. Source: Hospice EMIS, May 2019

Sixty-three percent of very late referrals (a length of care of two days or less) were admitted for diagnoses that could have benefited from earlier intervention (Figure A3.9). Length of care differed by whether someone had cancer or not (Figure 6, Chi-squared= 117.5; $p <$ 0.0001); the median number of days of care for cancer patients was 78 and 7 for non-cancer patients.



Source: Hospice EMIS, May 2019

Figure A3.9 Hospice length of care of patients with and without cancer who died between October 2017 and May 2019.

Need for community support

In 2018, 70% of persons died with a palliative condition from the four categories (cancer, neurodegenerative, dementia/frailty, organ failure) mentioned in the death certificate. Out of this group, 70% (424 persons) lived at home. Assuming that people living at home have similar preferences to Hospice patients, 40% would have preferred to die at home. This would mean that approximately 170 persons would have preferred to die at home. Eighty-nine persons (21%) died at home as recorded in the death certificate, leaving an additional 81 persons would have possibly preferred to die at home and did not. In addition, 30% of residential home residents died in Noble's Hospital and 56% in their residential home. It is difficult to tell how many persons who died in hospital could have been supported in their residential home without additional information. Ninety-one percent of nursing home residents died at their nursing home. Community support is mostly needed for persons who die at home or at a residential home; however, nursing home staff may require specialist support in certain cases. Although it is difficult to determine a person's wishes at the very end, this provides an estimate of generalist and specialist palliative care support needed in the community.

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Appendix 4: Views of the public

Listening Events

Adults

Responses were obtained from 278 people, of whom 63% were female and the proportion of those aged 55 years and over was 68% (Figure A4.1). This is different to the Island population and younger persons were under-represented.

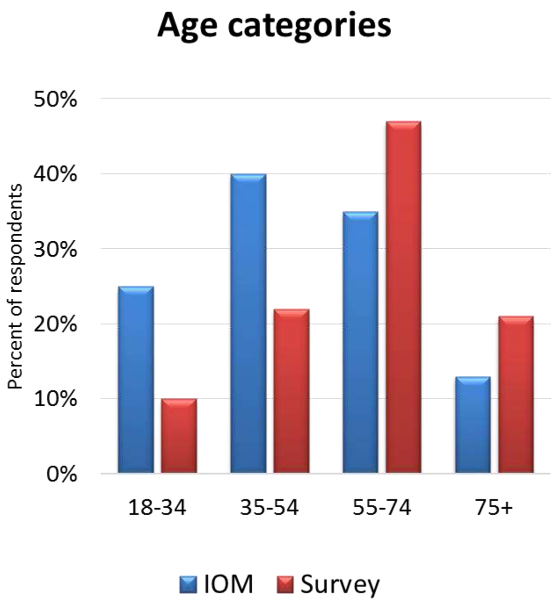

Figure A4.1 Respondents to the public engagement and comparison with the population

The responses are compiled below under the questions which prompted them.

1. What do you know about Hospice?

Amongst the people who had experienced or had a connection with Hospice (n=89), the majority (82%) regarded it positively, 3% were negative, 4% had mixed feelings, and 10% were neutral. Of those with no prior experience, the majority felt positive (52%) or neutral (43%) about Hospice with only a few who had negative (2%) or mixed (3%) feelings. There was no significant difference in these attitudes by age but women were more likely to have a positive perception than men (65% women and 56% men, Chi-squared=8.04, p=0.05). The overall response from all adults is shown in Figure A4.2.

<u>Quotes</u>

"A place where people go to die"

"Good thing to have one on IOM"

"Hospice came in at the end but it was too late and she died a few days later"

"I have never had to use the service but know that one day I might have to"

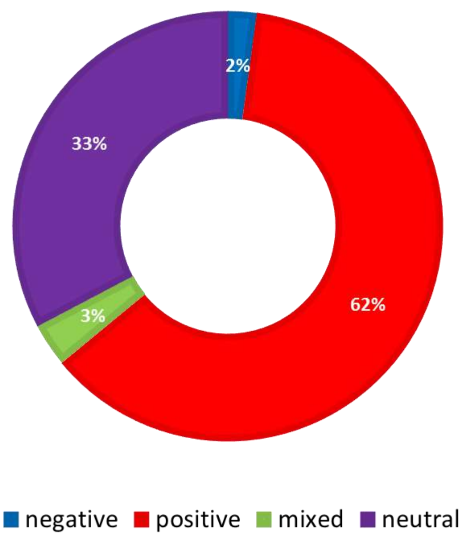

Figure A4.2 Public's perception of Hospice

2. What would matter to you?

Many themes emerged from the data, including effective care, emotional support, person-centred care, equity, the environment, sustainability, communication and education. The top ten qualities, in terms of number of mentions made by respondents, are shown graphically in Figure A4.3. Other themes were information, preferred place of care, kindness, honesty, knowledgeable staff, personal visitors, calm environment.

Quotes

"To be treated like I wasn't a dying person, make the most of time I'd have left"

"I would want to get the most out of my time"

"Pain relief would matter most if I were watching one of my relatives die"

"To have caring staff who are kind"

Figure A4.3 Responses to question: “If you or your family had to use Hospice services, what would matter to you?” Size of text denotes how often this item was mentioned.

3. How do you think Hospice can best serve the Isle of Man over the next five years?

Respondents suggested recommendations for ways in which Hospice could best serve the Isle of Man, the most frequent relating to sustainability, working in the community, expansion and wider access. Specific comments included the need for more information, being sustainable, bereavement support, and having an advice line for people who want to find ways to support friends and co-workers at end of life. Also mentioned was education for carers, people using off-Island services, stronger partnerships to complement existing care, financial support for patients and carers, transport options other than taxis, and help with transitions between hospital and home. Requests included more information about Hospice and encouraging people to have earlier discussions about death.

Quotes

“Going in the right direction - it’s a good thing much needed”

“Continue doing what you are doing”

“Can't think of anything as I've only ever heard positive things”

“Feels disappointed that government do not fund as would like more certainty around it as a service”

“Accessibility - let people know how to use the service and make it easy for them”

“Get out in the community and raise awareness of what you do”

Schoolchildren

In total, 203 students (48% female, aged 11 to 16 years) took part in discussions during the “Listening Events”.

1. What do you know about Hospice?

The majority of students who participated had not used Hospice services and had limited understanding of what Hospice offers. However, many respondents associated Hospice with illness and reported a wide range of ideas about Hospice, frequently noting words relating to “helping”, “caring”, “supporting” and “looking after”. Some linked Hospice with care of the dying, and others knew that respite was available. Cancer was the only specific disease mentioned by respondents. Some responses indicated a belief that Hospice is for older people, but others were aware of the children’s Hospice, Rebecca House, and some of the bereavement care provided by Hospice. Whilst many participants reported not knowing anything about hospice, some identified Hospice as a charity and mentioned fundraising. There were a number of misconceptions about Hospice and the services provided, such as confusing Hospice with cancer research agencies, thinking that it provides financial assistance, considering Hospice to be a mental health facility or believing that Hospice delivers toys.

Quotes

“A hospice is where people with a serious illness go so they can look after them. And if they pass away, they don’t have to pass away in a hospital”

“I think Hospice looks after people who are very very ill like people who have cancer. When I hear the word Hospice I think of cancer patients and people who are really ill”

“Help people who have lost loved ones”

“Gives people a better life when they are ill”

“I only know Hospice for their charity shops, I think”

“I’ll be honest, I’ve never heard about it”

2. If you or a member of your family became seriously unwell and needed to use one of Hospice's services, what would be most important to you?

In terms of what matters to young people, there were three main themes: to be treated as a living person not a dying one, friends and family matter, and comfort. Staff who promote patients' independence and respect their rights, while helping them to forget about their illness, could create a sense of normality. It was suggested that Hospice could do this with a bright, colourful, homely and non-clinical environment and a young-person-friendly and positive atmosphere. Animals, technology, games, TV and films and other entertainment would provide helpful distractions. Staff should be able to support patients to do valued activities for as long as possible. Respondents considered it important that staff were honest about their or their loved one's illness and prognosis. They also wanted confidentiality, responsive staff and company, as well as privacy and space to be alone. The term "carer" was not used frequently by the young participants but many said that it was important for friends and family to be able to visit at any time of the day or night, ideally with beds available. Participants also valued support for families and friends, both pre- and post-bereavement. Finally, a sense of comfort was also important to young people, which could be created through appetising food and drink and a pleasant outdoor environment.

Quotes

"Their mind would be taken off of the fact that they are ill as much as possible. They are happy and enjoying themselves"

"Have a part more suitable for teenagers as it goes from kids straight to adults and elderly – can be hard for teenagers to be surrounded by people too young/old all the time"

"To feel supported but for the nurses to be realistic and not act like everything's ok"

"Friendly, smiley but know when to let you be alone"

"To be able to do things that they want to do before they die"

"I'd want my family/friend to come and keep me company all the time so I don't feel lonely ever"

"That once I die my family are looked after"

"I would want the building to have a warm feeling to it and be very homely"

3. Thinking about the future, what could we do to make Hospice a better service?

Participants suggested that it would be helpful for Hospice to feature more prominently within the local community and online in order to increase awareness. This might reduce the stigma and/or fear around using Hospice services. Some participants shared a desire for greater understanding and awareness of palliative and end of life care, and suggested that greater partnership working, including with schools and providing work experience, would enable this. Finally, some young people felt that Hospice should work towards meeting the needs of more families, whilst increasing respite facilities to provide a break for loved ones. Some suggested that this ought to be funded through increased government subsidy.

Quotes

“Make people more aware of it as I didn’t really know much about it and now I do know I would feel better going into Hospice knowing I will be looked after”

“The Hospice might want to take in young volunteers so that they can get a chance to see what it’s like to work in a Hospice”

“More beds so more people can be seen/looked after without a worry to get one of the limited beds”

“Maybe more inpatient beds should be available to help the patient and to let the family have a rest”

College students

Six-hundred and forty-seven students participated across 22 workshop sessions; their ages ranged from 16 to 39, an average of 17.7 years with 59% male. Participation was voluntary and most students were open and willing to discuss death and dying. There was a theme around the language used to denote a ‘good’ death. Participants felt the concept of a ‘good’ death is subjective, but ideally quick, with time to prepare and before quality of life is impaired. Control of what was happening was a key theme in preserving the dignity of the dying person. Physical, psychological and spiritual peace and comfort were important as well as aftercare of the family. Many felt we should plan for the end of life but live life to its fullest now. Participants believed that the Hospice of the future would accommodate all ages and have activities for young people, be bright and colourful as well as calm and quiet. It was also important to the young people that people who use Hospice services should be treated normally.

Quotes

“Subjective to the person and their situation. Choice and control”

“Peaceful/not painful. People dying in sleep. Died knowing you've done everything you wanted.

Drugs to relieve pain. Comfort, having people you love around you”

“The aftercare of the family once their loved one has died helps them to be able to move on”

“The hospice of the future should be less clinical and more homely. It should offer comfy furniture, flowers and decorations in bright colours and the input of the patient should be taken into account”

“If I am dying I want to be treated the same as I were to live for 60 years more”

Whilst most participants agreed that planning for end of life is important, it was not something they were ready to consider yet. Most did not know about end of life care or advance care planning on the Isle of Man. However, there seemed to be a thirst for knowledge, with participants recommending public engagement to increase awareness of Hospice and reduce the taboo around death and dying. Very clear themes emerged as to the type of care participants would value, and this fits with Hospice’s existing values and plans for the future.

To participants, “the right care at the right time in the right place” translated as care at the Hospice inpatient unit. Participants suggested that it is important that there are plenty of inpatient beds to meet the needs of the population. There was also a theme related to being able to choose to die which many participants favoured.

Quotes

“Don’t make it feel like a hospital, make it feel homey. Make it feel comfortable for the people who are there.

As a community it needs to be more acceptable to talk about, be more open about the subject of death. A subject that is too easily shut down”

“The patient should be the one to decide when it's time. Also be able to choose where”

Appendix 5: Views of patients and carers

Judy's Case Study

As revealed by analysis of diaries kept by those with long-term illness and their carers, the number of services encountered when dealing with a complex or terminal illness can be vast, crossing all sectors. Judy's case study is based on a patient with a neurodegenerative condition. Figure A5.1 shows the services, professionals and charities providing care in the last 18 months of life.

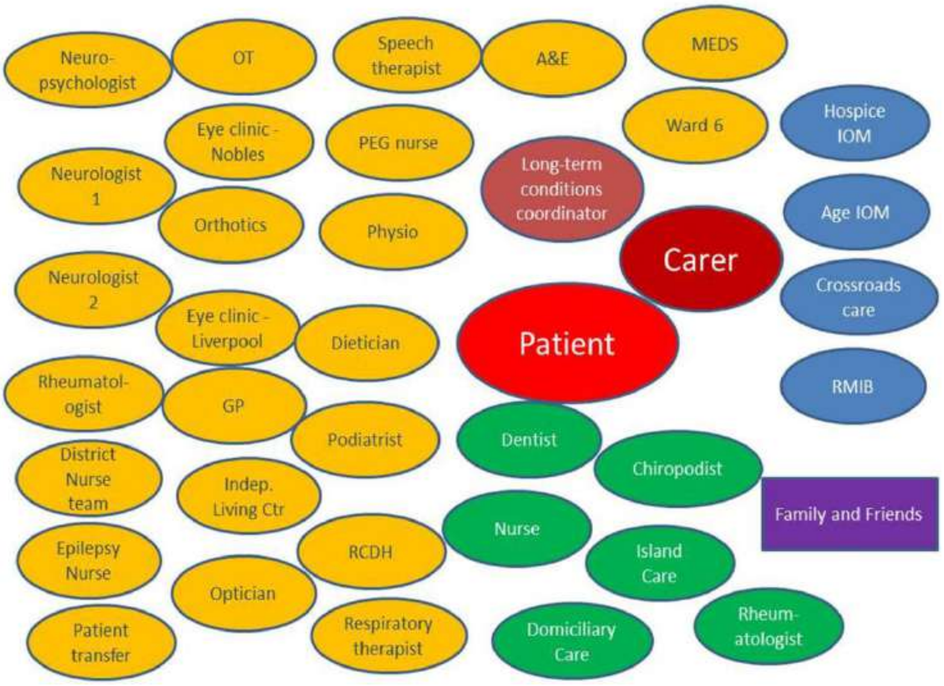

Figure A5.1 Judy's care map during the last 18 months of life

The diaries detailed multiple contacts with these care providers from public services, private services and charities. Figure A5.2 shows the number of contacts per month by sector and Figure A5.3 the purposes of those contacts.

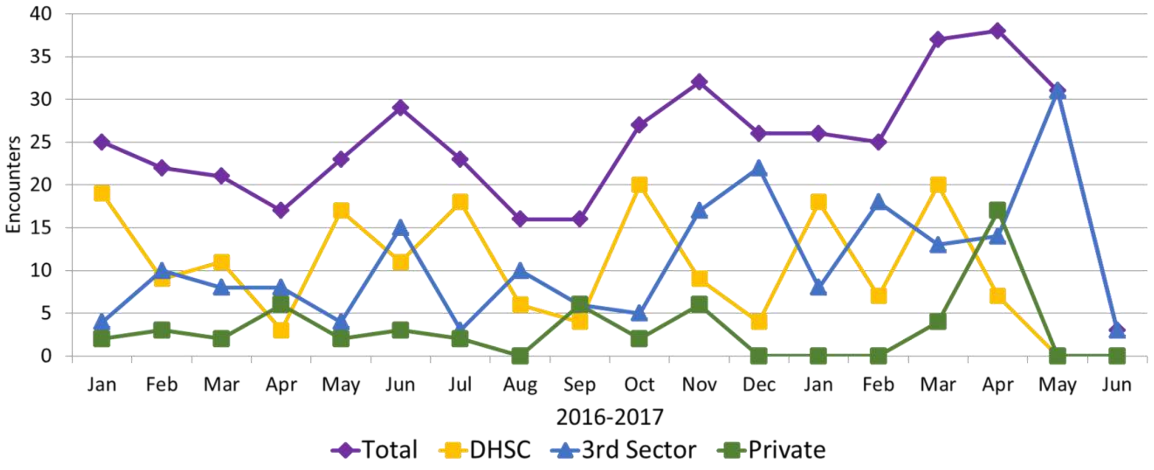

Figure A5.2 Number of encounters per month by sector

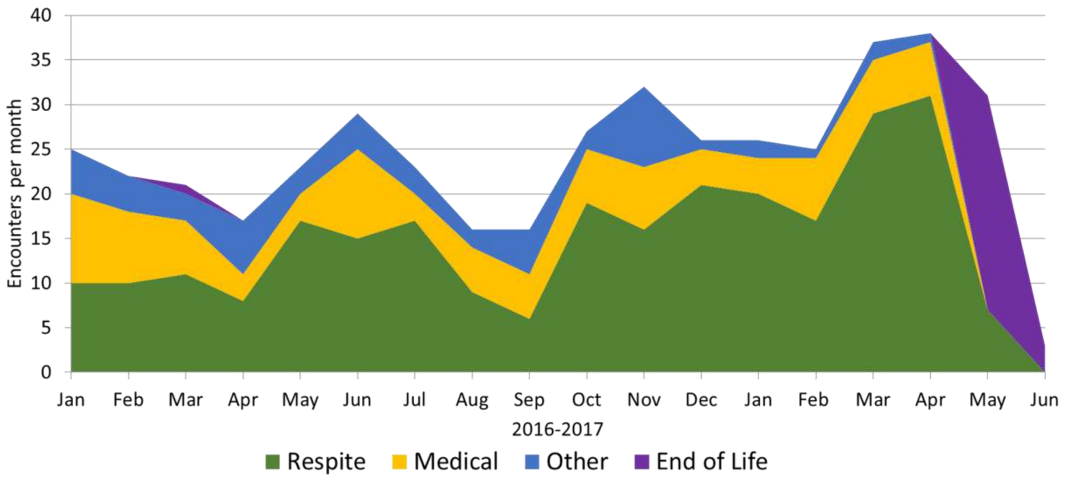

Figure A5.3 Purpose of care provided in the last 18 months of life

Figure A5.4 shows the number of hours of care provided by the different care providers in each month. On average, there was one hour of respite per four carer hours of care.

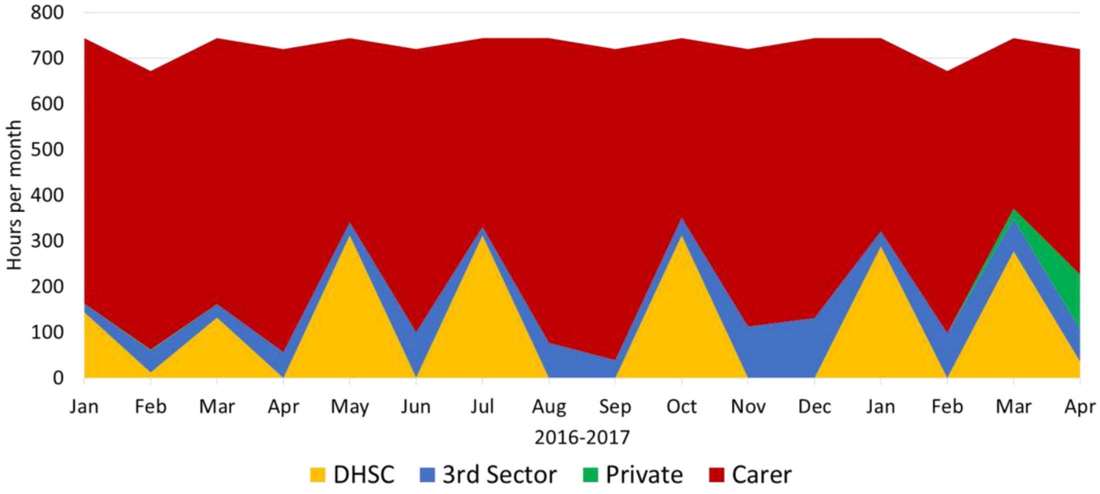

Figure A5.4 Hours of care provided by the carer and services by month

Interviews with patients and carers

The interviews with twelve persons, who were patients with a life-limiting condition, carers or in some cases both, revealed the following main themes:

- **Need for better communication between professionals**

All patients and carers report having to repeat their health history at each new encounter. Continuity of care is poor. Patients witness the difficulty of accessing records and information; professionals often spend a long time trying to extract information during consultations which takes up time and gives patients the impression they are not prepared. GPs do not always get letters from consultants or they are not notified in a timely manner.

“Why can’t they just look on the system? … A consultant in one department in a hospital must be able to look at my overall results… there's no interaction between departments”

“We were going to see different consultants who would say, ‘Why are you here?’ And ‘What’s happened?’ … I got the impression they hadn’t prepared themselves”

“I think what it is between the surgery and the chemist is they have a fight going on about who is responsible… one blames the other every time”

“Every time we went to a new consultant we had to start the history all over again.”

- **Need for better communication with patients and families and involvement in decisions**

Discussions take place where decisions about care are made but in which the patient or carer is not involved.

“We are not told that we’ll have an MDT (multi-disciplinary team) meeting about your care, they just happen. Sometimes we are not told until after they happen. They make decisions and tell you what is going to happen.”

“Patients might feel more in control if they were more involved in decision-making as to their care.”

Families feel excluded. Doctors only look at specific problems in isolation rather than considering the situation from the perspective of the patient. Patients are not always copied into communication between professionals, including those that happen off-Island.

“There seemed to be a team of people for which we were pretty much excluded.”

“I don’t dispute that they are all clever people (clinicians), they know their job. It’s just that it’s not working. Each doctor is only seeing it from their point of view”

“I think where the health care providers let patients and carers down is with lack of communication”

“We like to have information because sometimes when you have information, you can deal with something. If you don’t know what is going on, then you are just left wondering”

When families are told their loved one is “being monitored” but not given any details they don’t know when or how and it leaves them feeling anxious.

“Did anybody ever visit her? We don’t know because nobody ever told us unless you happen to be there at the time”

Communication about diagnoses is not always carried out in the right place or conducted sensitively. Patients and families have found out about a diagnosis incidentally and have not been prepared. In certain cases, because of a family’s background, professionals make assumptions about the person’s ability and willingness to deliver difficult news. This leaves people feeling vulnerable and ill-prepared with the responsibility. When the family has not had the opportunity to discuss the end of life care plan with professionals, they feel that they are “hurtling out of control towards death”.

“The consultant came along, stood at the end of the bed, didn’t consult me at all or speak to me until suddenly they have their attendees… and said ‘Well this one, the cancer has gone everywhere. There’s nothing we can do here, we’ll move on to the next patient’”

“I got a phone call… while I stood in IKEA… he (consultant) said… ‘It’s terminal. It’s grade 4. It’s nasty. And could you please let your family know’”

“It did feel like you were just hurtling out of control towards the death that you were trying to manage, to make sure it was managed in the most humane way possible and it didn’t turn out like that. It was distressing and agony”

“You feel almost like you’re being swept along in a tidal wave because you’re out of control… being involved and included in the process of discussion is helpful”

"You are trying to piece all these little bits of jigsaw together instead of having the whole picture"

Patients and carers expressed frustration at not being able to speak to someone when they call a professional or service. The DHSC appointment desk is not always well-informed about the complexity of a patient's needs and this leads to a lack of coordination and stress due to failed appointments. Patients and carers would like to be able to make appointments when it fits in with their schedule as well as the provider's availability.

"You've got to wait for the GP to phone. You just feel nobody is interested"

"They [appointment desk] don't seem to understand that it is somebody's life that is involved with that appointment."

Communication about the reasons and benefits of palliative care is also needed. One patient felt that once referred to palliative care, the consultant had "washed their hands" of them after saying there was nothing more that he could do. Palliative care needs to be introduced earlier in the disease.

- **Carers provide and coordinate care but they are not recognised by the system**

Poor coordination of care has led to the carer becoming the coordinator. Carers have devised systems to organise documents and relevant information in order to keep track with the complexity accompanying care. Carers become record keepers and organise information from various sources of care for providers and follow-up on appointments. They know about all aspects of care and are able to identify areas to reduce duplication. For example, if a patient has a routine blood exam and another professional requires another test it can be coordinated to happen at the same time. Carers also identify when certain exams or procedures need to follow a sequence in order to fit in with other aspects of care. Managing pharmacy orders can be complicated. Carers keep track of medications and are able to spot errors in doses and supplies. Through experience, carers learn to identify symptoms that require urgent care and require them to go to the emergency department (ED).

Although carers are central to the care team, the system does not formally recognise their role in providing care. Carers face difficulties when discussing care and making appointments. Formal processes to provide consent for this to happen are not clear and require substantial work on behalf of families. Training for carers would be beneficial as many aspects of care were learned through experience and trial and error. Patients with carers commented on how they could not imagine how they would manage without the support of their carer.

"It would be nice to know what can go wrong and what you need to treat urgently and what can wait"

"We've learnt… that appointments get forgotten and they don't always get made… I always have a back-up that if we've not received an appointment, I will phone up"

"The problem is that they won't speak to me if (patient) is not there to say it is okay. I had to phone him, to phone them, to say they could speak to me"

"I appreciate I couldn't survive without her (carer)"

- **Having a professional to help navigate the system is invaluable**

Patients feel daunted by the complexity and lack of transparency of the system. Persons who had a professional liaising with other professionals and services found it to be the "biggest relief", "the main safety valve", and a "breath of fresh air". The long-term conditions coordinator "made all the problems appear solvable". Others expressed the desire for "somebody we could pick up the phone and say help, can you come? We are banging our head against a brick wall". Patients and carers felt that having a key person to contact helped them maintain their independence by knowing that help is available when needed.

A variety of professionals can fulfil this role; e.g. long-term conditions coordinator, the patient's GP or Hospice clinical nurse specialist (CNS). A coordinator or key worker can take a holistic view of the patient's situation and help advocate for what is important to them.

"Somebody could take over that worry and say 'I'll go sort it out' like a patient carer or coordinator—somebody that will liaise with everybody and you don't feel like you were just left alone"

"You don't know who to go to."

"CNS knows us quite well because she's been coming for so long; had there been anything wrong I'm sure (CNS) would see it and kind of pick up on it which is reassuring, really"

"(CNS) dos a little bit of knitting some of them together and she can contact some of them and if there's a problem, deal with that"

"On the Isle of Man our medicine is done on little segments and no one anywhere marries them up together and only by marrying them could you have a holistic view of the patient"

- **Patients and professionals need better information about services**

For those who are aware of Hospice services, referral criteria are not clear and families express "how you get in is a mystery." The current system requires a referral from a medical professional. Not all professionals are clear on when it is appropriate to refer to Hospice. Patients, carers and professionals did not always know that they could contact Hospice seven days a week. People are not aware of the range of services Hospice provides.

“Hospice itself, how you get in is a mystery. Some people obviously do because you see in the obituaries they die in Hospice”

“About six months before we were told that Hospice wouldn’t help… there was no help in contacting them”

“I think that Hospice support is not just for the patient, it’s for the family”

“Families and friends don’t always realise Hospice is there as an asset to be used”

“We knew the hospice was there but we didn’t know how to get access to it”

“It’s nice to know that help is there rather than you get to that point and you think ‘where do I go?’”

- **Carers need physical, social, financial and emotional support**

Carers feel that “nobody can do a lot of the things that I do” and do not always know how to take up offers of help, when given. Respite care is essential and give carers “the strength to carry on”. Professionals can make assumptions about who the carer is in a family. For one family, the daughter was the main provider of care but carer support was provided for the husband under the assumption that he was providing care. Caring can be a “full-time job” and financial assistance for carers is insufficient. Carers give up work or make major life changes to care for their loved one. Carers are often living with conditions of their own or are caring for another family member as well. Both patients and carers underscored the importance of maintaining connections outside the caring role. Peer support from other carers, who would understand, was thought to be potentially helpful for emotional support.

“Nobody is going to come at 7:30 in the morning and sort out the meds… Nobody’s going to come and give him a shower… We just find it’s not practical really for somebody to come and do anything”

“Hospice have given me a sheet of paper with about 10 different private agencies involved. Then I’ve got to pay for it, how? I'm working as well. So how can I pay £25, well some (charge) £17 and now I've don’t even earn that”

“She’s (carer) had to give up work. She could have been earning three times that… I feel my hands are tied (because) I can’t do more”

“To be honest, it’s a full time job (caring)… They (services) could put me in a nursing home and it will cost them £1000 a week to keep me and at the moment they are getting it for £100 for (carer) is doing everything!”

"I'm not so much a wife anymore. I'm more a carer"

"Maybe other carers would have ideas about how you create your 'me time'"

"It's people that maybe you don't know but are in a similar kind of situation so if you say something to them (other carers) they won't say 'You shouldn't say that!' and they say 'I feel exactly the same'"

"Having Hospice at Home and the night nurses we hired gave me the strength to carry on during the day"

"If you could just ring someone and say 'Oh, I've really got to go out. Can somebody come and sit with (patient)?'"

- **Patients and carers feel alone and not understood**

Patients and carers can experience isolation. Some cases are due to 'self-imposed' isolation where a person does not want to interact with others. However, in other instances patients with life-limiting illnesses find that "people when you get sick don't want to know you. They don't know what to say to you and so you lose your friends." There is a sense that people in the community can be inconsiderate and oblivious to difficulties faced in daily tasks such as grocery shopping while in a wheelchair. Patients would also like to hear about what to expect from someone who has experienced what they are about to go through.

"There is nothing worse than when you get someone who comes up to you and says, 'I know how you feel'. Have you been there? No. Then you don't know how I feel"

"The clinicians can tell you but they have not experienced it"

- **Off-Island care is a substantial burden for patients and carers**

Off-Island care results in financial burden for patients and families. Patients not wishing to travel back and forth during long spells of care must pay for weekend accommodation out of pocket. The burden of travelling on people who are not well outweighs the benefits of a short follow-up appointment with off-Island providers. Patients are required to leave on a very early flight and spend an entire day out of their usual environments for short appointments. Planes can be full leaving patients on their own without the support of their carer or some patients may not have a carer. Patients wondered why teleconferencing was not used more widely as well as why off-Island personnel could not come to hold a clinic locally. Travel can cause substantial anxiety especially when airport staff has no knowledge or sensitivity for their condition. In some cases, patients need to arrange back-up care off-Island in a very short time frame when flights are cancelled or delayed. Care plans are not always in place for patients returning from off-Island treatment.

“The plane was three hours late I probably got home at ten o clock, eleven o clock at night, carrying my own feeds… I felt like less than 10%”

“The flight leaves at 7:10 in the morning so you have to be at the airport at a ridiculous time”

“Some of these security people are bloody rough. The last thing you want! You’re weak and you’re very debilitated, you may be working in to 20% to 30% of your normal self and you have to go through this trouble… travel is very traumatic”

“I had to go back to Liverpool… literally 30 seconds she looked at mine (fistula) and said ‘yeah, that’s fine’”

“I used to travel with my feeding tube and they would give you the third degree, ‘please don't pat me too hard on my stomach because I will bleed’”

“If the flight delays… if he couldn’t get home… they would have to find him dialysis the following day and accommodation… that just adds to the stress”

- **Out of hours service is lacking**

Patients can have a team of professionals supporting them at home that are “fantastic” but in cases of rapid deterioration out of hours, the response is poor. Carers who have experienced this describe the lack of clarity as to whose responsibility it is to look after a patient and doctors might not have all the relevant information such as codes for ‘just in case’ boxes. Even if ‘just in case’ boxes are in place, administration of medication requires a specifically trained professional.

“My dad became very unwell very quickly just before he died and as always happens, this started on a Friday evening”

“Out of hours, the service is lacking with very limited help available… I was a nurse and could give the meds (end of life medications) but I should never have been put in that position (as a relative)”

- **Patients want to maintain independence but need to know they are safe**

Maintaining independence is important to patients as it affects their mental health. However, patients and carers need the reassurance that if they need help, they can get it at any time in a timely manner.

“Let them (patients) have their independence… because I think it’s vitally important for their mental well-being. Things are not taken out of their hands”

- **Care staff in the community need skills to recognise when a patient is in the last days of life**

Community care staff do not always recognise when someone is in the last days of life and this can lead to unnecessary suffering for the patient and anxiety for the family. Although care staff are “kind” and “caring” one family felt that end of life skills could be improved.

“The nursing care staff… they are presumably not experts in end of life care, maybe they didn't recognize the signs, I don't know, but nobody told us (she was dying)”

- **Patients and carers experience mental health problems when facing end of life**

Patients expressed that at times they felt that their family would be better off without them. Patients feel helpless and hate being a burden on their family. This is especially in cases where a wife or husband has the responsibility of providing most of the day-to-day care. The change in role from wife or husband to carer also has an effect on mental health. For carers, accessing help is not always easy. Accepting that they need help can be difficult. Carers experience complex emotions related to their caring role. They have guilt that they don’t have the physical strength to provide care.

“I (carer) felt that I was failing if I needed help”

“I’m not one for committing suicide but there are times when I think they would be better off without me. Less grief and they would manage and cope without me. They don’t need me”

“He (patient) doesn’t know I’m going to counselling because I just thought it might add to his feeling that you know, he’s put more on”

“A lot of carers feel guilt that they don’t have the physical strength to care”

Patients and carers feel that they have little control and feel overwhelmed by living their lives around appointments and when they are not kept informed of the situation.

Appendix 6: Views of professionals and Third Sector

This section describes the views of 63 professionals and volunteers working with people at the end of life or requiring palliative care. According to one, the dream is “24/7 palliative care irrespective of location” and another “Hospice ten times the size”. These comments accord with the concept of integrated care as the *right care* in the *right place* at the *right time* and the *Hospice-influenced care* of the current Hospice strategy (1).

End of life care services can be conceptualised as a pyramid with specialist care at the top, generalist in the middle and community-based support at the bottom (Figure A6.1) The levels represent the expected need in a population; e.g. where support is provided by a limited number of specialists to a smaller proportion of the population with complex needs. In this report, the first part is related to the specialist level, the second to the generalist level and the third to the community level of the pyramid. All three levels interact and the themes are contributed by interviewees from public, private and Third Sectors.

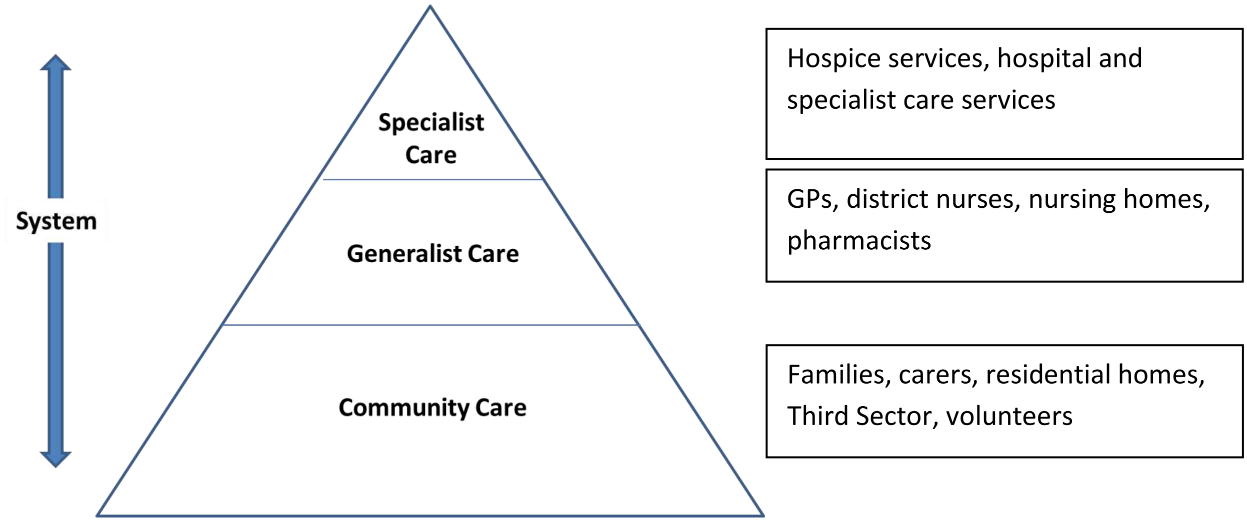

Figure A6.1 Pyramid of resources for Palliative and End of Life Care

Specialist level

This level is mainly informed by views of specialists and the main themes were around perceptions of Hospice and hospital care, the interaction between Hospice, other professionals and users, communicating about end of life, integration of care and perceived inequities.

Perceptions of Hospice and hospital care

Hospice care is good

The extension of working hours to cover weekends makes a massive difference to some other services; the support given to Nobles' bereavement team is excellent. Hospice at home team is really stretched so cannot support MEDS as much as wished.

"Hospice as an organisation is proactive and forward thinking"

"Hospice at Home isn't really a very big service and so they struggle sometimes to meet the needs"

"We didn't think there was anything that doesn't work well within Hospice"

Hospital care is good

Hospital ward staff do their best with end of life cases e.g. moving to a side room if possible. UK consultants can be very helpful with video links and visits, although some professionals ask why we do not have more video communication.

"I've got a really good relationship with the consultants across. They're really good"

How people use Hospice

Being at home with a patient for respite can also facilitate the anticipatory care planning (ACP) discussions. Some hospital referrals to Hospice may be because they need to free a bed, rather than that the patient needs IPU**.** The Hospice at Home nurse can be the default because someone cannot afford private care or it's not available even if they can.

"(It) may not be that they generally would have chosen Hospice but they have to take that-that road because they can't afford the care to stay in their home"

Change perceptions of Hospice care?

People are often frightened of going to Hospice so it is good to get them involved with Hospice earlier; it is useful to introduce Hospice as respite care before further intervention is needed, give people easier access, emphasise the quality of life, not end of life.

"I would rather refer earlier than later… to get patients to get to know the staff and, and how things work"

Interaction between Hospice, other professionals and users

Better inter-professional communication would be good

Data protection prevents Hospice alerting the specialist service that a patient is admitted to the inpatient unit; ward nurses usually know, when someone is admitted to the hospital, that palliative care is involved because the patient tells them; palliative care is not always informed of late stage cancer admissions and discharge. The Hospice referral form seems a bit laborious (4 pages) and many ward staff don't know about the services e.g. the Fatigue and Breathlessness programme (FAB).

"There's a thing about Hospice… no one knows what the referral criteria are"

Patient discussions in the UK about stopping treatment or referral to palliative care may not be discussed with the Island specialty team or even the family; the patient may also receive inadequate information from the UK staff.

Simple handover between specialist and Hospice not ideal

The end of life process for some conditions can be drawn out complicating a simple hand-over referral from specialist to Hospice; patient and family acceptance can take time and input from both specialist and Hospice for a time would be ideal – this is also an opportunity for the specialist nurse to improve palliative skills; if this process does not go well, the patient may end up in hospital at a late stage and die there.

Communicating about end of life

The end of life is not always acknowledged in hospital and people are put through inappropriate tests; end of life arrangements are made too late at times because doctors shy away from being open with the family; there is a perception that consultants might just 'send to Hospice' rather than discuss a patient's needs; it is suggested that doctors should talk more openly about death e.g. when end-stage patients come into the ward with medical problems.

"The consultant hadn't had that conversation with the family, and I'm thinking, well actually somebody needs to"

"People are scared of being honest and open with family and they aren't"

Integration of care

Due to expansion of services, there is more fragmentation and inadequate information transfer, e.g. someone admitted to hospital with no communication that they are already under mental health or district nursing services. There is variable attention to holistic care in hospital, mainly because of time pressure, although some specialists have helped set up support groups.

“It's getting so big it's getting fragmented, and it's hard to keep track of everybody”

“If you’re looking at someone as a whole person you need to see every aspect otherwise you can’t do your bit to help”

The ‘virtual hospice’ concept could really help hospital staff to nurse those dying on the ward but there is a need to find a balance between upskilling and de-skilling hospital staff. A clearer distinction between generalist and specialist palliative care needs would be useful to assist the allocation to appropriate level staff. It would help if staff could have/use wider skills to avoid calling out other specialists and could offer volunteers more training and expanded roles.

“I would love to see end of life as a known skill for everybody”

There is a need for an urgent care response which might e.g. come to a nursing home to put an end of life plan in place and avoid the emergency department (ED); could we have a Hospice-ED link person? Palliative care is seen as quite integrated but other care sectors only talk about doing it. Specialist services are trying several new initiatives but there is no cross-fertilisation or knowledge of what one another is doing; regular updates on new projects would be useful. This might include Third Sector where some services already have links; it would be good if secondary, primary care and Third Sector could know about new initiatives regularly e.g. every month. Some new initiatives have been agreed quickly but take a long time to implement.

“… there’s an awful lot of things happening very much in isolation of each other”

“We come up with policies …and they go in the drawer and forgotten”

“It has for me been frustrating in terms of the time we have given over the years to different projects that have fallen by the wayside”

Perceived inequity

Those who travel for care in the UK have to pay upfront for their travel and accommodation and some find it difficult to afford. There is a feeling that some disease groups e.g. cancer and stroke have more services available to them perhaps because of Third Sector campaigning and funding. Island specialist nurses do a lot more than UK-based ones such as arranging travel and communicating with a lot of off-Island providers.

"…if they have to go off Island for radiotherapy, obviously there are costs in that. And then they have to pay upfront.

"...if you get any other kind of cancer, 'oh shame', and they don't have that same platinum service that breast cancer patients get"

Generalist level

The middle, generalist level has been organised into one of the main themes which emerged: right place, right care, right time.

Right place

The right place for end of life care was believed by many to be the home - care homes are also considered as 'home' in this section. Even more professionals felt that home for as long as possible, with Hospice in the last stage, was what people tended to want. The main themes relating to care in the right place were the **resources available for end of life in the community**, **inter-professional and inter-sectoral relationships** between community-based providers, system issues, in particular **communication**, the **ability of families to manage** care at home and the need for **better outcome measures** in all services and better resource allocation.

Resources available in the community

An important sub-theme related to maintaining someone at home at end of life is how to deal with an emergency**,** especially **out of hours** and for this, the most appropriate solution may be a ***rapid response team***. It may only be an emergency as perceived by the family but still needs an immediate response.

"…we know people don't die between 9 and 5"

"If we have something like a team that would go out and just crisis manage until the morning"

"But because they knew there was a phone number there, that's all they needed. Whereas at the minute we can't do that after working hours"

While managing end of life emergencies is now easier with Hospice visits available seven days a week and a limited on-call service at night, end of life emergencies still end up in the emergency department (ED) if Hospice is not available or the person is not registered with Hospice; MEDS is the only medical service available out of hours but might not be able to respond due to lack of staff time and pressure of cases and because, in theory, end of life cases should have a pathway already in place. Faced with uncertainty, families will call an ambulance but the ED staff may be unable to do anything other than register the patient and create an end of life pathway, families' expectations may be raised and the patient might die in hospital causing further family upset. The urgent response service could enable people to remain in their homes. Such a service has been proposed using specialist practitioners who would cover based on a rota. Extending the remit of ambulance staff is also possible; these are often trained to a level where they could administer end of life drugs, carry out necessary tests and do administrative tasks if they were digitally equipped.

"We don't have a rapid responses service or intermediate care service and they are the areas we feel would add most value"

"GP's and the MEDS are really good at coming out when they can"

"You know, that gap is really very marked between 6 and 10. Because 9 times out of 10 that's the time when people either need medication or they die"

A second sub-theme is ***lack of appropriate respite care***. There is almost no respite available for those with nursing needs, especially in an emergency. Nursing homes might make a temporary vacant room available but only until a permanent resident needs it. There are very few double rooms so couples are split up or, in the case of co-dependent couples both may have to go to hospital. Residential homes have some respite beds but these are oversubscribed. The lack of appropriate, temporary, respite care can result in someone being transferred to permanent residential care. Each week there are 1 or 2 notified crises requiring respite. Particularly with dementia cases, the services struggle to keep them at home, even in a nursing home. If kept in the family home, lack of respite care can result in exhaustion of carers.

"They've had a dreadful experience in trying to maintain Mum at home but still they push on and want to do it and they do get, they are extremely tired"

“And it's getting increasingly difficult to maintain the respite that some carers have already had”

“If the nursing homes had the option of keeping beds available perhaps partly paid for and then that being reimbursed by families when they use it”

Residential homes are not always convenient places to manage end of life because of space. They would not accept an end of life case but would try to keep an existing resident in their home and are keen to be involved in end of life care but, with no nurses on site and no access to medical records, they need support from district nurses and GPs and feel they need to improve the skills of their staff. There is a felt need for extra-care housing on the Island, something between a residential and a nursing home, especially with the rise in dementia referrals of about 10% a year.

A ***rapid discharge*** from hospital at end of life might be desired by staff and family but there can be a number of problems: lack of available care staff, even if the family is willing to pay; inability of the family to pay; a delay in equipment to maintain comfort at home due to limited warehouse opening hours or logistical aspects in the home and no available Hospice bed. A ***two tier service*** is effectively created when some families can pay for overnight support to keep someone at home and some cannot.

“Often it's difficult to get people home in time either because of equipment or because there’s a lack of care available in the community”

“The pulling together of a package of care, depends upon the strength of the person who's coordinating it.”

The issue of ***funding for end of life care*** was mentioned in a variety of contexts. The cost of overnight or 24 hour care from a private agency is high and a possible driver of preferences for Hospice care; the cost and the scarcity of available carers can complicate discharge from hospital and support at home. If people qualify for Government subsidies, the incentives are towards residential care, rather than care at home.

“You know its £20 per hour for one person and you think those type of people usually need two, so that’s £40 an hour before you even start. People can’t afford that”

“I’ve got to pay for it. How? I'm working as well. So how can I pay £25 … , I don’t even earn that.”

“Not everybody can afford the care that perhaps they would want”

Lack of staff at all levels of the community care system was expressed. Some services such as district nursing can use bank staff but these need enough hours to maintain skills so might not be confident with end of life cases. In spite of being short of time, district nurses try to have the same nurse regularly visit an end of life case.

“We are completely under-resourced. The staff that are in place are put under undue stress because of it”

Inter-professional and inter-sectoral working

Our health care professionals have become increasingly specialised and several may contribute concurrently or over time to an individual’s care and everyone is busier. This contrasts with previous times when ‘tea and sympathy’ meetings could raise issues at an early stage and build up relationships so professionals ‘knew their families better’.

“I think there is an essential part of relationship building when you are doing personal care and that’s just gone”

While some professionals previously carried out a wide range of tasks, the level of specialisation means ***no-one now has all the necessary skills***; they hand people over at end of life or ask another professional to take charge while they take a step back. This results in further de-skilling and a loss of satisfaction for the professionals; however current caseloads and the need for minimum numbers to maintain a level of skill demand it and some professionals now feel too ‘task-oriented’. In particular, a district nurse might be co-managing a patient with specialist services e.g. Hospice at Home. It is suggested that, at times, the district nurse might take the lead in end of life care, thereby improving their skills and freeing the specialist’s time.

“While others won’t, not won’t do it, but maybe don’t have the competencies or feel that’s not their role and sadly I think we’ve lost that a wee bit, a bit”

A decline in statutory services has resulted in the services being unable to provide large care packages for more than a few days for complex conditions. This requires greater ***involvement of private agencies*** but usually needs two or three of them to work together and so it often takes longer to establish a satisfactory service. Private services can build up a good relationship with someone over time but at end of life the presence of statutory service can be disruptive while the private agencies might not wish to reduce their support for financial reasons. A difficult situation arises when the family are happy with the care from a private agency but the statutory service is not.

“We have a few issues with a few of the agencies… because anyone can start one up”

Some disciplines feel they ***don’t share skills and ideas very well***, especially with other professional groups. There were many requests for opportunities for multidisciplinary group meetings to allow knowledge sharing. Not knowing what other professionals do was listed as a gap by many respondents. For example, the ambulance staff are trained to be an emergency gateway to the health system but many professionals, as well as the public, do not know the range of tasks they can do on site. Multidisciplinary teams that share the same ‘roof’ or those who can ***get together regularly*** report the positive impacts this has in understanding others’ roles, ensuring timely exchange of information on cases and arranging cover for one another.

“What happens is it’s a close working relationship.”

The pilot of Integrated Care in the West, even though it does not include a shared workplace, appears to be creating a better understanding of one another’s roles and changed attitudes; people have the same goal so different job titles become less important. Expectations of this pilot are high along with the hope that virtual meetings will maintain this closeness.

Intersectoral relationships are working well in several services and improving in others. For example mental health works with the Alzheimer’s Society and found embedded Third Sector staff very useful. District nurses are working more with private agencies and Third Sector, adding to their links with statutory services and the hospital signposts people to the Third Sector. There were a few barriers reported: there were gaps in necessary services to back up private care at end of life, a lack of knowledge of available services which prevents appropriate signposting to useful services and the public perceiving that a Third Sector service would be ‘poorer’. Statutory service providers expressed concern about the ability of Third Sector organisations to provide a service in a consistent manner, especially for those relying on volunteers who might not always have the staff to respond. Some interviewees acknowledged that we have a very rich and varied Third Sector and some charities continue to care for those they have had a relationship with, even after they are admitted to a residential home. The Third Sector interviewees perceived the end of life care offered by health organisations as good.

"Usually, usually end of life treatment, palliative care we get nothing but praise"

"It might be partnership between Government and also between Third Sector organisations so that the focus of what you do would be bottom up, not top down. You'd start with the problems"

In spite of the barriers mentioned above, there was a ***general feeling that many things are going in the right direction*****.** It was considered time consuming to develop the necessary shared vision and the lack of systems to support good communication was a significant barrier but 'the Island could lead on integrated care' if it could concentrate resources on the areas of need and integrating care was believed to have the potential to solve many of the problems services are facing.

"You know, what worked years ago is not going to work now."

System issues: communication between professionals

Every single respondent that shared patients with or referred to other professionals said that the ***non-connectivity of IT systems*** was a big problem for communication resulting in duplicated work, duplicated referrals and patient confusion, complicated and time-consuming referral processes and lost contact with patients. It also impacted workload besides duplicated tasks, for example hours being used to gather facts from different systems which all have parts of a patient's information; that is, if one even has access to all the relevant systems which may professionals did not. Clinicians described 'hanging around waiting' for someone to help them access a necessary piece of information. The community use EMIS, the hospital uses Medway and Mediviewer, the mental health and social services use Rio and some, but not all cancer specialist nurses use the Somerset Cancer Registry. Ambulances rely on paper records because they have no access to digital services in the van. Another problem is that there is ***no feedback*** in many systems so that a referring clinician will not know if a referral is delayed or not taken up and so cannot follow up.

"You've got mental health using RIO (which) doesn't talk to EMIS, which is used by the primary care and we use Medway as currently none of them talk to each other.

> *"But you know you have got Medway, got EMIS, got RIO, all for one department, quite bizarre isn't it?"*

It appears community staff share a lot of ***informal communications*** and most community-based staff 'know who to contact'. Several professionals said their communications were mostly by email but required them to remember to do it. Discharges from on- or off-Island specialist care required individuals to remember to contact other individual professionals to ensure community care was re-started. Others described trawling through lists to see if their patient had been admitted to hospital. Several commented that their patients assumed the professionals were all 'joined-up' so would not have thought to alert them so, for example, regular management by a district nurse may not be communicated to ward staff. One suggestion was that, with a suitable system contributed to by the multi-disciplinary team, recent information could be viewed by all and people could be 'bumped up or down' the ladder of care as appropriate. Many professionals commented that personal relationships were essential for good communication and to provide joined-up care.

> *"… I think what works well here on the Isle of Man is, I think, the fact that we are small, we have an 85,000 population, and most people who work here know who to contact."*
>
> *"… it wastes hours and hours of time, having to open up one, two, three, four different IT systems, and trawl through it"*

Mobile coverage in some districts prevented ***EMIS*** from connecting in people's homes. In spite of these problems, there were several comments that EMIS was helpful. However, all these respondents wished that all community staff were on EMIS together. Others said that EMIS had not saved them any time. Lack of ***data sharing agreements*** hindered communications between some groups.

System issues: other

It is acknowledged when attempting to integrate care that it is ***difficult to slot new ways of working into an old system*** and this was expressed by several professionals describing colleagues becoming demoralized and frustrated at being unable to move into ways of working which they had seen work better in other places.

Several people felt that ***integrated care on a small island*** should be easier in theory. Some services, notably older persons' mental health and those forming part of the Integrated Care in the West pilot report many benefits of integrating their work and being able to call on relevant skills as required. It was generally felt that end of life care in the community was working well because people know who to contact and Hospice are responsive. Others describe the difficulties of non-integration e.g. handing cases over from specialist to community-based care or residential home so both specialist and patient lose contact with one another, chasing up necessary services which have no spare capacity and not knowing referral criteria.

Ability of families to manage care at home

Under this theme people mentioned two issues already listed above: the lack of availability of ***respite care*** to ensure carers could cope and the lack of availability of ***urgent care*** at night when families became frightened but transporting someone to ED is not helpful. Families can be ***confused about who to contact*** even during the day; for example, calling for an ambulance when the problem could be better dealt with by the district nurse.

"Because everybody's just lost and they don't know where to go for help"

Other themes were the ***lack of facilities for those with dementia***; a facility somewhere between a residential and a nursing home would be welcomed.

"I certainly think extra care housing and dementia care housing as well, is a gap"

Professionals thought that some families did ***not know what Hospice could offer*** and so did not ask for the service.

"…people are genuinely surprised about the services here."

Care pathways which would allow for ***last minute changes*** if families felt swamped were important but there was uncertainty about how to manage the ***holistic needs assessments***. At present specialist services try to ensure these are done at some point after diagnosis but finding the correct time and engaging with the patient and family for this purpose can be difficult. It was suggested that Third Sector colleagues might be better placed to do these.

"In the plan they generally want to stay at home... As things progress, that's when it changes"

“I literally just don't have time to do a HNA (Holistic Needs Assessment) at all with our patients”

The need for better outcome measures

Some professionals commented that they did not have the correct outcome measures in their service since the most appropriate one would be keeping people in their homes and out of hospital. For example, performance of a provider based on number of visits per day (activity based), which created the wrong incentives, rather than the number of clients who were enabled to remain at home (outcome based). Others felt that the current allocation of resources was not correct and should be based on needs, but that lack of data prevented appropriate allocation of resources.

“I think the lack of data is a big problem because I’m just kind of guessing here because we don’t have very good data on it, so that’s big gap”

Right care

The main themes raised under the concept of the right care were ***how good Hospice support*** in the community is, questions about how to get the ***right provider*** in specific cases, including those missed by Hospice, and the tendency ***for services to go ‘above and beyond’***.

Hospice support

There were many positive comments about Hospice support including that it is much better that they take non-cancer cases too, that the services offered are very useful e.g. the FAB service is excellent in offering social, psychological and physical support, that Hospice at Home provides an essential urgent response at night for a few and during the day for many, there is a good interaction between Hospice and other community service providers, although the ambulance staff were sorry not to be included currently in multidisciplinary team meetings. Hospice support to residential and nursing homes is working well.

“Hospice at Home is the best kept secret on the Isle of Man”

The right provider

Knowing who is at end of life can be challenging. Previously, all those concerned would find out if someone was at end of life at the Gold Standard Framework meeting but not all

GP Practices continue to hold regular meetings and district nurses are not always invited if they do. It was felt that some people ***missed out on Hospice services***. In the particular case of those with learning difficulties there is no end of life pathway and end of life care could be distressing for those living around the person in a care home as well as the individual who had limited understanding. It was suggested a Hospice link person might help manage these cases.

"There maybe people over who are end of life in hospital who aren't known to palliative care team and it's that group that I'd be concerned about"

Interviewees asked why some people, but not others, are seen by Hospice staff; for example a residential home staff member reported that a cancer case had regular Hospice visits while another terminal cancer case did not. There was also a request that Hospice consider offering their complementary services again in nursing homes, as they had been able to do in the past.

"…that is all he wants really … he remembers dad dying in the same Nursing Home, but he had aromatherapy service from Hospice"

Other challenges were how to ***identify people who might benefit*** from a particular level of care. For example, some were uncertain when to refer to Hospice and about who would benefit most from the long-term conditions coordinator (LTCC) who managed many end of life cases. GPs were supposed to stratify their patients for high risk but that doesn't always happen. It was suggested that all those under the LTCC might be suitable for registration with Hospice; this is estimated at about 240 cases and includes neurological and respiratory conditions.

Others who lack end of life pathways include groups which are ***difficult to engage with*** such as substance abusers. Those with mental health problems were often well managed at end of life within their own service. The ***very frail*** who are not known to the GP and other ***isolated people*** are likely to miss out on services since they are often housebound. Professionals believed that there were a lot of socially isolated people on the Island and many people who have no family or significant others living locally. Engaging these people with relevant community services presents a challenge but this might be met if all services were to pick them up on alert. The mobile library was mentioned as useful and some services have created a local event to give out information along with e.g. 'flu jabs'.

“Some of my patients are so socially isolated. Unbelievably”

“I really think it’s very sad that if somebody happens to be an only person without a network of family or friends they can’t stay in their preferred place of care”

The ***involvement of specialist services*** seems inconsistent as some specialist nurses report noting cases under Hospice care who have never been seen by the relevant specialty team. Other cases may have been diagnosed some time ago but not followed up and can be very poorly when admitted to hospital and die there. There are a number of smaller charities who might support end of life care and a suggestion that maybe they could work together.

Going ‘above and beyond’

It was clear that people working in every sector ‘go above and beyond’ to ensure good care is delivered in the appropriate setting. For example, staff reported working extra hours in their own team to ensure this and being impressed with those working in the same way in other services. The system only works at present because of this extra commitment but it is not considered sustainable. There is an Island culture of wanting to work together and to be collaborative and people are passionate about delivering good end of life care.

Right time

Under the heading of right time, the main themes were the ***usefulness of early referral to Hospice*** and the problems with ***services being initiated late***.

Early referral to Hospice

Being able to refer people to the Hospice ***day unit*** meant there was no need for separate referrals to the lymphoedema and complementary therapy services. It was suggested that being able to ***refer people at the time of diagnosis of cancer*** could help manage their later problems, especially in cases of very sudden deterioration; this would also be useful for patients with organ failure who can deteriorate quickly. For example, there might be a service similar to that initiated in several specialties where regular clinic appointments have been dropped and replaced with a rapid access service.

“*I just thought if he’s in Hospice as a Day Patient in the Day Unit and he feels comfortable, if he ever needed the in-Patient Services that would make it easier.*”

Late initiation of services

Currently staffing issues often get in the way of early identification of cases and the appropriate professionals are not always involved. People come to hospital at the end of life but are not under any specialist service; often these people are alone. Specialist nurses sometimes feel they referred to palliative care too late but this is sometimes because communication with Liverpool specialty teams was poor and the patient status was not communicated.

The community level of the pyramid of care

Some of the themes generated from interviewees in the Third Sector mirror those from the health professionals: a general lack of respite care; the need for alternatives to sending frail people off-Island; the perception that Hospice care is very good; that everyone, including neighbours, could identify those at risk of isolation; that better supported accommodation would help people stay at home and that volunteers as well as staff go ‘above and beyond’ to help people.

Interviewees from the Third Sector also told us about an urgent need for more ***carer support,*** that the Third Sector ***needs to work together***, the role of ***volunteers***, the need for a ***variety in the types of support available***, problems due to lack of hospital ***discharge plans and care pathways***, perceived ***inefficiencies*** in service use, lack of ***recognition of some services*** and ***talking about end of life.***

Carer support

This was a constantly recurring theme among all interviewees and many charities offer support services. Some people have no carers. Some carers don’t ask for help because they don’t recognise that they are carers, that they need help or they might be afraid of being separated from their loved one. Carers’ needs are often overlooked and can be complex, causing problems even after bereavement although there was a perception that carers with links to Hospice were well supported.

> *“Obviously carers needs get overlooked and if you’re not careful, the carer turns into the cared-for”*

Carer assessments are useful but have to be requested so are not always done and they sometimes raise expectations that cannot be met e.g. no suitable volunteer may be available. There is also a large need for support for those dealing with neurological problems. Some of the carer skills courses have been discontinued. Carers' problems can be financial, practical, psychological, self-care, recognising their limitations and needing to coordinate many services and appointments. The subsidised carer support service is always full. Overnight support is a particular problem and has to be paid for out of pocket, if available. An overnight support service is needed and a suggestion that a night- as opposed to a day-centre might help.

"The reason my husband's in here is so that I can get a good night's sleep … most nights I'm up two or three times"

"A lot of the time carers are actually struggling to get the package of caring that maintains basic needs and that is very sad"

Some carers cannot provide adequate care and navigating the health and social care system can be onerous. On the other hand, family and financial support to loved ones is perceived to be good within most families although travelling to UK, possibly staying there for support, can be unaffordable. Some Third Sector groups work with the district nurses to support carers and it was suggested that the Third Sector staff might be further trained to assist with other tasks including symptom management.

Third Sector working together

Third Sector groups are well placed to identify small changes in health condition and make appropriate referrals. However, multi-sectoral communication, particularly with Government was sometimes poor as was communication between Third Sector groups. Working in partnership improves the use of resources such as training, financial management, evaluation skills, sharing venues or equipment and some groups have already adapted their services to avoid duplication. There were concerns about differing standards across organisations which hindered collaboration and an acknowledgement that previous attempts at collaboration were not sustained. Lack of funding can undermine collaboration but perhaps larger charities could support smaller ones and smaller charities might come together to support end of life care.

"Some of the smaller organisations have been built up by individuals … and therefore it becomes very personal."

“Some of us in our charities are overlapping and hogging whereas actually we should be collaborating”

The role of volunteers

Volunteers are an essential resource without which there would be many unmet needs. However some roles do not attract many volunteers, others need paid staff and needs tend to be seasonal. Specific skills are needed to be a good volunteer organiser and the volunteers bring many skills to the group. Mental health benefits and friendships result from volunteering and the cared-for person is eased into more formal services. Non-experts with time to talk to someone would be a useful complement to district nurses who can only make quick visits.

“I tell you without the volunteers on the Isle of Man, there would be, it would crumble, the NHS, the DHSC would crumble. I am sure of that”

“… if we maybe had a volunteer, that might be the way that they could go out and see them once a week”

Variety of types of support

The variety of clients and age ranges served means that Third Sector groups provide a range of services. However, specific clients can still be excluded if they have specific needs e.g. toileting, that cannot be catered for. Some of the marginalised groups helped by charities have rapid declines when ill because chronic conditions have been neglected. Third Sector groups are a good source of information in a variety of formats. There has been a notable rise in requests for dementia support, some groups are promoting self-management approaches where appropriate and intergenerational activities appear to be producing two-way benefits. It is notable that clinical care is better with clinical nurse specialist support so some charities have pump-primed such posts while private sector groups have given practical help or training to charities.

“…it gives them a bit of self-worth you know that they’re helping somebody else, tends to be the way the group works really, to sum it up”

Lack of care planning

Some Third Sector groups have noted that a lack of appropriate hospital discharge planning and appropriate care plans have compromised care of clients. They perceive that some poor hospital outcomes are due to staff not understanding the condition or patients being unable to properly communicate. There is a perception that mental health needs are not always met and, although a dementia pathway was developed, it was never implemented. There is often no care coordinator and the quality of care appears to differ between services. It was suggested that agencies coordinate their end of life planning because they currently use different approaches.

"You know the notion of a discharge plan for every individual, I'm not sure is actually happening"

Other inefficiencies

Some services were felt to be used inefficiently because of insufficient training. Good initiatives in the past have gone to waste because they were not fully implemented or were discontinued; changes in Government might have been the cause or there may not have been a sustainable plan. Some groups now feel they are over-stretched while others could offer more in end of life support.

"We were told … that Government would then develop a strategy which they did, but then there were no funds to take it forward so nothing happened"

"There were a number of senior business people as well as people from the public sector and from charities and voluntary organisations who were all giving up time… and the Government then disbanded it"

Recognition

It was felt that the contribution of the Third Sector is not always recognised e.g. by Government and that legislation governing Third Sector organisations is lacking. The befriending services contribute a lot to primary prevention of mental health problems. Some services feel their contribution is forgotten when someone moves on to more intensive care. Some find it difficult to obtain sponsorship of intangible benefits like training. Some non-health services, e.g. airport staff, do not appreciate the difficulties of frail people having to travel off-Island for care. Some groups feel the Third Sector should lead new initiatives and some are becoming involved in integrated care.

"I think sometimes this perception that a charity plays at it… instead of recognising that we are professionals"

"That the capacity that exists in the Third Sector and the voluntary sector is the greatest and least cared for element of Manx society"

Talking about end of life

From both health care and Third Sector professionals there were comments that some people find the words 'Hospice' and 'palliative care' frightening but also that they did not want to lose the concept of these services, especially as Hospice was considered a comfort to many. It was felt that expectations needed to be managed, perhaps starting with young people and children. Third Sector groups would like to normalise discussions about end of life and some felt it is not as much of a taboo as it used to be. There were many comments, also from health care staff, about not knowing when and how to have the conversation and how to deal with those who do not want to talk about it.

"When is the right time, you know, it's, to have that conversation, there isn't a set time"

Some specialists might not discuss end of life but rather fear of the disease. Many felt staff needed more confidence, which might come with training, and also regular reminders to initiate such conversations. Recognising when it was appropriate was a problem for some e.g. staff in residential care homes who do not access medical records. Most felt that earlier was better to prepare patients and/or carers and some said that patients were thinking about it even before it was discussed. District nurses felt they needed to improve, long-term care coordinators felt they were improving and specialist nurses prefer to signpost people to palliative care, especially the cancer specialties since their support is now more about diagnosis and treatment.

"I think in terms of having the conversations early on with patients and carers, certainly in terms of planning care, that needs to happen earlier"

"I don't tend to do it, by that stage, usually I will have referred the patient over to the palliative care team and then they would do the advance care plans"

Anticipatory care plans (ACPs) were felt to be useful by most types of staff and the lack of one made the emergency department's tasks difficult. Like do not resuscitate (DNR) requests, ACPs might not be seen when required; this might be because they are in a system that the practitioner does not have access to. For ambulance staff, a paper-based ACP is needed.

"The worst case scenario is that somebody hasn't got a DNRCPR, they have a cardiac arrest, the paramedic crew are called, …and actually we've lost all of that end of life pathway"

The DNR requests do not travel between hospital and community which some interviewees found frustrating and regretted that people were being asked repeatedly when they shifted service. On the other hand, patient and family views might change so a flexible system was required. Some felt that, at present, a DNR request was not always properly discussed with the patient and family nor reviewed as required. Even when present in the notes, it was not always seen. The ACP conversations could be difficult but people and their family often felt better afterwards. It was suggested that Third Sector staff and volunteers could be trained to discuss ACPs with clients.

GP Survey Summary

Definition of 'end of life'

The majority of GPs defined end of life as the time when 'curative treatment has not worked and treatment is for symptom control'. This suggests that in the community the definition of end of life is based on the definition of palliative care without a specific reference to time. Only one person mentioned the surprise question (Would you be surprised if this person was no longer alive in 12 month's time?).

Referrals

To understand the current practice regarding referrals to Hospice, GPs were invited to participate in a short survey. GPs were asked when they might refer a patient with cancer, organ failure, neurodegeneration, dementia/Alzheimer's or any other condition they thought appropriate to Hospice Services. Seven GPs answered the questionnaire. Appendix 2 describes the methods for the survey.

GPs cited a number of reasons and timing for referral of cancer patients that included referrals at any time after diagnosis depending on patient or family needs (physical or emotional), uncontrolled symptoms, once the patient reached the palliative or end of life phase, and/or upon discussion with the patient.

GPs were less clear on referrals for organ failure, four out of seven said they would refer and one GP that gave a reason mentioned uncontrolled symptoms as a reason for referral. One

GP felt that this patient group rarely required a referral and another felt that there were patient factors that limited referral saying that this group of patients 'may take longer to come round to the idea of Hospice'. Another person had never referred patients with organ failure to Hospice.

As with cancer, all GPs indicated they referred patients with neurodegenerative conditions. The reasons and timing of referral mentioned included any time depending on need, uncontrolled symptoms, and when the 'patient is struggling to maintain independent living'.

The majority of respondents (5/7) did not regularly refer patients with dementia or Alzheimer's for Hospice services. The reasons cited were that these patients are likely to be looked after elsewhere (e.g. nursing home) or by another organisation (medicine for the elderly). One GP felt Hospice did not have the capacity to care for dementia patients at this time.

As far as any other specific conditions, the only answer was for 'family members or patients of chronic disease especially for outpatient/complementary services'.

Meeting patient needs

GPs were asked about their opinion on how well Island services for palliative and end of life care meet the needs of patients. Respondents were asked to rate on a scale of zero to ten, where zero was not well and ten very well. Four respondents (57%) felt that Island services for palliative and end of life care meet the needs of patients well (scores of 8 and above). The reasons being: 'end of life care tends to bring out the best in all the services involved' and 'they provide an excellent service'. Three respondents felt that services met the needs less well. The perception is that in 'recent years the care has declined', there is insufficient community support and there are issues accessing services: 'very little Hospice at Home service, but great if you can access it' and 'not enough Hospice beds for patients who chose Hospice as preferred place of death'.

Proposed changes to the provision of palliative and end of life care

The comments provided by the GPs mirrored those of other professionals in the community. The key themes pertained to resources, communication and person centred care. Increased resources in the form of staff to provide palliative care; support from the Government for Hospice and staff working in palliative care; access to Hospice services; time to provide the 'human' element of care; and better practical support in the community including appropriate packages of care to be in place at the time of hospital discharge were mentioned. Improving communication with other services, in particular patient access to oncology clinical nurse specialists to discuss concerns; honest communication and ‘realistic clinic advice’ from consultants; improved liaison with nursing homes to discuss end of life issues (DNACPR, end of life medications) with patients and families at nursing homes would promote better planning and avoid unnecessary hospital admissions. Finally, providing options for care at the preferred place of care of the patient whether at home or in-patient care at Hospice.

Workshop on integrated care

The identified gaps in care and areas of need included the following:

1) *Pre-diagnosis to diagnosis*
    - Identifying complex cases
    - Triggers for signposting and community support
    - Self-management programmes
2) *Increasing complexity and disability*
    - Care navigation – all sectors
    - IV antibiotics at home
    - Emotional wellbeing and respite
    - Anticipatory care planning
    - Carer support
3) *Last year of life*
    - Out of hours availability
    - Review of preferred place of care

The challenges included the disconnect between Third Sector groups, lack of coordination between services, unavailability of population level data to allow for appropriate planning, regional identities of services despite being on a relatively small island, difficulties in information sharing and our inability to support as full a range of services as we might wish.

The group concluded that as a small island we have some advantages such as clear geographic boundaries, personal connections and a sense of community but many of the same barriers to integration observed in other settings apply. After completion of the needs assessment, the piloting and evaluation of effectiveness of cross-sector integration initiatives in end of life care is needed.

References

1. Hospice Isle of Man. Much More Than A Building: 2018-2023 Strategy: Hospice Isle of Man; 2018. Available from: https://www.hospice.org.im/assets/d525f5dcd6/2018-2023-Strategy-compressed.pdf. [2018 Oct 11]

Appendix 7: The current services available for palliative and end of life care

Statutory Services

Across statutory services, consultants, specialist nurses, general practitioners (GPs), long-term conditions coordinators, allied health professionals and district nurses provide palliative and end of life care.

Hospice and other Third Sector organisations

Hospice Isle of Man is the only specialist service provider on the Island for palliative and end of life care.

Table A7.1 Hospice Isle of Man services

Hospice service	Description
In Patient Unit (IPU)	End of life care, specialist palliative respite care (limited)
Medical/Nurse Consultants/Clinical nurse specialists (CNS)	Clinical medical staff provide consultations primarily in IPU but also in out-patient clinics, the Day Unit, Rebecca House, Noble's Hospital and in the community (patient's home, nursing homes, residential homes)
Hospice at Home	Care for those who choose to die at home and respite
Rebecca House	Respite, palliative and end of life care for children with life-limiting or life-threatening conditions from birth to 18 years
Scholl Wellbeing Centre	Supports people to remain independent by encouraging them to sat well for as long as possible
Complementary therapy	Help ease specific symptoms, improving mood and aiding relaxation
Rehabilitation	Help adapting to specific conditions, maximising physical function and prolonging independence, includes physiotherapy, Fatigue and breathlessness (FAB) and Occupational therapy (OT)
Lymphoedema Management	Compression bandages, lymphatic drainage and advice on self-management
Day Unit and Drop In Days	Group support, RN support, complementary therapies, art therapy and exercise
Psychological support	Assisting patients, families and carers to overcome emotional challenges
Bereavement support	Care for the bereaved through individual counselling and group support
Social Work	Works in partnership with other services to help or advise on discharges, benefits
Young Person's Support	Psychological support for those under 21 for pre- and post-bereavement and for those affected by life-limited conditions personally or indirectly
Spiritual and Pastoral Care	Team of volunteer chaplains supports patients and families. Weekday communion service in Hospice Chapel and special services and funerals
Hospice Volunteering	Coordination of volunteer roles including shops, events, reception, Compassionate Isle of Man
Compassionate Isle of Man	Volunteer patient support with Friend to the End, Back Home Boxes and carer respite

There are a number of organisations that support patients with specific conditions e.g. Parkinson’s disease, motor neurone disease, head and neck cancers and Alzheimer’s disease. In general, these charities provide support through fundraising, social support, advocacy and signposting. In certain cases, organisations have provided seed funding for clinical nurse specialists or raised funds for special projects that involve statutory services. Some charities work closely with clinical nurse specialists at Noble’s Hospital to support patients.

Other organisations provide services that are relevant for palliative and end of life care, such as organisations that offer respite or support for carers e.g. Crossroads Care, home care e.g. Live at Home, or bereavement support e.g. Cruse Bereavement. Most organisations rely heavily on volunteers to provide their services.

Table A7.2 details some of the services available through Third Sector organisations. The list is not a comprehensive inventory of organisations on the Isle of Man.

Table A7.2 Third Sector organisations providing relevant services to palliative and end of life care

Service or Organisation	Services description
Age Concern	Provides direct services appropriate to the needs of individual elderly people or groups of elderly people to improve wellbeing and welfare. Provides a lunch club, computer training and advocacy
Alzheimer's Society	Supports and helps people with Alzheimer's and dementia. Provides dementia awareness training and supports research
Arthritis Care Ellan Vannin	Promotes and provides social activities, welfare, information about Arthritis Care's services and publications. Fundraises for the branch. Grants advice and provision for local people with arthritis, self management programmes, organising holidays at Arthritis Care centres.
Breathe Easy	Aims to improve lung health and care through prevention, education including classes, helpline, web community, support and research
Bridge the Gap	Enhances the support and emotional care available for those with complex/chronic and palliative medical needs through teenage years, in the transition to adult medical care and in bereavement in the Isle of Man.
British Red Cross	Provides support for people in crisis including victim support, therapeutic care and working with other emergency services. Provides a wheelchair loan service
Butterfly Flyer	Allows passengers with hidden disabilities passing through United Kingdom airports (including Liverpool) to carry a discreet butterfly card. Once shown to airport staff they provide help through all stages of the airport process, from check-in to boarding. (Note: this service is not available at Ronaldsway Airport)
Care in Mann	Provides transport for those who find using public transport difficult or who have nobody to assist them to attend medical appointments to hospital, doctors, dentists, clinics etc. Helps with shopping, collecting prescriptions, emergency requests to take people to visit family in hospital, trips to vets, library or hairdressers
Churches Alive in Man (CAIM)	A fellowship of churches that aims to further the relationships that exist between the churches and other organisations to promote the wellbeing of all who live in and visit the Isle of Man. Established with the objective of advancing the Christian religion on the Isle of Man and relieving poverty on the Island and elsewhere in the world
Council of Voluntary Organisations	Aims to allow members (charity, voluntary and faith groups) to work together to influence local policy and represent third sector organisation, to share best practice and resources for the benefit of the community

Service or Organisation	Services description
Crossroads Care	Provides practical and emotional support for carers living on the Isle of Man, including respite and psychological services. The shops provide carers an opportunity to get back into the workplace. Provides a social club for people with severe and complex disabilities. Contracted to provide services for the MS Society and Parkinson's Disease Society
Cruse Bereavement	Provides counselling and bereavement support to all bereaved persons
Graih	Provide emergency accommodation help and advice with a range of issues for males over 18 including emergency accommodation
Huntington's Disease Isle of Man	Raises awareness and provides support for patients with Huntington's disease, their carers and professionals on the Isle of Man. Provides financial assistance to patients and carers to enable attendance of seminars and other educational events. Promotes research into Huntington's disease
Lisa Lowe Centre/ Manx Cancer Help	Provides psychological support, including support for patients with cancer and/or chronic pain. Provides a venue for complementary services and charities
Live at Home	Aims to improve quality of life and eliminate isolation and loneliness among older people aged 60+ (some 55+) by providing befriending staff and volunteers as well as social activities, thus allowing them to live happily at home for as long as they can
Macmillan Cancer Support	Provides physical, financial and emotional support for cancer patients from diagnosis, through treatment and beyond, offering emotional, physical and financial support. Supports research and provides education for people affected by cancer, including carers, family members, volunteers and community members
Mannin Sepsis	Promotes and protects the physical and mental health of sufferers of sepsis through provision of support and practical advice. Supports those in the Isle of Man affected either directly or indirectly by sepsis. Advances the education of the public in the Isle of Man in the subject of sepsis
Manx Decaf	Provides a mobile cafe for people and carers of people with memory problems and dementia
Manx Swallows	Provides peer support and socialising opportunities for head and neck cancer patients and carers, supported by medical professionals at Noble’s Hospital who put patients in touch with the group
Motor Neurone Disease Association (MNDA)	Provides information about motor neurone disease including symptom management and latest research. Staff and volunteers provide emotional and practical support, social and financial information

Service or Organisation	Services description
Parkinson's Disease Society	Raises funds to support people with Parkinson's disease and their families in the form of paying for respite care and equipment, and organising social opportunities with transport provided where necessary. Offers support, advice and care for all those affected in any way by Parkinson's disease
Praxis Care	Provides services for adults and children with a learning disability, mental ill health, acquired brain injury, and for older people, including people with dementia.
Reayrt Skyal Day Centre	Provides therapeutic advice and other activities for persons diagnosed with dementia or memory problems
Samaritans	Provide support and information to those experiencing distress and despair
Southern Befrienders	Befriend and give social support to elderly residents in the south of the Island at risk of isolation or who live alone
Southern Community Partnership	Investigates pathways and means of signposting to reduce loneliness and isolation. Creates an atmosphere of traditional neighbourliness by connecting people and services. Seeks ways to improve inter-sectoral collaboration. Coordinates Men in Sheds
St John's Ambulance	Provides event first aid, first aid training and equipment use (including hoists) training. Supplements the Isle of Man Ambulance Service in response to 999 calls. Campaigns to raise awareness of first aid. Provides company training. Previously offered specific carers training
Tabitha's Trust	Supports families through child bereavement
The Silver Line	Provides a free confidential (United Kingdom based) helpline for older people, offering information, advice and friendship

Community engagement

Various organisations in the Isle of Man sponsor events during Dying Matters Week every year in May. Dying Matters is a coalition of organisations across England and Wales. The aim of Dying Matters is to “help people talk more openly about dying, death and bereavement, and to make plans for the end of life”. Third sector organisations such as Cruse Bereavement Care Isle of Man, Hospice Isle of Man and the Isle of Man Freethinkers have sponsored events to raise awareness and to start conversations about death and dying. Events in 2019 included a Death Café, sponsored by the Isle of Man Freethinkers, “Before I die…” community boards at four Island locations sponsored by Compassionate Isle of Man and creative writing workshops discussing death, fear, grief and loss sponsored by the Isle of Man Arts Council.

The End of Life Matters initiative is a working group with representatives from various organisations including Cruse Bereavement Care Isle of Man, Hospice Isle of Man, Kirk Braddan and the Isle of Man Government Department of Health and Social Care. End of

Life Matters has published an information booklet “Putting your house in order” with information about talking and planning for end of life. Other resources available include Cruse Bereavement Isle of Man’s “My End of Life Plan” and Hospice Isle of Man’s “Advanced Care Plan” booklets available to community members.