



Health and  
Community Services



**Jersey Hospice Care**  
your care, your choice, your time

# A Palliative and End of Life Care Strategy for Adults in Jersey

2023-26



Government of Jersey

# Citation

<b>Title</b>	<b>A Palliative and End of Life Care Strategy for Adults in Jersey 2023 – 2026</b>
<b>Author</b>	Gail Caddell, Director of Clinical Strategy JHC
<b>Co-Authors</b>	Hilary Hopkins, Director of Palliative Care Services JHC Marco Vidal, Change Manager HCS Daniel Speck, Executive Assistant JHC
<b>Published</b>	October 2023
<b>Cover Image</b>	Public domain image
<b>Enquiries</b>	GailCaddell@jerseyhospicecare.com

# Foreword

We are very pleased to present the Palliative and End of Life Care Strategy for Adults in Jersey 2023-2026. The strategy is essential in ensuring positive access to high quality care for all people and their families when approaching the end of their life. This Island-wide strategy is the result of a collaborative effort between Jersey Hospice Care, Jersey End of Life Care Partnership Group, Health and Community Services, and Public Health. Together, we have worked diligently to outline our vision, aims, objectives, and priorities that will guide our approach to palliative and end of life care over the next four years. By utilising evidence-based approaches, we aim to ensure that all individuals in Jersey will receive the highest quality of care and support during their end of life journey.

The overarching aim of this strategy is to enhance the quality of palliative and end of life care for adults in Jersey, regardless of their condition or care setting. To achieve this, we have set out specific objectives that include identifying local population needs and priorities, engaging with stakeholders, and agreeing on deliverables for the coming years.

While this strategy focuses on adult care provision, it is important to emphasise that our commitment to supporting Islanders extends from pre-birth to after death. To fulfil this commitment effectively, we must address the needs of individuals of all ages who are living with dying, death, and bereavement, as well as their families, carers and communities. Therefore, palliative and end of life care for children and young people will be the theme of a separate strategy document in the future.

This strategy acknowledges that palliative and end of life care is a continuum that encompasses the entire journey from the diagnosis of a life-limiting condition to death and bereavement. It provides a framework for delivering high-quality care, emphasising the importance of early identification of individuals in need of palliative care, the integration of palliative care with chronic condition management, and the development of skills necessary to anticipate and provide quality end of life care.

Furthermore, this strategy recognises and promotes the invaluable contribution of families and carers in providing informal care for their loved ones within our community. It highlights their role in interdisciplinary and interagency teamwork, which is central to delivering good quality palliative and end of life care.

The development of this strategy has been informed by a range of national and international strategies, as well as local initiatives undertaken in Jersey. Our aims are framed by the UK national framework that provides evidence-based principles translated into local action. Thus, this strategy provides a framework to support commissioners and care providers in achieving the desired outcomes outlined in the evidence-based framework Ambitions for End of Life Care.

This palliative and end of life care strategy is built on a collective responsibility that involves all stakeholders. By highlighting this fact, we aim to increase awareness and recognition of the social responsibility we all share in providing help and being actively involved.

Looking ahead, we anticipate a significant increase in the demand for palliative care in Jersey, driven by projected population growth, a high prevalence of individuals aged 65 or older, and an increase of Islanders with co-morbidities. The numbers indicate a 50% increase in the need for palliative care by 2026 and nearly double the number of individuals requiring such care by 2036 compared to 2016.

We estimate that approximately 75% of the population in Jersey who passed away in 2021 could have benefited from generalist or specialist palliative and end of life care. These figures align with national and international trends, emphasizing the importance of our efforts in this area.

The desired outcomes of this strategy are clear. We must strive to ensure that people in Jersey who require palliative and end of life care are treated as individuals, encouraged to make and share advance care plans, and are involved in decisions regarding their care. They should receive timely recognition of their needs and conditions, ensuring fair access to services regardless of their background or characteristics. We aim to support them in living well for as long as possible, respecting their expressed wishes and maximising their comfort and wellbeing. Care should be well-coordinated, provided by well-trained individuals who continually update their skills and competencies. Ultimately, we seek to foster communities that openly discuss death and dying, prepared and willing to provide the necessary support.

To achieve these outcomes, we have identified four essential enablers: active engagement with the public and patients, the use of technology to inform and improve care, education and workforce development, and the co-design of an island-wide integrated model of palliative and end of life care.

We extend our deepest gratitude to the Jersey End of Life Care Partnership Group, patients, carers, and those involved in the development of this strategy. With your support and commitment, we can make a profound difference to the lives of individuals and families during their most vulnerable moments. Together, let us strive to provide compassionate and person-centred palliative and end of life care that truly meets the needs of our community, ensuring every individual's journey meets their individual choices and is filled with dignity, comfort, and care of the highest quality.



A handwritten signature in black ink that reads "Karen M. Wilson".

**Karen Wilson**  
Minister of Health and Social Services



A handwritten signature in black ink that reads "Mike Palfreman".

**Mike Palfreman**  
Chief Executive – Jersey Hospice Care

# Acknowledgement

I would like to take the opportunity to formally thank all those who have participated in the development of this Palliative and End of Life Care Strategy 2023-2026 for Jersey.

The voice of the patient and carers has been an essential element throughout this document, and thanks go to all those who devoted their time to inform us as to what services work well, where the gaps are and the needs going forwards.

Palliative and end of life care impacts all areas of health care and as such the End of Life Care Partnership Group has worked together to ensure we develop a plan to improve care and services for patients and their families.

In addition, I would like to thank all my colleagues across Jersey Hospice Care, HCS Commissioning and Public Health teams, particularly my co-authors, who have all worked together to bring this strategy to publication, reinforcing that 'Together we are stronger'.

Finally, I give special thanks to my family for their continuous support and understanding during the long hours spent developing this Strategy.



**Gail Caddell**  
Director of Clinical Strategy – Jersey Hospice Care

# Contents

Citation.....	2
Foreword.....	3
Acknowledgement .....	5
Contents .....	6
Introduction .....	7
Vision, Aim and Objectives .....	10
Evidence to Support the Need for an End of Life Care Strategy .....	12
Statistics .....	15
Addressing The Challenges of End of Life Care in Jersey .....	28
Services .....	33
Workforce .....	35
Governance Arrangements.....	37
Stakeholder Engagement .....	39
Outcomes and Actions.....	45
Key Enablers .....	51
Success Criteria.....	53
References .....	54
Appendix 1. Stakeholder Engagement Event Discussion Summary .....	58
Appendix 2. Integrated Model of Palliative and End of Life Care .....	62
Appendix 3. Action Plan.....	64

# Introduction

This Island-wide strategy sets out the vision, aims, objectives and priorities that will help Jersey respond to local priorities over the next four years using evidence-based approaches to care and support.

Palliative care should be strongly responsive to the needs, preferences and values of people, their families and carers, 24 hours per day, 7 days per week.

A person and family-centred approach to palliative care is based on effective communication, shared decision-making and personal autonomy. Palliative care should be available to all people living with an active, progressive, advanced disease, regardless of the diagnosis.

Palliative care affirms life while recognising that dying is an inevitable part of life. This means that palliative care is provided during the time that the person is living with a life-limiting illness, but it is not directed at either bringing forward or delaying death.

Dr Ros Taylor (National Director for Hospice Care, Hospice UK) outlined the key challenges that palliative care providers face as (1):

- Response to a dramatically escalating demand for palliative and end of life care
- Adaptation to meet the needs of an ageing population living with and dying from chronic illnesses and multiple co-morbidities where longevity is frequently compromised by frailty, disability and dependence
- Ability to deliver equitable, quality care to those who need it in an environment of financial constraint

Furthermore, Dr Taylor cites that these challenges are contextualised today where personal autonomy is paramount as people are increasingly expressing the importance of choice and independence as major components of dignity in advancing illness and old age. This supports people's expectations to make decisions, not only on how we live the last years, months, weeks and days of life but also on how and where we die.

She is clear that to meet the needs of the future, palliative care providers must be prepared to do things differently.

Whilst this strategy relates specifically to adult care provision, as a community, we aim to support Islanders from pre-birth until after death. To do this well, the needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities must be addressed, considering their priorities, preference and wishes. Palliative and end of life care for children and young people will be the theme of a separate strategy document in the future.

The strategy recognises that palliative and end of life care forms a continuum of care that may apply from diagnosis of a life limiting condition, right through to death and bereavement. Within this context, the Strategy provides a framework for high quality palliative and end of life care, emphasising the significance of early identification of an individual's need for palliative care, the interplay between palliative care and chronic condition management and the importance of ensuring that the skills are in place to anticipate and deliver quality end of life care.

In addition, the strategy recognises the significant contribution within communities which families and carers make in providing informal care for their loved ones. It promotes their role in the interdisciplinary and interagency teamwork that is central to good quality palliative and end of life care.

It is known from national (2) and local evidence that as a community, when we or our loved ones approach the end of our lives we want to:

- Have choice about where we want to receive care
- Be involved in decisions about our care
- Be treated with dignity, respect and to be heard
- Have access to support when we need it
- Be cared for by professionals who are well trained to deliver palliative and end of life care
- Know that our loved ones will be supported

Palliative and end of life care has been very topical in the media recently as discussions have taken place in Jersey around “Assisted Dying” which is due to be fully debated in Government 2023 following a vote after the recommendations of the Citizen’s Jury. If assisted dying is to be an option, it is crucial that we ensure there are robust palliative care services across Jersey, so islanders have a real choice around end of life decisions and are not pushed into making any decision based on lack of alternative services. There have been robust discussions between Policy and Clinical Palliative Care leads, and all parties are adamant that this is an essential component in taking the Assisted Dying Bill forward.

## **Palliative and End of Life Care Definition**

According to the World Health Organisation (WHO), palliative care is “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual” (3). The NHS defines end of life care as a form of palliative care that can be received in the final year of life (4).

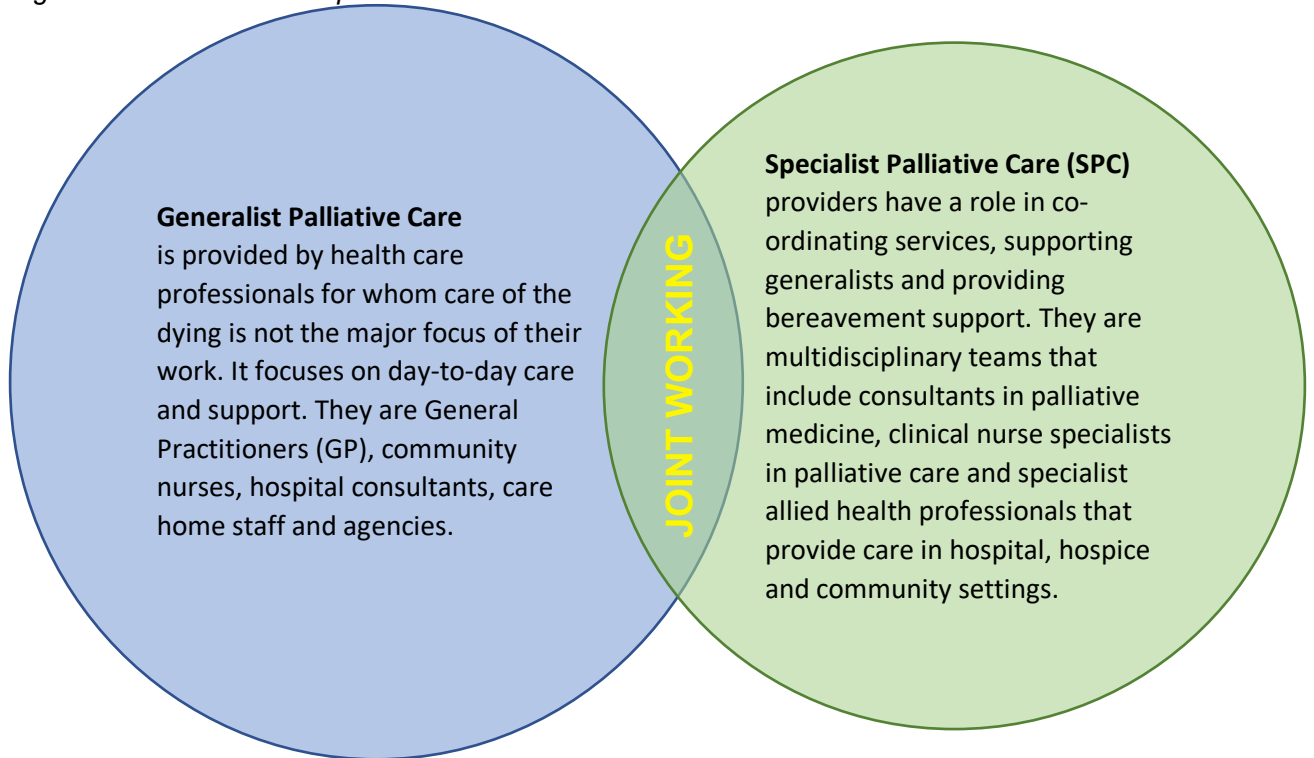
Palliative, supportive and end of life care aims to provide the best possible quality of life for people with life-limiting or life-threatening illnesses who are approaching the end of life. It is evidence based, holistic and improves not only patients’ experience of their care, but also the experiences of their families and loved ones at the most difficult of times. In addition, palliative care contributes towards the cost-effective functioning of the health and social care system, enabling greater patient choice where it is available. Such support is needed in all places where people are cared for by managing symptoms to ensure people are supported in having the best quality of life possible whether home, community, hospital, hospice or care home.

Furthermore, as discussed within the Prague Charter developed by the European Association for Palliative Care, palliative care is a recognised component of the right to the highest attainable standard of health, which is protected in article 12 of the International Covenant on Economic, Social and Cultural Rights, and in article 24 of the Convention on the Rights of the Child (5).

Most people living with a life-limiting illness will require generalist or specialist palliative and end of life care (P&EOLC) (6). The interface between these two teams demonstrates the joint working that is essential for care around the patient and the family. The distinctions between these services can be seen in Figure 1.



Figure 1. Generalist and Specialist P&EOLC Teams



The care delivered by these providers also presents its intricacies (7):

**Generalist and Core Level Palliative Care Provision:** All professionals and staff in health and social care have a role in the effective provision of palliative and end of life care services across all care settings. The Specialist Level Palliative Care multidisciplinary team (SLPC MDT) are expected to proactively support, advise, assist and guide education and training to these staff.

Professionals and staff working in services providing core level palliative and end of life care make an important contribution and may be specialists in other disciplines and services; however, unless they are led by a SLPC MDT they cannot be considered to provide a specialist level palliative care service.

**Specialist Level Palliative Care Services:** Specialist level palliative care is required by people with progressive life-limiting illness, with or without co-morbidities, where the focus of care is on quality of life and who have unresolved complex needs that cannot be met by the capability of their current care team. These needs may be physical, psychological, social and/or spiritual. Examples include complex symptoms, rehabilitation or family situations and ethical dilemmas regarding treatment and other decisions.

Specialist level palliative care is delivered by a multidisciplinary team (MDT) of staff with the requisite qualifications, expertise and experience in offering care for this group of people, to support them to live as well as possible during their illness ensuring their comfort and dignity are maintained as they come to the end of their lives. Input from specialist level palliative care professionals to the care of a person must be based on the needs of the person and not the illness they have.

# Vision, Aim and Objectives

## Vision

The vision of this strategy is to ensure that all Islanders with a life-limiting illness will have access and informed choice to the right care, by the right person, at the right time and in the right place.

## Aim

The overall aim of this strategy is to improve the quantity and quality of palliative and end of life care for adults (over the age of 18) in Jersey irrespective of condition or care setting by:

1. Providing the foundations for a policy and commissioning framework which will enable the development of an integrated pathway through which public, independent, community and voluntary care providers can deliver high quality palliative and end of life care to the people of Jersey.
2. Ensuring that palliative and end of life care is focussed on the person rather than the disease and that the principles and practices of high-quality care are applied without exception to all who need it.

## Objectives

The strategy objectives are:

1. Identifying patients in need of palliative and end of life care earlier
2. Increasing the involvement of palliative and end of life care patients in decisions regarding their care
3. Improving the access and quality of the support provided to palliative and end of life patients, families and carers
4. Maximising the comfort and wellbeing of palliative and end of life patients to live well as long as possible
5. Improving patients', families' and carers' experience
6. Increasing willingness and ability of the community to support people who need palliative and end of life care, their families and carers
7. Strengthening the palliative and end of life services in Jersey
8. Optimising cooperation, coordination and collaboration across different organisations in Jersey

In order to design the objectives, the following steps were taken:

1. Establish an end of life partnership group
2. Establish a working group

3. Identify local population needs and priorities
4. Engage with all stakeholders
5. Agree deliverables for 2023-2026
6. Provide a framework to support commissioners and providers in achieving the outcomes identified in the national evidence-based framework Ambitions for End of Life Care

# Evidence to Support the Need for an End of Life Care Strategy

## Global Picture

Each year, an estimated 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care (8).

In the UK there were approximately 600,000 deaths in 2021, of which around 75% (450,000) were expected deaths that could have benefited from palliative care (9). Approximately 200,000 people in the UK die each year with palliative care needs that are not met (10).

It is recognised that the UK's population is ageing and it is estimated that by 2050, one in four people will be aged 65 years or over (11). In England and Wales it is projected that, by 2040, the number of people requiring palliative care will grow by 25% to 42% due to complex multiple long term health conditions, dementia and cancer being the main drivers of increasing need (12).

## Predisposing Causes

According to the World Health Organization, the majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%) (3). Furthermore, research has shown that the conditions recognised as needing palliative care are (13):

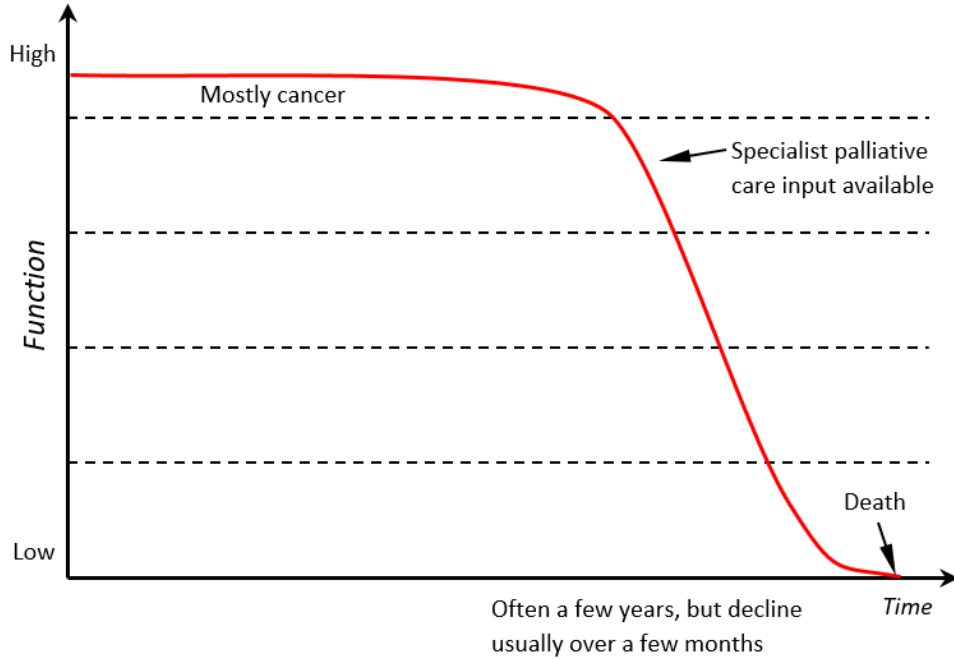
- Cancer
- Heart disease, including heart failure
- Cerebrovascular disease (stroke)
- Renal disease (chronic renal failure)
- Liver disease
- Respiratory disease (chronic respiratory disease and respiratory failure)
- Neurodegenerative diseases
- Dementia, Alzheimer's disease, and senility
- HIV AIDS

## Illness Trajectories

There is good evidence that integrating palliative care with disease-modifying therapies improves symptom control, quality of life, and family satisfaction. Moreover, early access to palliative care can reduce the provision of clinically non-beneficial therapies, prolong life in some populations, improve the quality of life of people with a life-limiting illness, and significantly reduce hospital costs (14), (15).

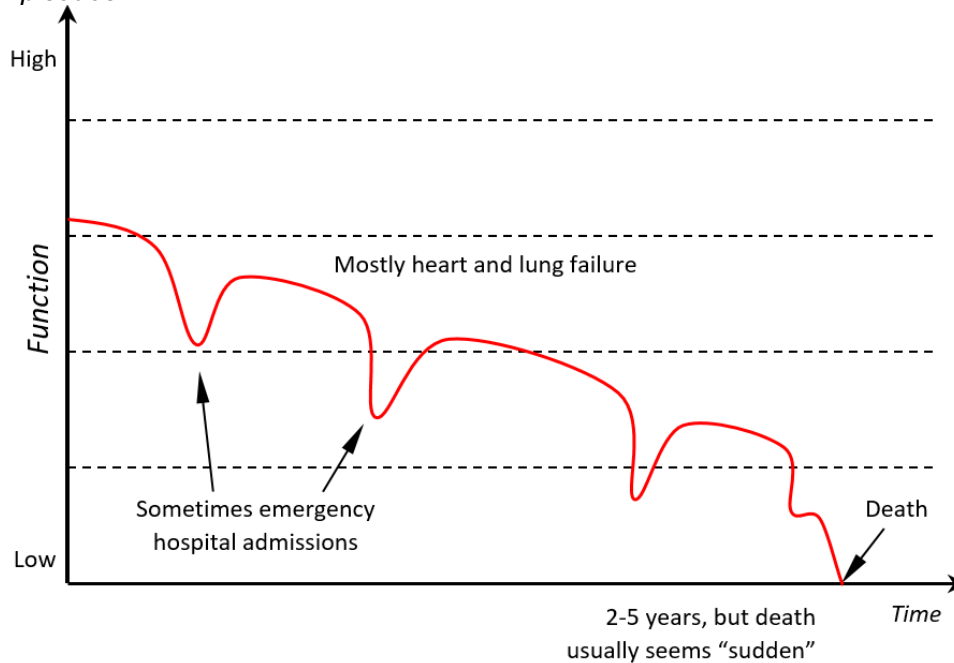
Planning should also be informed by an understanding of typical illness trajectories among people dying an expected death (16) as shown in Figure 2, Figure 3 and Figure 4:

Figure 2. Illness Trajectory for Patients with Short Period of Evident Decline



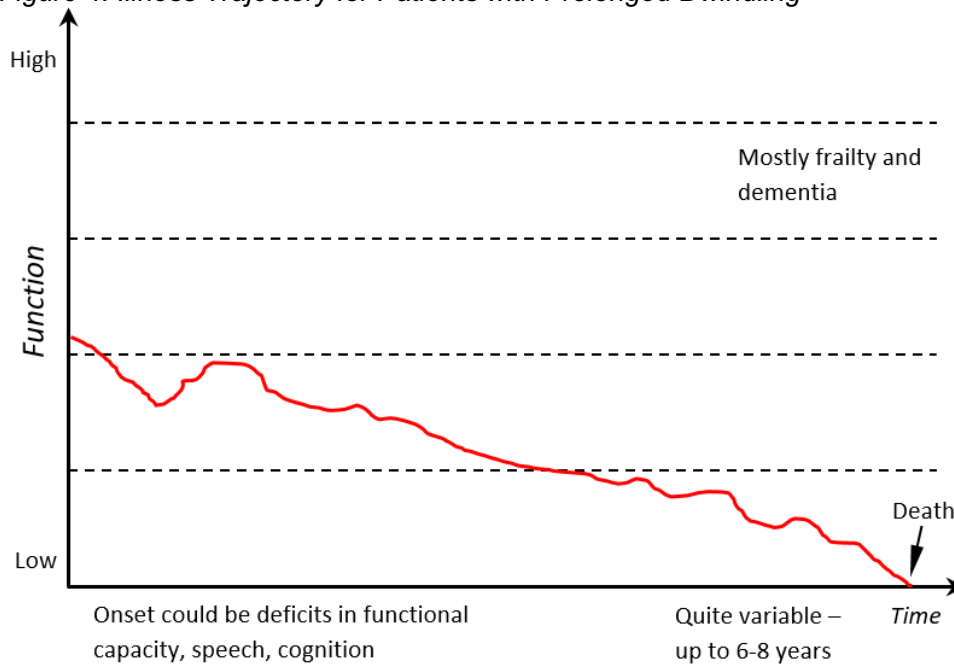
There is long maintenance of good function which may be followed by a few weeks or months of rapid decline prior to death. Most reduction in function occurs in the person's last few months of life.

Figure 3. Illness Trajectory for Patients with Long-term Limitations with Intermittent Serious Episodes



There is a gradual decline in function, interrupted by episodes of acute deterioration. While there is a risk of dying during each of these acute episodes the person may survive but will continue to decline in function. The time of death usually remains uncertain.

Figure 4. Illness Trajectory for Patients with Prolonged Dwindling



There is long-term, progressive disability and reduction in function. Death may follow other events such as infections, falls and fractures.

Based on typical illness trajectories Jersey has proposed a model that conceptualises the population of people living with a life-limiting illness as falling within three broad groups outlined in the graphs above based on the complexity of their needs for palliative care, as follows:

People with straightforward and predictable needs - this group comprises people whose needs are generally able to be managed through their own resources (including with the support of family, friends and carers) and/or with the provision of palliative care by their existing health care providers (including GPs, community nurses, geriatricians, oncologists and other health professionals). People in this group do not usually require care delivered by specialist palliative care providers.

People with intermediate and fluctuating needs - this group includes people who experience intermittent onset of worsening symptoms (such as unmanaged pain, psychological distress and reduced functional independence) that might result in unplanned and emergency use of hospital and other health services. People in this group may require access to specialist palliative care services for consultation and advice. They will also continue to receive care from their existing health care providers.

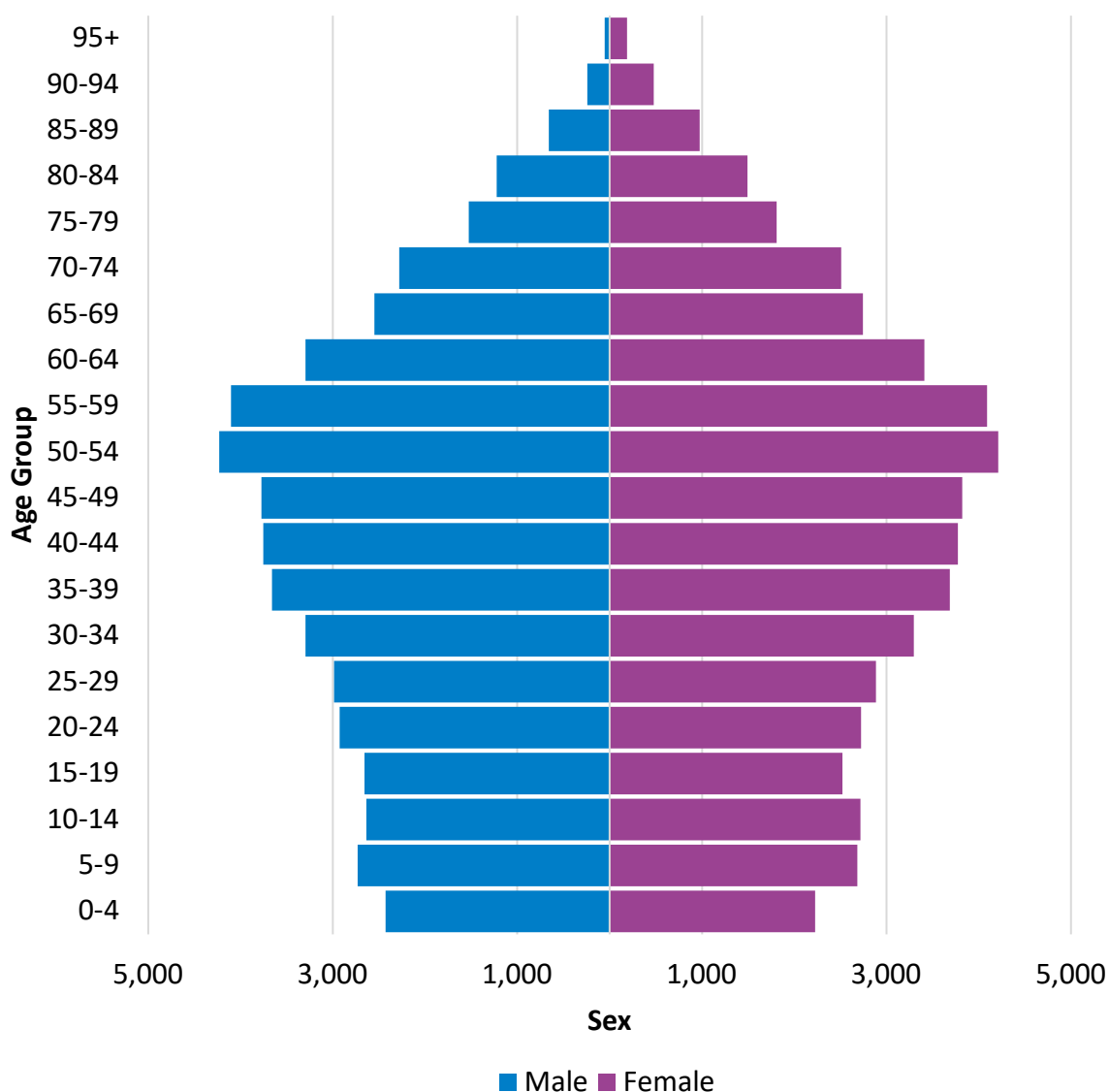
People with complex and persistent needs - this group comprises people with complex physical, psychological, social and spiritual needs that are not able to be effectively managed through established protocols of care. While people in this group will require more ongoing direct care by Specialist palliative care providers, this should occur through partnerships and shared care models with existing health care providers.

# Statistics

## Demographics

The 2021 census found that the population of Jersey on 21<sup>st</sup> March 2021 was 103,267. It consisted of 52,264 females and 51,003 males and was characterised by more people in their middle age than in the other age groups. Figure 5 shows how Jersey’s population is distributed across age groups and genders.

Figure 5. Population Structure of Jersey 2021 (17)



In 2021 the greatest proportion of people by age were those in their fifties. Around 18% of the population were aged over 65 which represents an increase since 2011 when it was 15% and is consistent with an overall ageing of the population over the last decade (18).

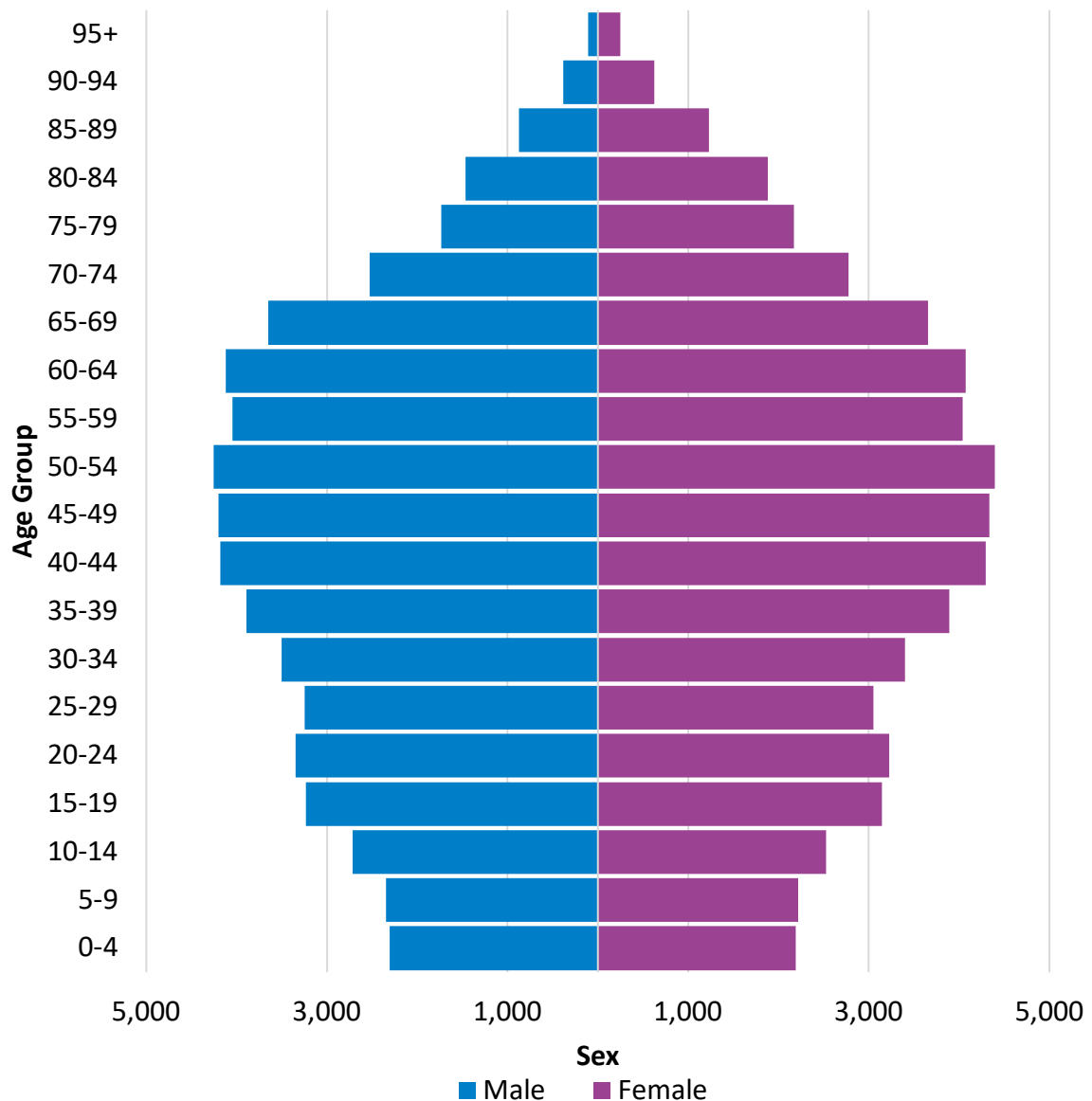
As the 2016 Jersey Health Profile (19) highlighted, it is therefore important to consider the accumulation of morbidities in these individuals as they age since health issues tend to

accumulate over time, and individuals who are 65 years or older typically experience poorer health outcomes compared to those who are younger (19).

## Population Projections

In 2032, the projected population is 113,498, an overall increase of 9%. The proportion of those aged 65 or over is projected to increase from around 16% in 2016 to 22% in 2032 (Figure 6).

Figure 6. Population Pyramid, as at 1 January 2032 Assuming 1,000 Net in Migration per Annum (20)



By 2036, the population is projected to increase by another 11 per cent, to 130,000, under the +1,000 net migration scenario. Around one in five of the population would be aged 65 or over. Having a larger population of those aged 65 or over has implications for the health service, especially if these individuals have accumulated morbidities over their lifetime.



## Projected Numbers of Population with Palliative Care

Given the prediction that Jersey's population will increase, with higher prevalence of those aged 65 or older and with a higher number of co-morbidities, it is not surprising that there is a projected 50% increase of people needing palliative care in 2026 and almost twice the number of people needing palliative care by 2036, compared to 2016. This represents an increase of around 400 patients as shown in Table 1.

Table 1. Projected Numbers of Males and Females with Palliative Care needs by Age in Jersey Between 2016 and 2036 (20)

	2016	2026	2036
<b>Projected population with Palliative Care Needs in Jersey</b>	400	600	800
<b>Projected percentage variation from 2016</b>		+50%	+100%

## Advance Care Plan

During a limited study of Gold Standards Framework (GSF) Red patients undertaken in 2021, it was found that an average of 53% of Hospice patients had had an Advance Care Plan discussion.

## Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

Data from Jersey General Hospital show that approximately 1,000 DNACPR forms are completed every year and 2022 has seen a total of 979. Furthermore, 11 GP practices had a total number of 553 DNACPR forms in 2021.

## Age-Standardised Mortality Rate in Jersey 2021

The age-standardised mortality rate is a measure of the overall mortality in a population, adjusted for differences in age distribution. The age-standardised mortality rate is expressed as the number of deaths per 100,000 people and is used to compare mortality rates between populations with different age and sex distributions.

Comparison with England shows that Jersey had a lower overall age-standardised mortality rate, and both lower male and female age-standardised mortality rate than all the English regions as seen in Table 2.

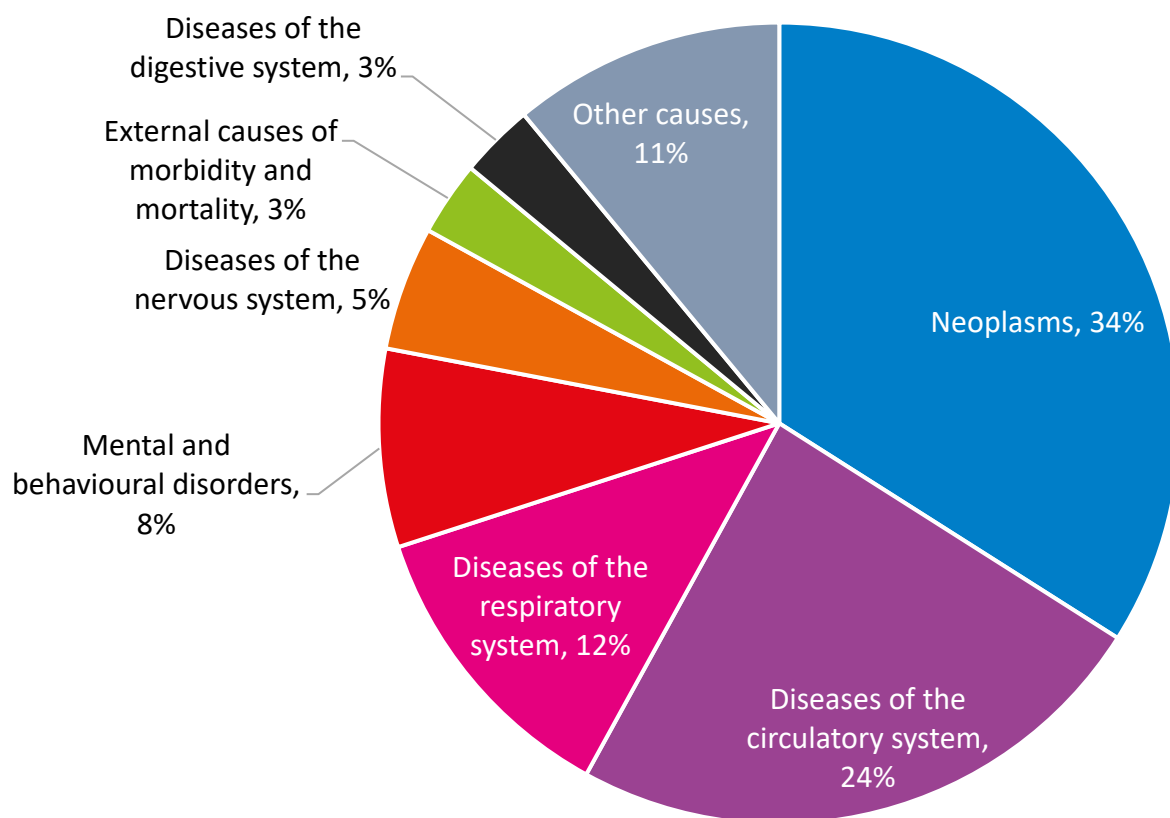
Table 2. Age-Standardised Mortality Rates per 100,000 Population, by Sex, for Jersey, England and UK Nations 2021 (21)

	Males	Females	Persons
<b>Jersey</b>	871	667	759
<b>England</b>	1,153	844	985
<b>Wales</b>	1,235	917	1,062
<b>Scotland</b>	1,375	1,024	1,181

## Cause of Death

Figure 7 details the main causes of death in Jersey in 2021 where neoplasms account for 34% of all deaths, making it the lead cause (18). Diseases of the circulatory system are responsible for 24% of deaths, while diseases of the respiratory system account for 12%. Mental health and behavioural disorders contribute to 8% of all deaths, and diseases of the nervous system are responsible for 5% of deaths. External causes of morbidity and mortality, such as accidents and injuries, represent 3% of deaths, while diseases of the digestive system account for another 3%. The remaining 11% of deaths are caused by other factors. This highlights the need for effective end of life care strategies that address the specific needs of individuals with different illnesses and conditions.

Figure 7. Main Causes of Death in Jersey in 2021 (18)



## Non-sudden Deaths

Considering Figure 7, the leading causes of death in Jersey are neoplasms (cancer), diseases of the circulatory system (heart disease and stroke), and diseases of the respiratory system (chronic obstructive pulmonary disease and pneumonia). These diseases, along with diseases of the nervous system, are all considered to be life-limiting, meaning that they can cause death within a relatively short period of time and therefore be considered as non-sudden deaths. Considering that most people living with this spectrum of diseases would require palliative and end of life care, 75% of the population of Jersey that died in 2021 would have benefitted from generalist or specialist palliative and end of life care. This estimation is in line with the numbers from England and Wales that also evaluate that 75% of people would benefit from palliative care as they approach the end of life (22).

## Preferred Place of Care and Preferred Place of Death

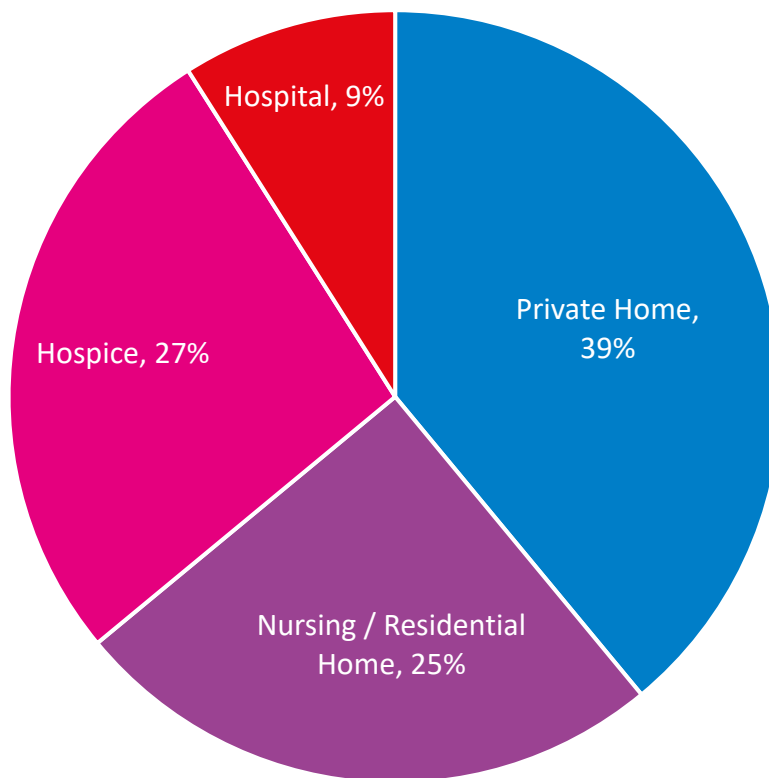
End of life care can be provided in a variety of settings depending on individual needs and preferences. However, it tends to be provided at home, in a care home, in a hospice or in hospital (4).

The preferred place of care is a person's choice of where they would like to receive end of life care and eventually die. The preferred place of care can have a significant impact on the person's quality of life and their sense of comfort and dignity. People who are dying often have strong preferences about where they would like to receive care.

People in Jersey who are under the Specialist Palliative Care Team, have their preferred place of care and preferred place of death recorded as part of their advance care plan. The preferred place of care was achieved for 79% of those.

In relation to the preferred place of death, the majority of Islanders under Specialist Palliative Care wish to die at home (39%), followed by hospice (27%) and nursing or residential home (25%) and only 9% expressed their desire to die in hospital.

*Figure 8. Preferred Place of Death of Patients in Jersey under the Specialist Palliative Care Team in 2021*

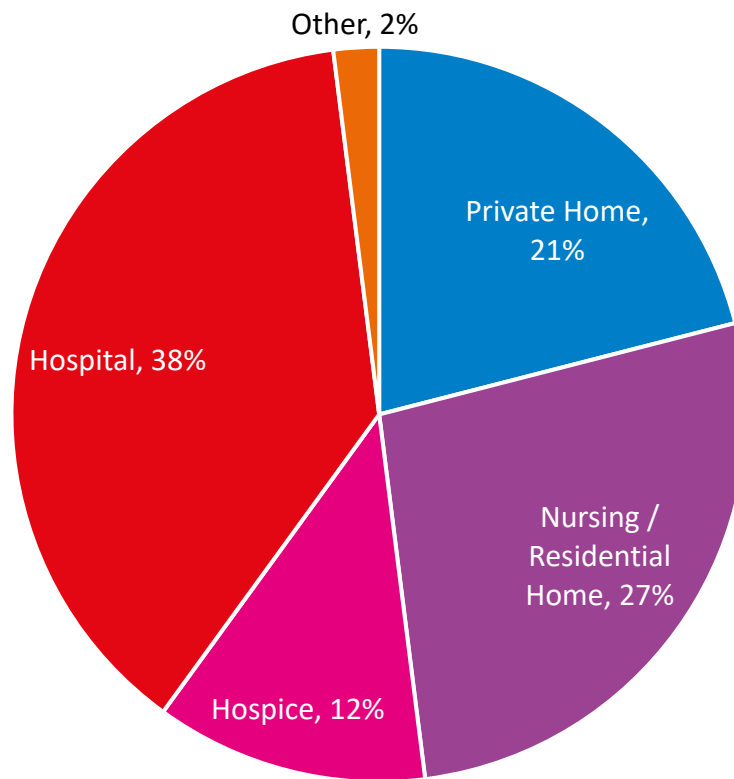


## Location of On-Island Deaths

Contrary to the above, and despite the need to take into account that these numbers include sudden deaths, in 2021 in Jersey, the highest proportion of deaths (38%) occurred in hospital followed by nursing and residential home (27%). One in five died in a private home and one in eight died in Jersey Hospice.

Nonetheless, the proportion of deaths of Jersey residents occurring on-island which took place in the hospital has decreased over recent years, from one in two (50%) to under two in five (38%).

Figure 9. Location of On-Island Deaths in Jersey 2021 (21)



In 2021 in Jersey, the highest proportion of deaths (38%) occurred in hospital; one in five died in a private home (21%); one in eight in Jersey Hospice (12%) and approximately one in four in a nursing home or a placement for residential or personal care (8%).

However, figures show a different scenario when people are under specialist palliative care in Jersey as shown in Figure 10. There is a small reduction of people dying in hospital (35%) and Nursing or Residential Homes (20%) and more people die in hospice (25%). There is no significant change for the proportion of people that die in their own private home.

Figure 10. Location of Deaths under Specialist Palliative Care in Jersey in 2021

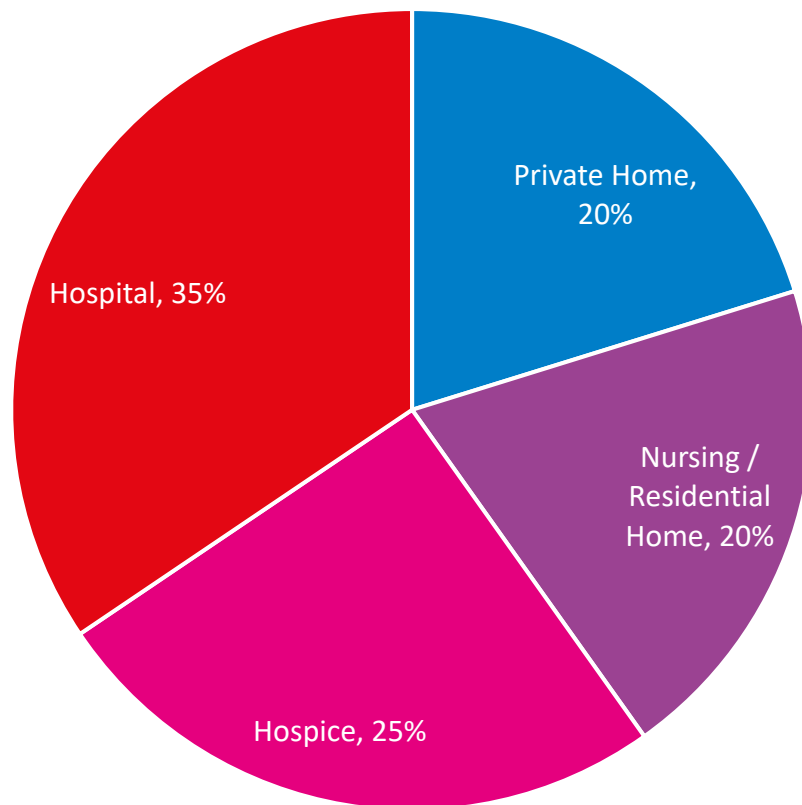
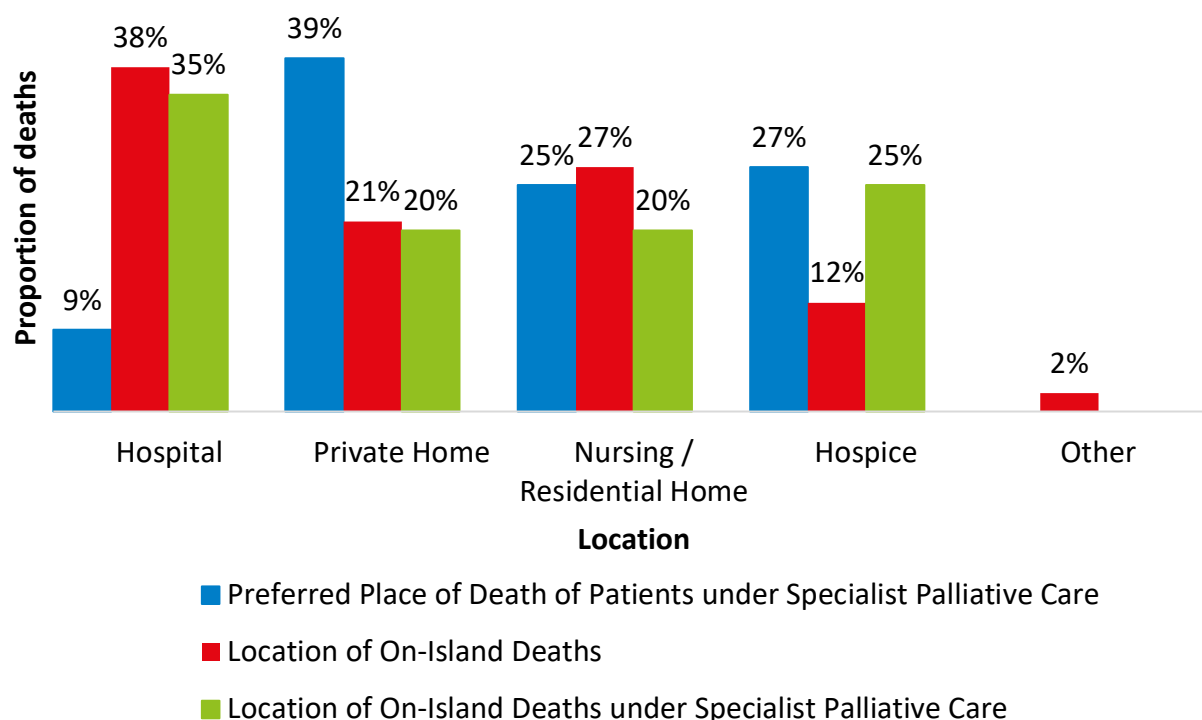


Figure 11 compares the three charts above about preferred place of death with the actual location of on-island deaths in Jersey whether the person was under specialist palliative care or not, broken down by location.

Figure 11. Comparison of Preferred Place of Death of Patients under Specialist Palliative Care with Location of On-Island Deaths and Location of On-Island Deaths under Specialist Palliative Care in 2021



As observable, there are significant differences between the preferred place of death and the actual location of on-island deaths in Jersey. For example, 39% of people would prefer to die in their own private home, yet only 21% of deaths in Jersey occur there. Hospice is the preferred place of death for 27% of people, but only 12% of deaths in Jersey occur in hospice. This suggests that more needs to be done to support people to die in their preferred location, particularly in their own homes or in Hospice.

In England (23), information shows that 44% of people die in hospital followed by 29% in private home, 20% in nursing or residential home and only 3% in hospice. However, it is important to note that the two locations have different healthcare systems and cultural attitudes towards end of life care, which may account for some of these differences.

Furthermore, when looking at the data for those under specialist palliative care, there are some differences compared to the overall figures. For example, a higher proportion of people die in hospice (25%) than in the general population, indicating that specialist palliative care services are better able to support people to die in their preferred location.

It is also worth noting that for people under specialist palliative care in Jersey, the preferred place of death is split almost equally between their private home (20%) and hospice (25%), rather than being predominantly in a hospice as might be expected. However, the actual location of on-island deaths for people under specialist palliative care in Jersey is still predominantly in hospitals (35%) with only 20% occurring in private homes and 20% in nursing or residential homes. This suggests that there may be need for increased support and resources for people under specialist palliative care to help them die in their preferred location, whether that be at home or in a hospice, even though 85% of those patients died in their preferred place in 2021.

## Referrals to Jersey Hospice Care

Jersey Hospice Care provides a variety of end of life services to Islanders. These include the Palliative Care Inpatient Unit, Specialist Palliative Care Team and Day Hospice and also Therapies and Bereavement & Emotional Support to the general Jersey population that have lost their loved one. Analysing the referrals to these services will provide insights into its utilisation and the trends in referrals over the years. Understanding these referral patterns is crucial for developing an effective end of life care strategy for the community.

Figure 12. Annual referrals to Jersey Hospice Care by Service Between 2016 and 2022

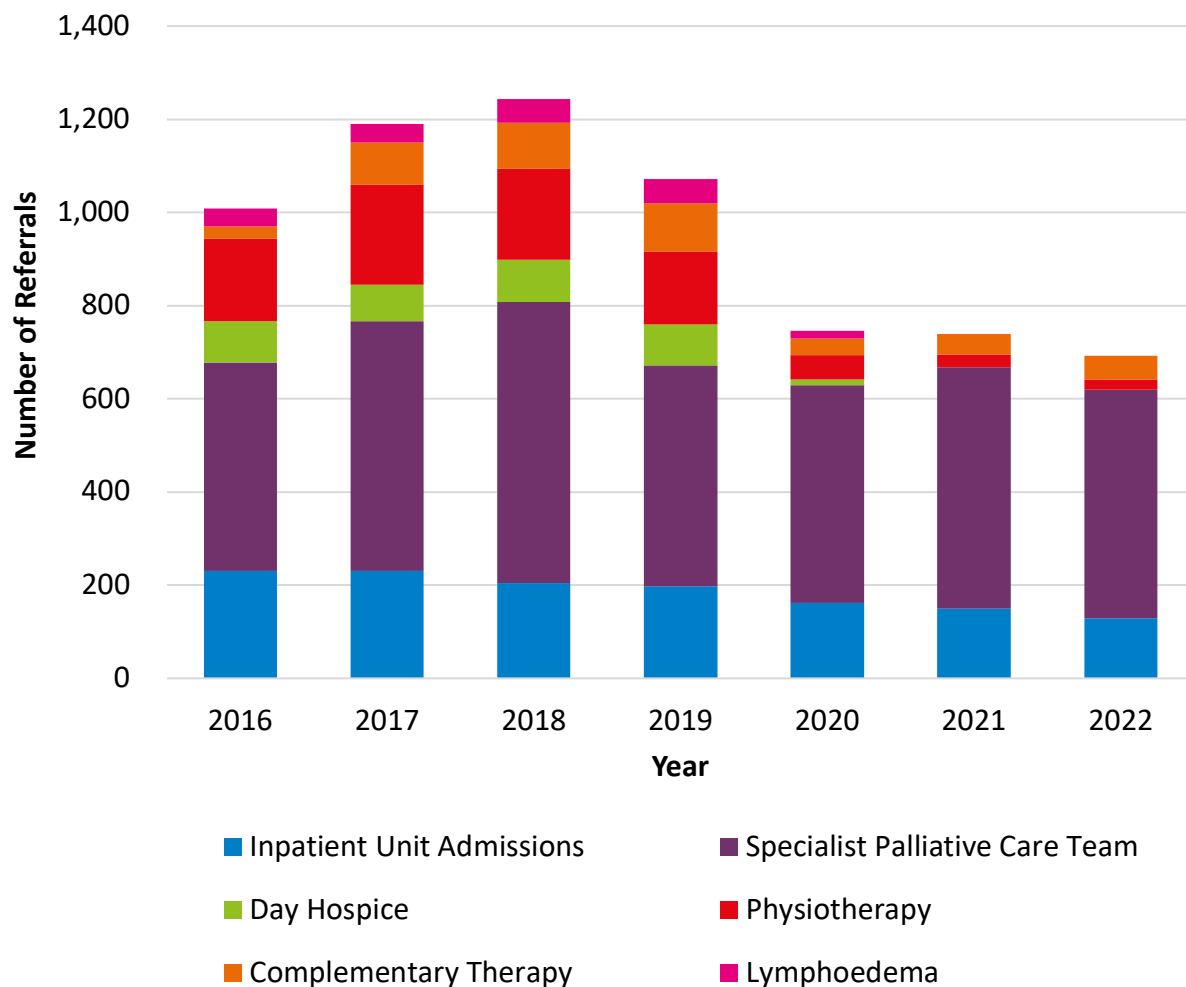
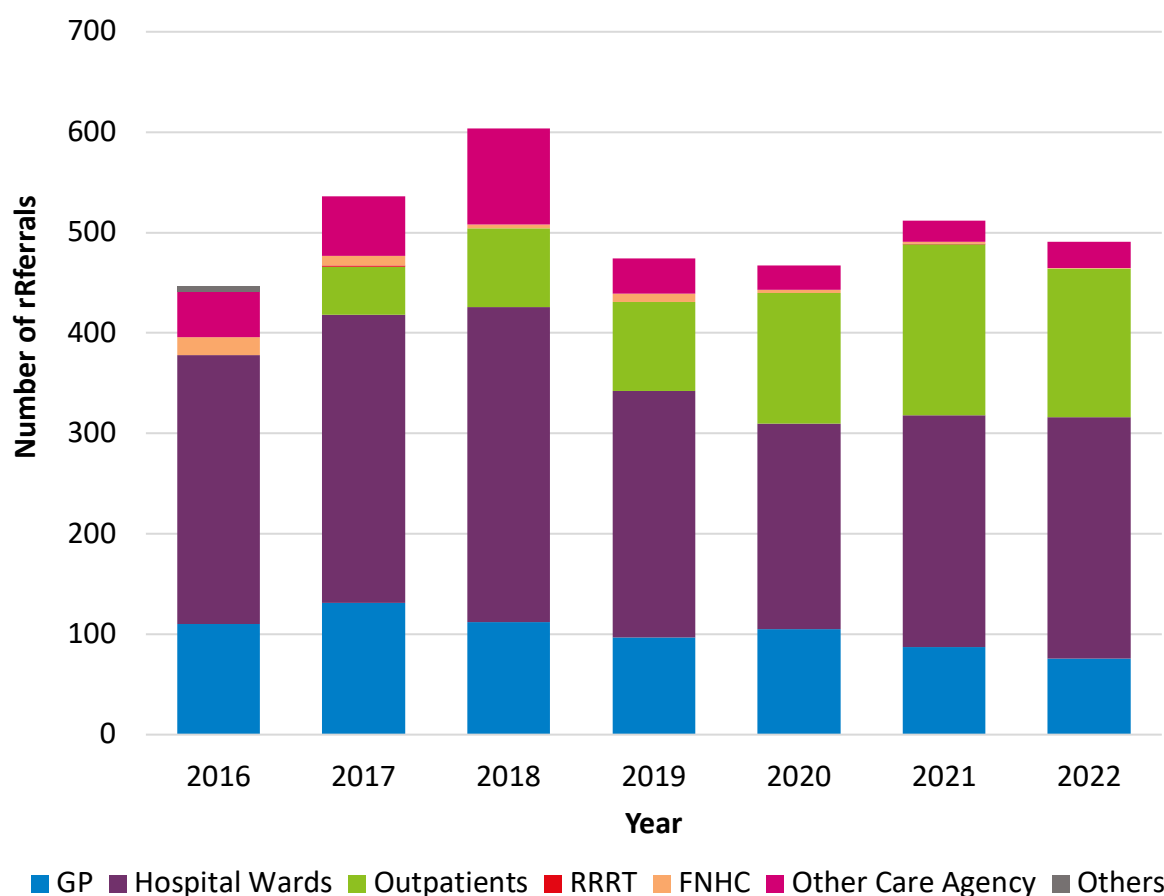


Figure 12 emphasises the significance of inpatient care and indispensable role of the Specialist Palliative Care Team in managing complex medical conditions and symptoms. It is important to note that the Bereavement and Emotional Support service wasn't available between 2016 and 2019 and both Day Hospice and Lymphoedema services were closed in 2021 at the outset of COVID.

Figure 13. Number and Origin of Referrals to SPC in Jersey from 2016 to 2022

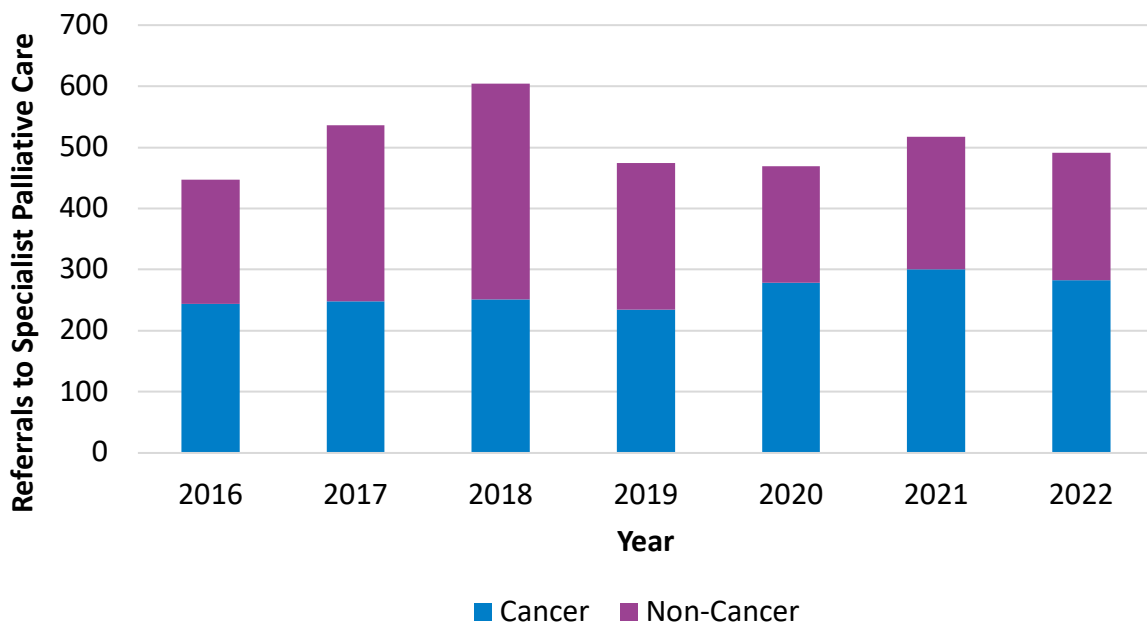


By understanding the source of the referrals to Specialist Palliative Care, providers can work with other healthcare professionals and the general public to ensure that people who need palliative care are able to access it. As Figure 13 shows, since 2016 most referrals come from hospital wards, GPs and outpatients. The outpatient referrals have gradually gained more emphasis over the years making it the second leading source from 2020 onwards. This might suggest there is a growing awareness and recognition of the importance of palliative and end of life care among healthcare professionals as well as an increasing prevalence of chronic illnesses.

Furthermore, by making the distinction between cancer and non-cancer patients referred to SPC (Figure 14), care providers can ensure that they are meeting the specific needs of both groups of patients and all patients that need palliative care are able to access it.



Figure 14. Annual Cancer and Non-Cancer Referrals to SPC in Jersey Between 2016 and 2022

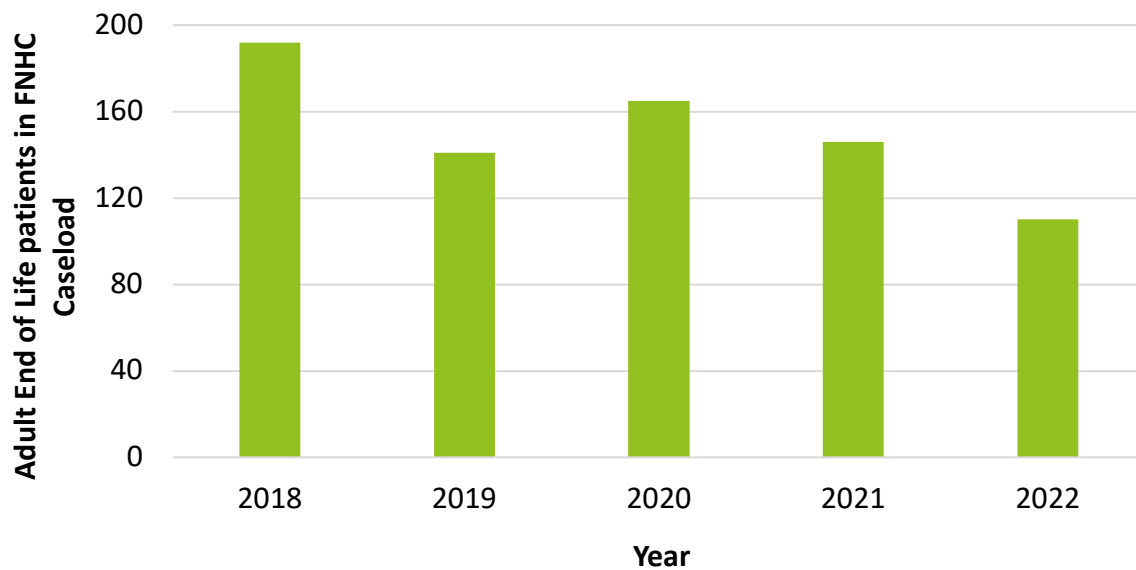


This data shows that until 2018, and before the COVID-19 pandemic, patients without cancer but with other life-limiting illnesses referrals were increasing, going down to levels similar to 2016 in 2020 and remained relatively static until last year. This highlights the importance of both cancer and non-cancer patients having access to specialist palliative care by reducing barriers, expanding the availability of palliative care services, improving communication and coordination of care and increasing awareness.

## Referrals to Family Nursing and Home Care for Palliative Care

Family Nursing and Home Care (FNHC) is an important provider of generalist palliative care in the community both through District Nurses and the Rapid Response and Reablement Team (RRRT). Figure 15 shows the adult caseload in FNHC for District Nurses and the Rapid Response and Reablement Team from 2018 to 2022 that had one of the palliative or end of life care codes added to their record.

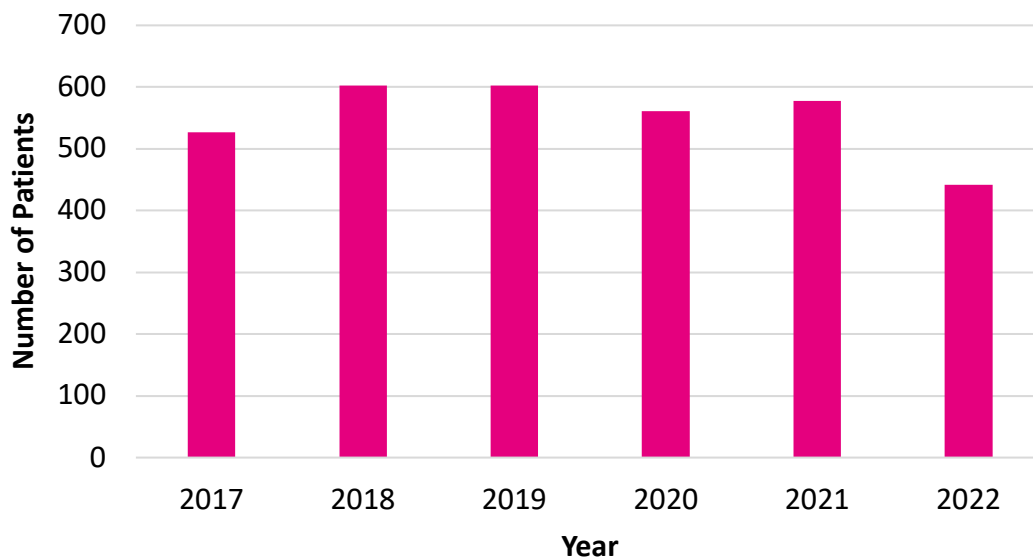
Figure 15. Adult EOLC Patients on FNHC Caseload from 2018 to 2022 (Source: FNHC)



## Patients on the GP register for Palliative Care

Placing the patient on a GP Palliative Care Register has been shown to lead to better coordinated care, by triggering specific support. In Jersey, monthly data on the number of patients on the palliative care register started to be extracted from EMIS in 2017 as part of the Jersey Quality Improvement Framework (JQIF). This data may exhibit some variability and potential limitations, requiring careful consideration for accurate interpretation. Nevertheless, Figure 16 shows the peak of patients in need of palliative care registered in EMIS each year.

Figure 16. Highest number of Patients Annually on the GP Palliative Care Register from 2017 to 2022 (Source: HCS Primary Care Governance)



## Care Homes and Care Agencies using Gold Standards Framework (GSF)

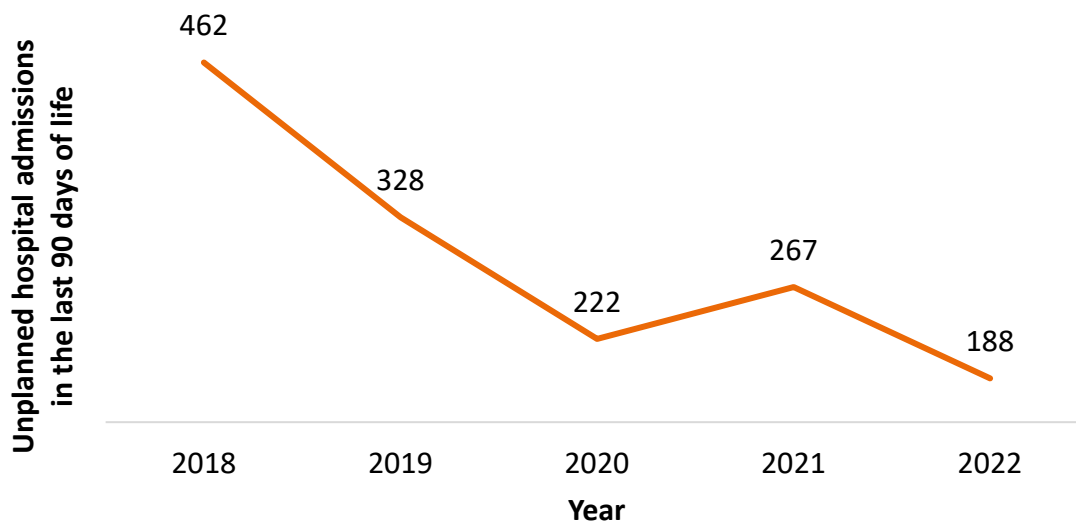
During the implementation phase of GSF, training was provided to staff members at 25 care homes and 13 care agencies.

## Unplanned Hospital Admissions in the Last 90 Days of Life

Unplanned hospital admissions are a good indicator of how well the health and social care system is serving people in the last year of their life. If our care is well-planned then emergency admissions and visits to emergency departments should be a last resort (24).

In Jersey, since 2018 we can clearly observe that the number of patients that die in the following 90 days after a hospital admission has been decreasing and the number of deaths in 2022 is approximately a third from 2018 (Figure 17).

Figure 17. Unplanned Hospital Admission on the Last 90 Days of Life (Source: HCS)



This trend shows that the services offered in Jersey to support a patient with palliative and end of life care needs is improving and likely to lead to better outcomes. Reasons for these positive trends could include the introduction of the GSF, advance care planning and personalised care records along with increased awareness of palliative and end of life care options among healthcare professionals and the general public.

Data from England show an opposite tendency from 2009 to 2018 where there was an increase of 33.9% of people with 3 or more emergency admissions in the 3 months before they died (25).

A recent development to improve access has been the introduction of out of hours community nursing which enables patients in the community to receive appropriate and timely care. Furthermore, support and partnership working with the Emergency Department, FNHC and the Specialist Palliative Care Team has resulted in faster access to palliative care assessment, hospital admissions prevention and rapid discharge from hospital when appropriate.

Whilst there is recognition that the Long Term Care Fund has been put in place to financially support patients' care in the community, there continues to be an issue around timely access to care funding at end of life.

# Addressing The Challenges of End of Life Care in Jersey

## Ambitions for End of Life Care

The development of this strategy has been informed by a range of national and international strategies and developments in palliative and end of life care as well as work that has been undertaken in Jersey. Our aims are framed by the Ambitions for End of Life Care (14), a national framework that provides evidence-based principles which are then translated into local action (Figure 18).

This strategy offers a framework which will support commissioners and providers in achieving the following outcomes as identified in the national evidence-based framework Ambitions for End of Life Care (14).

Figure 18. Ambitions for End of Life Care



## Community Awareness

Even though death and dying is a certainty we all face, it remains a difficult subject to discuss. This is particularly so due to the cultural sensitivities of island-life within Jersey and its demographic breakdown. It is apparent not just within our community but also across health professionals that there is often a reluctance to have difficult conversations.

Enabling and empowering people and health care professionals to make plans around their own end of life care and choices and to share these with family and loved ones will ensure they support those wishes when the time comes.

Each year Jersey Hospice Care (JHC) invests in a Dying Matters Campaign aligned to Hospice UK which looks to motivate the community to get involved in this crucial area that impacts on each and every one of us.

The concept of good end of life care is regularly promoted through social media channels thereby constantly keeping the discussion at the forefront of our community's mind.

Palliative and end of life care is everybody's business and by highlighting this to all stakeholders will not only increase their awareness but also increase recognition that we all have a social responsibility to help and be involved.

## **Holistic Support**

End of life care can be provided in a variety of settings depending on individual needs and preferences. However, it tends to be provided at home, in a care home, in a hospice or in hospital (4).

When an adult is approaching the end of their life, to provide the right support when it is needed, an initial holistic needs assessment should be carried out with the person and documented. This will enable consideration of all aspects of their wellbeing, spiritual, health and social care needs and ensure that their concerns and problems are identified so that support can be provided to address them (26).

A valuable tool to perform a holistic needs assessment is the Integrated Palliative Care Outcome Scale (IPOS) (27). The IPOS is a valuable tool for improving the quality of palliative care and is used to assess physical, psychological, social, and spiritual symptoms and concerns of people receiving palliative care. It is a brief tool that can be completed by patients, their family members, or healthcare providers.

## **Early Identification of Palliative Care**

Historically, it was assumed that palliative care would commence only once all treatment aimed at 'curing' people had finished. Now, it is well-accepted that there is benefit in providing palliative care in association with disease-modifying therapies that aim to prolong life. It is also recognised that many people with life-limiting illnesses are not 'cured' but continue to live with these illnesses for many years.

Healthcare providers can be supported to promptly identify adults who are likely to be near the end of life by using a systematic approach like the Gold Standards Framework Proactive Identification Guidance. Guidance can ensure that people can have their needs assessed and managed, and their carers and people important to them can also be offered support, offering the opportunity to make informed decisions about their care, make plans for their future and establish their preferences for how and where they would like to be cared for and die (28).

## **Gold Standards Framework**

In order to support a consistent approach to palliative and end of life care, Jersey embarked on a transformational journey with the introduction of a nationally accredited framework for the care of patients in their last years of life called "The Gold Standards Framework".

Jersey is now internationally recognised as the only jurisdiction to implement this framework across all its health boundaries, as cited by Prof Keri Thomas, the founder of the Gold Standards Framework (GSF) (29).

This three-year programme gave all health and social care professionals in Jersey General Hospital and across the community the opportunity to learn about how to identify patients in their last years of life, assess and plan their needs throughout their journey both before and following death, and those of the family and carers.

This journey also led to the development and introduction of key policies and documents to support throughout this period such as the island wide DNACPR Policy and record, advance care

plans (ACPs), anticipatory medications in the community for end of life care and the Personalised Care Record (PCR) to support the care of the patient in the last days of life.

## **Advance Care Planning**

“Advance Care Planning” is the term used to describe the conversation between people, their families and carers and those looking after them about their future wishes and priorities for care (30).

Advance Care Planning should happen after a holistic needs assessment to ensure that it fully takes into account all of the things that are important to the person. It is an ongoing process, so the advance care plan may change over time, based on the person's circumstances and wishes (28).

Over the last eight years a great deal of work has been undertaken across Jersey to support patients as individuals and share their advance care plans.

## **Preferred Place of Care**

End of life care can be provided in a variety of settings depending on individual needs and preferences. However, it tends to be provided at home, in a care home, in a hospice or in hospital (4).

The preferred place of care is a person's choice of where they would like to receive end of life care. The preferred place of care can have a significant impact on the person's quality of life and their sense of comfort and dignity. People who are dying often have strong preferences about where they would like to receive care.

## **Treatment Escalation Plan**

The Treatment Escalation Plan (TEP) Guideline (31) was approved in February 2023 by the Policy & Procedure Ratification Group (PPRG). The TEP helps healthcare professionals, patients and those close to the patient communicate about the patient care. It also helps to ensure that the patient receives the right level of treatment, regardless of the stage of illness that deterioration occurs. It promotes patient autonomy and shared decision-making between patients, relatives and clinicians ensuring patient preferences are considered.

“Treatment Escalation” is the process of increasing the level of care provided to a patient as their condition worsens up to a designated “ceiling of treatment” promoting a proactive, collaboration approach to end of life care planning and improving decision making in the event of a deterioration.

The TEP is reviewed regularly, at least weekly, and updated as needed. It is important to note that the TEP is only valid for the duration of the patient's current admission and documented in the notes.

## **Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)**

DNACPR means that if a person has a cardiac arrest or dies suddenly, there will be guidance on what action should or should not be taken by a healthcare professional. This includes not performing CPR on the person given the fact that this is not always successful and does not work for patients with advanced and irreversible illness. It is crucial therefore, that discussions

regarding DNACPR are introduced to increase the possibility of a peaceful and dignified death (32).

When done well, DNACPR decisions are an important aspect of advance care planning, and people should be fully involved in discussions about their care.

The Jersey Multi-agency Unified DNACPR 16 years and over Policy (33) was ratified in February 2021 with the following purposes:

- To ensure that a patient can have a dignified and peaceful death
- A dying patient may be at risk of a cardiac or respiratory arrest where CPR is not clinically appropriate
- The risks and uncertain outcome of CPR could outweigh any potential benefits
- A patient with capacity has expressed a clear wish to not be given CPR
- Good practice for healthcare professionals set out in GMC's end of life care guidance.

## **Personalised Care Record**

This care record is designed and in place to support best possible clinical care at the end of life in accordance with the person's needs and wishes. It is a multi-organisational document to be used by all professionals and is to be shared with the person, their family and carers. It is designed to record the communication and collaboration between the multi-professional team, individual adult patients and their family / carers.

The development of the "personalised care record for the last days of life" (PCR) incorporates all of the patients' wishes and preferences enabling health care professionals to do all they are able to meet these needs.

## **Anticipatory Medications in the Community**

Anticipatory prescribing means making sure that someone has access to medicines they will need if they develop distressing symptoms at home or in a care home. The medicines are prescribed in advance so that the person has access to them as soon as they need them (34).

Anticipatory medicines are often given towards the end of life. However, these are all medicines which can be used for symptom management and given at any point in someone's illness if they need them (34).

An individualised approach to anticipatory prescribing should ensure that the drugs prescribed are appropriate to the anticipated needs of the dying person, and prevent distressing hospital admissions and waste of medicines (35).

Jersey Hospice Care, Family Nursing & Home Care and General Practitioners have put in place an island-wide policy for "Just In Case" (anticipatory) medicine to support patients in the community in terms of their symptom management at end of life.

## **Integrated IT System**

The development of an Adult Specialist Palliative Care Team has brought together all the health and social care providers involved in the care of the patient to ensure that decisions around treatment plans and escalation are shared.

Shared advance care plans are central to coordinated palliative and end of life care, ensuring critical information is available during emergencies and that people are not required to repeat information each time to their care provider.

The introduction of the electronic patient record system (EMIS) within the community has seen patient records being shared between GPs, FNHC and JHC and improved communication between community organisations. However, the information contained within the digital patient record is not easily available to all other health care providers and community plans are not visible in hospital electronic patient records or Jersey Ambulance systems. At present practitioners are dependent on paper copies to ensure key information is available.

This enables care preferences, treatment recommendations and other advance care plans for patients approaching end of life to be shared. A list by GP surgeries of people under their care who may be approaching the end of life is held to facilitate this, the Palliative Care Register. GPs hold monthly GSF meetings in the community which JHC and FNHC attend to discuss patients on their palliative care registers.



# Services

The infographic below gives an indication of the services involved in supporting a patient and their family with palliative care needs.

Figure 19. Services Involved in Providing Palliative Care



## Coordination of Care

There is recognition that as people live longer and with the increasing prevalence of chronic conditions, it is essential that all care providers collaborate to meet the challenge of planning and delivering high quality palliative and end of life care services for increasing numbers of patients, families, and carers across Jersey.

Strong relationships have been built across the care sectors including statutory, community, Primary Care and third sector who are all committed to build on those achievements and continue to improve care at a time when Islanders are at their most vulnerable. We all want to ensure that people are encouraged to have conversations about what matters to them, to reduce unnecessary hospital admissions or reduce the length of stay and to ensure that all those who work with people nearing the end of their lives feel confident and competent in delivering care.

We want to make sure our services are accessible to all and that care is coordinated; the right care is delivered by the right person at the right time in the right place.

Community services have been developed across a wide variety of providers to support many people through day and outpatient services ensuring there is the availability for physical rehabilitation, reablement, emotional support, medical support and educational support. They have developed close working relationships with the respiratory and cardiac teams to ensure there is seamless support for all these patients.

FNHC continue to deliver home-based palliative and end of life care to support patients and their families and carers in the place they call home.

A standard operating procedure has been developed to avoid the duplication of health care professionals in the patients' home and is in place to ensure the patient is clear on which team is leading on their care. This is particularly relevant and pertinent as patients approach their last days of life.

Alongside the Personalised Care Record, further work has been done to develop a rapid discharge pathway to ensure patients who do not want to be in hospital can be discharged with all the required support efficiently.

Whilst Jersey is currently in the fortunate position of having both generalist and specialist palliative care services, there is more work to be done to build these services, ensuring all are aware of their scope of practice avoiding duplication, bridging gaps and developing the workforce.

# Workforce

## Specialist Palliative Care

Significant progress has been made in Jersey since the pivotal decision to develop an adult Specialist Palliative Care Team was made by Jersey Hospice Care in 2014 following the publication of the 2012 White Paper, “Caring for each other, caring for ourselves”.

The formation of this team saw, for the first time in Jersey, a team working across all health boundaries to provide consistent, seamless care to patients with palliative care needs and their families.

This team has brought together all the health and social care providers involved in the care of the patient to ensure that decisions around treatment plans and escalation are shared. The introduction of the electronic patient record system (EMIS) within the community has seen patient records being shared between GPs, FNHC and JHC.

As the services developed, there has been further investment in the Specialist Palliative Care Team to support the medical model which has culminated in this service becoming a consultant-led service, with on call consultant advice 24 hours per day, 7 days per week.

Specialist Palliative Care Services can be accessed by any care professional, family or patient. Patients will be triaged within 24 hours and signposted to the most appropriate service at that point. This referral process does not discriminate against any group.

## Education

Education has been key to the success of palliative and end of life care to date with programmes available around symptom management, communication skills, end of life care, syringe pump training as well as several post graduate courses in palliative care. This is evidenced through the reduction in admissions to Jersey General Hospital and the increasing numbers of patients achieving their Preferred Place of Death. The continuation of this will be crucial to the success of this strategy as our workforce changes and develops. The need for palliative care education that is delivered in an integrated, collaborative and cost-effective way is well documented (36).

Over the last five years there has been an increased focus on palliative and end of life education and training following the implementation of the GSF Programme. The commencement of an Education Team at JHC who have devised an education strategy to address the learning needs across the hospice and beyond to support the competency at generalist and specialist levels. Other courses are delivered by other providers including Qualifications and Credit Framework (QCF) qualification. The courses provided by JHC available to all stakeholders across the Island are as follows:

*Table 3. Available Education Provided by JHC*

Course Title
Advanced Care Planning
Communication Skills: Advanced
Communication Skills: Foundation
Communication Skills: Intermediate
Enhancing End of Life Care: Skills Based Training for RGNs

<b>Course Title</b>
<b>Post-Graduate European Certificate in Essential Palliative Care</b>
<b>Opening the Spiritual Gate</b>
<b>Palliative and End of Life Care Essential Training for RGNs and HCAs</b>
<b>Principles of Palliative and End of Life Care: Foundation</b>
<b>Sexuality, Body Image and Dignity</b>
<b>Understanding and Managing Grief and Loss</b>

There are also various study days that are offered by HCS, FNHC and JHC such as syringe pump training, Personalised Care Record training for care in the last days of life, Anticipatory Medications and Drug Calculations. Other study days are also available.

To support health and care professionals, course programmes have been established in advanced communication skills, advance care planning, symptom management, last days of life care, syringe pump training, spirituality training to name a few.

Within JHC, there have also been further developments in terms of holding reflective practice sessions and formal Mortality and Morbidity meetings to review practice, learn from experience and improve outcomes for patients and their families.

Nevertheless, the pandemic escalated the demand and brought the issue of death and dying to the forefront of the minds of professionals and the public alongside clearly identified training gaps, particularly around symptom management, breaking bad news and Advance Care Planning. Global and national reports (37), (38) demonstrate the need to upskill the existing healthcare workforce as it becomes increasingly apparent that caring for people with life limiting diseases is the responsibility of all.

# Governance Arrangements

This strategy is consistent with the aims of the Government of Jersey (GoJ) Strategic Plan (39) and the Health and Community Services Business Plan (40). The emphasis is now on increased collaboration and shared accountability. This commitment has led to the formation of the Jersey End of Life Care Partnership Group and the development of this Palliative and End of Life Care Strategy for Jersey.

## Jersey End of Life Care Partnership Group (EoLCP)

The EoLCP was formed in 2021 to work with stakeholders with a vision of ensuring all Islanders with a life limiting illness have access and informed choice to the right care, by the right person, at the right time and in the right place.

The EoLCP has been set up to involve stakeholders across services including GPs, the prison, mental health, community and hospital representation. This group is well placed to identify gaps in service provision and ensure they are a priority. It also enables stakeholders to gain a wider awareness of the various teams involved in the care of an individual patient.

It is imperative that all stakeholder groups position themselves to be able to ensure they can provide the requisite end of life services in the community. Its membership is shown in Table 4 and the stakeholder engagement event discussion summary can be seen in Appendix 1.

*Table 4. Jersey End of Life Care Partnership Group Membership*

Member Organisation	Representation
Care Agencies	Chairperson, Jersey Care Federation
Dementia Jersey	Lead Dementia Adviser and Counsellor
Family Nursing & Home Care	Operational Lead Adult Services
Funeral Directors	Representative, Pitcher & Le Quesne
	Representative, de Gruchy Funeral Services
	Representative, Maillard Funeral Services
Government of Jersey	Director of Local Services (CLS)
	Education Lead (HCS)
	General Manager for Medical Services (HCS)
	Head of Prison Healthcare (JPS)
	Improvement and Innovation Lead (HCS)
	Medical Director for Primary Care (HCS)
Jersey Care College	Senior Ambulance Officer (JAS)
	Senior Change Manager (HCS)
Jersey Care Commission	Education Lead
Jersey Hospice Care	Senior Regulation Officer
	Chief Executive
	Director of Clinical Strategy
	Director of Palliative Care Services
Les Amis	Palliative Medicine Consultant
	Chief Executive
MacMillan Cancer Support Jersey	Chief Clinical Officer
Primary Care Board	Representative GP

## Working Group

A working group was established to undertake the development of the Strategy with the support of Government of Jersey Commissioning, Public Health and Improvement & Innovation as shown in Table 5.

*Table 5. Working Group Membership*

Member	Organisation
Director of Palliative Care Services	Jersey Hospice Care
Director of Clinical Strategy	
Executive Assistant	
Consultant in Public Health	Government of Jersey
Senior Change Manager (HCS Commissioning)	
Change Manager (HCS Improvement & Innovation)	

# Stakeholder Engagement

## Patients, Families and Carers

The following feedback demonstrates a family's experience of services across the system when approaching end of life.

*"Following diagnosis of Stage 4 duodenal cancer, our mother attempted several cycles of chemotherapy. Unfortunately, she was plagued with reoccurring sepsis infections and other complications. There were countless visits to hospital and the Emergency Department, overnight stays in the AAU and several surgical procedures over the first few months following her diagnosis. It was a rollercoaster which she faced with great courage and bravery. Ultimately, however, the treatment was unsuccessful, the cancer was too strong, and as such, we were introduced to your team at the Hospice for palliative care."*

*"Mum spent a week as an inpatient at Hospice. The staff and volunteers we met there were, without exception, kind, helpful and knowledgeable. The facilities you have are wonderful and I remember Mum saying that it was like arriving at a 5 star hotel after her weeks at the hospital! I also remember feeling a sense of calmness and being hugely reassured and comforted by your staff, and by the superb level of care they gave her. Above all, they seemed to have so much time to help Mum. I am sure they were terribly busy but you never got that impression. We are hugely grateful to all of the staff and the volunteers at Clarkson House for their care over that week."*

*"Mum decided that her preference was to go home and to remain at home for the duration of her illness. We were introduced to our Community Palliative Care Nurse, and she very quickly became an absolutely vital part of Mum's care and the most important support to my brother and I during what was a very difficult few months."*

*"She was well organised and we were impressed with the sharing of information between her, Family Nursing and the GP. She made sure we knew who to call, when and what for and always informed us if she was going to be away from work."*

*"There were times, particularly towards the end, when my brother and I felt overwhelmed by Mum's illness and genuinely concerned that we couldn't provide her with the care at home that she needed. Our nurse's reassurance, expertise and daily "summaries" were particularly vital at this time. We as a family cannot thank her enough for her help and for literally carrying us through those last weeks of Mum's life."*

*"When Mum died we were heartbroken to have lost her but comforted that we were able to fulfil her wish to die at home. It was not easy but everyone involved in the community made it possible. We are so very grateful to them all."*

Patients and carers were invited to independent confidential focus groups to discuss key themes and ensure the overarching stakeholder engagement event was meeting the needs of those who use the services.

They were asked two key questions:

1. What matters most to people in their last year of life?
2. What does excellence look like?

The feedback from these questions was central to the planning of the stakeholder event and it can be found in Table 6 and Table 7.

*Table 6. Patient and Carer Feedback to Question 1*

<b>What matters most to people in their last year of life?</b>
<p>All agreed that this was very dependent on what stage of diagnosis, treatment and trajectory of illness someone was in. However, the key points that came up from the discussion were:</p> <ul style="list-style-type: none"><li>• A need for symptom control (particularly pain) if nearing the end of life</li><li>• A multi-disciplinary connected approach to care for the individual AND the family</li><li>• Clear and honest conversation with the individual and the family – checking with them what would be helpful to know including what information would help in the last days of life... and keep checking</li><li>• What is important to somebody during their life is likely to still be important towards the end – this will be different for everybody so needs focused conversations to find this out and individualised care</li><li>• Open mindedness to different approaches</li><li>• Quality of time with those around them – who is bringing them peace or comfort in some way</li><li>• Spiritual needs in the broadest sense (could be religion, nature, water, music)</li><li>• A feeling of control of what is happening</li><li>• A realistic choice about where the individual can end their life in dignity and pain free</li><li>• Relationships</li></ul>



Table 7. Patient and Carer Feedback to Question 2

### What does excellence look like? (Including gaps also and potential improvement)

- A co-ordinated multi-disciplinary individualised 24 hour approach that is 'effortless' for the individual and the family to access regardless of their circumstances and can be continuously renegotiated depending on the needs of the individual
- A well-trained workforce across all settings where palliative and end of life care is provided to ensure that the communication, symptom management, privacy and care is consistent wherever the individual receives care to ensure that the individual is able to die with dignity in a place of their choice
- Wrap around care to encompass the individual and family which includes clear and sensitive communication and information provision at all stages of their choice
- Options: which may include information about and option for Assisted Dying at a time and place of patient's choosing if approved in Jersey
- If an individual chooses to die at home, there is a need for a specialist support and information to support this
- Increased island-wide bereavement support should be available when it is required – structured approach to offering this in the months following a loss even if it has previously not been taken up
- More public awareness and acceptability of discussing the process of dying in families and in employment so that wishes are known and support can be offered (e.g., Advance Care Planning and employment support for sick leave or bereavement leave)

Additional feedback from an attendee has been highlighted:

*"I was very surprised to learn that Hospice only have 12 beds. It was great to hear first-hand of people's experiences with the level of support that is currently available. As there are such limited spaces at Hospice it must mean that patients end up dying at home with little specialised support after 11pm, or in hospital where we don't have a dedicated Palliative Care team or Palliative Care Ward. Patients and their families want their passing to be dignified, no one should have to remember that the last cherished moments with a loved one were behind Hospital curtains on a busy ward with absolutely no privacy. The few people I have spoken to that this has happened to were quite traumatised by their experience because of the lack of privacy at such an awful time."*

*"When my father died at 55 years old my mother just got a phone call. He had MS and his condition was deteriorating and she left the ward with specific instructions to ring if he worsened. The ward rang at 8.00am and informed her over the phone that he had died in his sleep and just contact your undertaker to collect his belongings. This was a few years ago, but it stuck in my mind that it was so insensitive and heartbreaking to hear that bombshell on the phone. I know that has been the case for many people due to COVID, but not then."*

## Professionals

In February 2022 we held the End of Life Care Engagement Event with key stakeholders from the various organisations and sectors represented (Appendix 1). In the first part of the session and with the support of a facilitator, they were asked to identify the enablers and "stones in the shoes" in providing palliative and end of life care in Jersey (Table 8).

Table 8. End of Life Care Engagement Event - Task 1

Task 1 Identifying our enablers and “stones in the shoes” (combined feedback)	
Enablers	Stones in the shoes
Compassionate island	Difficulties getting off island
Effective signposting / coordination of care	Financial issues
Excellent end of life care	Inconsistent / inequitable access
Good civil society and partnership working	Limited data sharing (patient care record)
Multi-agency / partnership cooperation	Service issues – poor out of hours provision / limited equipment in the community / repetition / inconsistencies / transition amongst services / single point of access
Resilient staffing	Staffing issues – recruitment / retention / immigration / upskilling / limited volunteer collaboration

The second part of the End of Life Care Engagement Event was focused on four key questions. The attendees were divided in four groups that with the support of a facilitator were guided through a discussion on one of the key tasks and the essential themes that emerged are shown in Table 9.

Table 9. End of Life Care Engagement Event - Task 2

Task 2	Separate Themes
<b>Group 1: How will we know we are getting it right?</b>	
Need island-wide approach – island-wide strategy / policy; shared pathways; centralise data with information sharing	
Aging demographic – equitable access for all	
Competent workforce – succession planning and recruitment	
Inter-charity / organisation communication and knowledge of service / roles	
Risk management	
<b>Group 2: Integrated care pathways</b>	
Service capacity is a key limiting step	
Need for Care Coordinator – assigned for pathway signpost / guide patient and act of information source for HCPs	
Delays create anger / worsening outcomes – avoid MDT fishing exercises / bouncing between services	
No central data hub; Ambulance lacks information when attending; disseminating information is limited and challenging	
Access to care issues verge on rationing – LTC can assist / have flexibility but need to be signposted early	
<b>Group 3: Developing the workforce</b>	

COVID difficulties – only e-learning continued but face-to-face preferable due to subject matter

Recruitment / retention challenges, review pay for upskilling, undertake employment survey, promote palliative care nurse role (day in life, opportunities, shadowing), collective recruitment across the sector

JHC / HCS liaison very effective – further linkages / blended learning needed to join up / reduce duplication – Project ECHO, open up Learning Club, masterclasses, use of retail outlets for training

Gold / silver / bronze palliative care nurse pathway established – need university link to continue (key gap)

Expand training availability within HCS and community partners

Online programmes are effective but access limited due to cost

#### Group 4: Digital technology and innovation

Jersey has the fastest tech in world but lacks innovation – vision shared but devices not coming together

New developments – Telecare / Telehealth replacing CAS alarm; EPR by year end; virtual consultations; COVID was a catalyst

Issues with accessing resources and data – organisations have to start from scratch on referral

Concerns re data sharing – but lack of sharing compromises patient safety – public view should be gained to balance perfection vs progress, sharing vs hiding; public expectation is that organisations talk / share more

Central hub would assist access and remove duplication

Demographics risk – aging population

The stakeholder engagement event discussion summary can be seen in Appendix 1.

#### Quotations

Below are the selected quotations that represent several of the themes on Table 9. The quotations are verbatim, although in some instances they do not represent entire contributions in the interests of brevity and anonymity.

*“We’re a compassionate island. We’ve got a huge percentage of Islanders who want to step up and volunteer to help”*

*“They go round the houses, there’s a delay and as a consequence there can be quite a lot of anger, patients can be really frustrated and rightly so”*

*“We’ve got the fastest connectivity in Western Europe, we’re not maximising what’s available. There’s all sorts of technology that we could use to support people in their homes”*

*“There’s lots of good partnership working, we’ve got some really good organisations, fantastically talented people who are very dedicated”*

*“It is so important that we work in partnership, government with all other providers, to serve Islanders and give them the very best care”*


*“What makes a difference in Jersey is the charitable sector, we are so blessed. So many people wanting to contribute”*

# Outcomes and Actions

**Outcome 1 - People in Jersey who need palliative and / or end of life care will be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decision**

The key actions for achievement of Outcome 1 are:


1. To continue the development of GSF across Health Care Providers (HCPs) in the community and hospital in Jersey.
2. To develop a central, integrated IT system (for example EPaCCS in the UK (36)) across health and care professionals to facilitate the sharing of Advance Care Plans and GSF recording and collate outcome performance data.



## **Outcome 2 – People in Jersey who need palliative and / or end of life care will have their needs and conditions recognised quickly and be given fair access to services regardless of their background and characteristics**

The key actions for achievement of Outcome 2 are:


1. To ensure all interested parties who represent patients requiring palliative care have a voice on the EoLCP.
2. To design and build a robust 24 / 7 model of palliative care that is accessible to, and meets the needs of, patients and families at a generalist and specialist level.
3. To educate and develop the workforce and volunteers, and increase public awareness, in relation to palliative care.
4. To consider access to emergency funding for end of life care and to responsive care in the community at end of life.
5. To collate public health data across all health care settings using a collaborative approach to IT systems and robust analysis with benchmarking.



## **Outcome 3 – People in Jersey who need palliative and / or end of life care will be supported to live well as long as possible taking account of their expressed wishes and maximising their comfort and wellbeing**

The key actions for achievement of Outcome 3 are:

1. To develop standard operating procedures across all partnership providers.
2. To improve and build on the Jersey community services and initiatives as we face an ageing demographic and therefore an increased need for services.
3. To undertake work to differentiate between specialist and generalist provision to ensure the most cost-effective model is designed with patient preferences built in.
4. To ensure hospital referrals to community services are completed in a timely manner.
5. To improve communication across all areas of the health system.
6. To develop a transfer of care process.
7. To develop an educational focus for GPs and care homes around advance care planning and end of life care to seek to prevent avoidable admission to hospital.




## **Outcome 4 – People in Jersey who need palliative and / or end of life care will receive care that is well coordinated**

The key actions for achievement of Outcome 4 are:

1. To ensure the right information is available at the right time to minimise duplication through the development of an integrated IT system across the whole health system in Jersey.
2. To expand and realign hospital discharge processes to present the opportunity to enable more people to transfer from inpatient settings to their preferred place of care with the care they require to support them as appropriate.
3. To ensure people receive the right care, at the right time, in the place consistent with their wishes and preferences avoiding the disruption of hospital admissions when they do not add value to care.
4. To develop a single point of access for referrals to help ensure patients have timely access to the most appropriate care in the most efficient way possible.
5. To develop an agreed pathway for access to anticipatory medicines and equipment out of hours.
6. To address care needs to support people to remain in their own home.





**Outcome 5 - People in Jersey who need palliative and/or end of life care will have their care provided by people who are well trained to do so and are receiving ongoing training to maintain their skills and competencies**

The key actions for achievement of Outcome 5 are:

1. To undertake a needs analysis of the health and care workforce across Jersey in terms of their knowledge and competence in palliative and end of life care.
2. To develop an island wide training plan and competency framework to support the entire workforce.
3. To develop consistent measurable standards and robust evaluation methods for quality education and training and ensure it is delivered by skilled and qualified providers.
4. To ensure all key staff are able, encouraged and supported to attend training programmes around core principles of palliative and end of life care.
5. To adopt a system-wide approach to the provision of palliative and end of life education. This should include all training providers across the island.
6. To extend membership of the Morbidity and Mortality Meetings to encourage island-wide attendance

## **Outcome 6 - People in Jersey who need palliative and/or end of life care will be part of communities that talk about death and dying and that are ready, willing and able to provide the support needed**

The key actions for achievement of Outcome 6 are:

1. To ensure everybody's voice is heard through this engagement including the most vulnerable members of our community. This should pay particular attention to those groups within the demographics of Jersey which will see an increase in need for palliative and end of life care such as our frail, elderly population and those suffering with dementia and their families.
2. To develop a proactive approach and plan to galvanise support and spread the message across our communities. Working together we can improve the quality and continuity of the care experience.
3. To develop a 'Carer Strategy' to ensure we address and meet the needs of these members of our community. This strategy needs to be in line with the island-wide approach.
4. To undertake a care assessment in order to establish need. NB: Carers Jersey have already written an island-wide strategy which needs to be considered for adoption (41).
5. To develop a strategic approach to utilise the volunteer workforce effectively.
6. To combine all Third Sector elements to develop a robust, multifaceted model of care delivery which is supported by members of our community who are then reinforcing the need, spreading the message and having the conversations.

# Key Enablers

In order to achieve the outcomes outlined, we have identified four essential enablers:

- The use of technology to inform, understand and improve care
- Education and workforce
- Public and patient engagement
- Co-design of island-wide palliative care pathway

## The use of technology to inform, understand and improve care

Taking maximum advantage of digital solutions and innovations will be central to the delivery of this strategy.

The emerging digital landscape offers real opportunities for:

- Direct clinical care
- Coordination of services
- Communication
- Patient empowerment and self-management
- Quality improvement
- Understanding the population needs and impact of services
- Education and research

Whilst improvements have been achieved through the implementation of EMIS across certain community providers, there is a real opportunity to extend this to ensure there is shared access across all health care providers. The benefit of an electronic palliative care record for patients would incorporate advance care planning tools, DNACPR record, key conversations and treatment escalation plans to name but a few.

This would also provide the platform to interrogate the data thereby giving us quantitative measures for the key performance indicators required to measure the success of the overall strategy.

Work is already underway to ensure that we maximise on digital solutions through the upgrade of the telecare system on the Island that will support people in the community. For people on the end of life pathway, the focus of telecare is to deliver comfort for patients or reduce anxiety for the care giver by offering an additional layer of support. Patients can receive care with minimal disruption to their daily lives by providing individualised interventions and care from the comfort of their own home, improving self-management and care plan adherence.

## Education and Workforce

Our health and social care workforce is our most important resource. An extensive range of staff roles with a wide variety of skills and specialisms are involved in caring for dying people. We want to ensure they have the skills, confidence and competence they need to deliver holistic, compassionate care for dying people and their families, regardless of where they are cared for.

At the same time, our workforce is also one of our biggest challenges. Difficulty in recruiting and retaining health care staff and maintaining stable teams with manageable workloads is a local and national problem that poses a real threat to the delivery and quality of care.

Lack of care support in Jersey is a very real issue that needs to be addressed urgently to support people to die at home.

There needs to be a strategic island-wide approach to address this issue. However, there is an opportunity within this strategy to make employment within this area an attractive career with a clear development pathway.

This strategy presents the opportunity to work together to co-design a model of care that requires all stakeholders to work collaboratively to meet the needs of patients and their families. This therefore gives us the opportunity to think about joint posts working across boundaries as well as maximising the utilisation of volunteers to support with the low-level support/befriending of patients and families. Consideration by Third Sector organisations of the pooling of their volunteer resources could make a tangible difference to capacity.

It is imperative that strategic decisions around education and workforce are in line with the island-wide strategy.

## **Public and Patient Engagement**

There is absolute recognition that before we commence any of the workstreams we need to ensure we have set up public and patient engagement workshops to test the strategy and gain consensus to move forward.

By undertaking these initial workshops, we can co-opt lay members onto the other working groups to ensure there is real co-design embedded within this strategy.

This is crucial given we recognise that *“palliative and end of life care is everyone’s business!”*

## **Co-design of Island wide palliative care pathway**

There have been vast improvements in terms of joint working across the system but there is clearly further work to be done.

We need to identify all the key services required within the palliative care pathway recognising that there is a wealth of stakeholders across the community.

It is essential that there is full engagement in this workstream to ensure we design a robust, collaborative, cost effective 24 hour per day, 7 days per week model which meets the needs of patients and their families whilst avoiding duplication.

Patient and public engagement in this workstream will enable professionals to hear about the gaps in current provision and the impact of those gaps. It will then ensure we then address these gaps thereby improving patient experience going forward.

Design of this pathway will also give us the opportunity to identify key performance indicators for each part of the service involved. The draft pathway (Appendix 2) is to be discussed, amended and ratified initially by the EoLCP prior to ratification.

# Success Criteria

Prior to measurement of the success criteria, it is imperative Jersey benchmarks itself against the National Audit of Care at End of Life (England and Wales) (42). This audit is aligned not only with national guidance including One Chance to get it Right, and NICE quality standards and guidance but also the Ambitions framework which this strategy is based around. This audit will support with further success criteria particularly aligned to carers and their support following a bereavement. These further success criteria would be agreed and ratified by the EoLCP.

In order to ensure that the actions we are taking are helping to improve patient and family experience and deliver the six outcomes set out in this document, we will initially track our progress against the following metrics:

1. 75% of patients with an expected death will have documented advance care planning which includes a treatment escalation plan and DNACPR record.
2. 100% of health and care professionals working across community, hospital and Hospice will have access to educational sessions around palliative care including GSF and end of life care on a monthly basis.
3. More patients will receive effective care, treatment and symptom control in the community. This will be demonstrated by ensuring that, for those patients who have a PPC within the community and an expected death, less than 30% experience an unplanned hospital admission in the last 90 days of life.
4. Services will be set up to enable more patients to achieve their wishes with these set out in their advance care plans. 75% of patients will achieve their preferred place of death.
5. 75% of patients will achieve their preferred place of care.
6. 100% of carers will be supported throughout the palliative care experience of their loved one.

Further work needs to be undertaken to establish and agree the methodology for collating all this information across all care settings to ensure we have robust data. Nevertheless, to support the road to success for this strategy, a draft of an Action Plan has been developed (Appendix 3). All elements need to be discussed, with agreed timelines, amongst all the stakeholders of the End of Life Care Partnership Group since it is imperative that implementation does not occur in isolation of other island-wide strategies such as the IT Strategy and the Intermediate Care Strategy.

# References

1. **Hospice UK.** Future needs and preferences for hospice care: challenges and opportunities for hospices. [Online] 2013. <https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2022-11/Future%20needs%20and%20preferences%20for%20hospice%20care.pdf>.
2. **NHS Benchmarking Network.** National Audit of Care at the End of Life 2021-22. [Online] 2022. <https://www.pslhub.org/learn/patient-safety-in-health-and-care/patientmanagement/end-of-life-care/national-audit-of-care-at-the-end-of-life-2021-22-12-july-2022-r7190/>.
3. **World Health Organization.** Palliative Care. [Online] 2021. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
4. **NHS.** What end of life care involves. [Online] 2018. <https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/>.
5. **Open Society Foundations.** Public Health Fact Sheet - Palliative Care as a Human Right. [Online] <https://www.opensocietyfoundations.org/uploads/e533cf3a-b2a2-46e6-9612-6aaf1bf54e77/palliative-care-human-right-fact-sheet-20160218.pdf>.
6. **Marie Curie.** Palliative care and the UK nations: An updated assessment on need, policy and strategy. Implications for England. [Online] 2016. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/reports-and-manifestos/state-of-the-nations-mariecurie-report-england.pdf>.
7. **NHS England.** Specialist Level Palliative Care: Information for commissioners . [Online] 2016. <https://www.england.nhs.uk/wp-content/uploads/2016/04/specialist-palliative-care-commissioning-guid.pdf>.
8. **World Health Organization.** Palliative Care - Key facts. [Online] 2020. [https://www.who.int/news-room/fact-sheets/detail/palliative-care#:~:text=The%20majority%20of%20adults%20in,%25\)%20and%20diabetes%20\(4.6%25\)..](https://www.who.int/news-room/fact-sheets/detail/palliative-care#:~:text=The%20majority%20of%20adults%20in,%25)%20and%20diabetes%20(4.6%25)..)
9. **Office for National Statistics.** Deaths registered in England and Wales: 2021. [Online] 2023. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationssummarytables/2021refreshedpopulations>.
10. **National Council For Palliative Care.** Palliative Care Facts and Figures for England. [Online] 2015. [http://www.ncpc.org.uk/uploads/NCPC\\_Facts\\_figures\\_v8.pdf](http://www.ncpc.org.uk/uploads/NCPC_Facts_figures_v8.pdf).
11. **Morgan, E.** Living longer and old-age dependency - what does the future hold? *Office for National Statistics*. [Online] 2019. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerandoldagedependencywhatdoesthefuturehold/2019-06-24>.
12. **Etkind, S.N. et al.** How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med*, Vol 15, 102. [Online] 2017. <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>.
13. **Murtagh, F.E. et al.** How many people need palliative care? A study developing and comparing methods for population-based estimates. [Online] 2014. <https://journals.sagepub.com/doi/epub/10.1177/0269216313489367>.
14. **Partnership, National Palliative and End of Life Care.** Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. [Online] 2021. [https://acpopc.csp.org.uk/system/files/documents/2021-05/FINAL\\_Ambitions-for-Palliativeand-End-of-Life-Care\\_2nd\\_edition.pdf](https://acpopc.csp.org.uk/system/files/documents/2021-05/FINAL_Ambitions-for-Palliativeand-End-of-Life-Care_2nd_edition.pdf).

15. **The King's Fund.** Dying matters – which is why we need to deepen our understanding of end-of-life care. [Online] 2022. <https://www.kingsfund.org.uk/blog/2022/05/dying-matters-understanding-end-life-care>.
16. **Murray, S.A. et al.** Illness trajectories and palliative care. [Online] 2005. <https://pubmed.ncbi.nlm.nih.gov/15860828/>.
17. **Statistics Jersey.** Report on the 2021 Jersey Census. [Online] 2022. <https://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/R%20CensusFinalReport%2020221213%20SJ.pdf>.
18. **Government of Jersey Public Health Intelligence.** Jersey Health Profile 2022 Data for 2016-2021. [Online] 2023. <https://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/Jersey%20Health%20Profile%202022.pdf>.
19. **States of Jersey Public Health Statistics Unit, Public Health Strategy Unit.** Jersey Health Profile 2016 - Data for 2013-2015. [Online] 2016. <https://www.gov.je/sitecollectiondocuments/government%20and%20administration/r%20healthprofile2016%2020161123%20hi.pdf>.
20. **Government Actuary's Department.** *Projected populations of the States of Jersey to be used for the 2021 review of the Social Security Fund and the Health Insurance Fund.* 2023.
21. **Government of Jersey Public Health Intelligence.** Jersey Mortality Statistics 2021. [Online] <https://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/Annual%20Mortality%20Report%202021.pdf>.
22. **Etkind, S.N., Bone, A.E., Gomes, B. et al.** How many people will need palliative care in 2040? Past trends, future projections and implications for services. [Online] 2017. <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>.
23. **Office for Health Improvement and Disparities.** Palliative and End of Life Care Profiles. [Online] 2021. [https://fingertips.phe.org.uk/profile/end-of-life/data#page/4/gid/1938132883/pat/15/par/E92000001/ati/167/are/E38000006/iid/93474/age/1/sex/4/cat/-1/ctp/-1/yr/1/cid/4/tbm/1/page-options/tre-ao-1\\_tre-so-0](https://fingertips.phe.org.uk/profile/end-of-life/data#page/4/gid/1938132883/pat/15/par/E92000001/ati/167/are/E38000006/iid/93474/age/1/sex/4/cat/-1/ctp/-1/yr/1/cid/4/tbm/1/page-options/tre-ao-1_tre-so-0).
24. **Marie Curie.** In and out of hospital: Emergency hospital admissions and A&E attendances in the last year of life in England. [Online] 2021. <https://www.mariecurie.org.uk/globalassets/media/images/policy/h408-in-and-out-of-hospital-emergency-admissions-v7.pdf>.
25. **Public Health England.** Emergency admissions in the 3 months before death. [Online] 2020. <https://www.gov.uk/government/publications/emergency-admissions-in-the-3-months-before-death/emergency-admissions-in-the-3-months-before-death>.
26. **National Institute for Health and Care Excellence.** End of life care for adults: Service delivery. [Online] 2019. <https://www.nice.org.uk/guidance/ng142/resources/end-of-life-care-for-adults-service-delivery-pdf-66141776457925>.
27. **POS.** Palliative care Outcome Scale. [Online] <https://pos-pal.org/maix/>.
28. **National Institute for Health and Care Excellence.** End of life care for adults: Quality standard. [Online] 2021. <https://www.nice.org.uk/guidance/qs13/resources/end-of-life-care-for-adults-pdf-2098483631557>.

29. **Thomas, Prof Keri.** Gold Standards Framework (GSF) in Jersey – Findings from a 3 year, island-wide cross-boundary care GSF Jersey project, enabling better integrated proactive, person-centred end of life care for all. [Online] 2019. <file:///ois.gov.soj/sojdata/HSSHomeDirs/VidalM/Downloads/Jersey%20-%20Poster%20Summary-1558627966.pdf>.
30. **Gold Standards Framework.** Advance Care Planning. [Online] <https://www.goldstandardsframework.org.uk/advance-care-planning> .
31. **Government of Jersey - Health and Community Services.** Treatment Escalation Plan Guideline. [Online] 2023. [https://soj/depts/HSS/Registered%20Documents/P%20Treatment%20Escalation%20Plan%20\(TEP\)%20Guideline.pdf#search=treatment%20escalation%20plan](https://soj/depts/HSS/Registered%20Documents/P%20Treatment%20Escalation%20Plan%20(TEP)%20Guideline.pdf#search=treatment%20escalation%20plan).
32. **Resuscitation Council UK.** FAQs: Recommendations about CPR. [Online] <https://www.resus.org.uk/home/faqs/faqs-decision-making-cpr>.
33. **Government of Jersey - Health and Community Services.** Jersey Multi-agency Unified Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) 16 years and over Policy. [Online] 2021. <https://www.fnhc.org.je/wp-content/uploads/2022/06/Multi-Agency-Do-Not-Attempt-Cardiopulmonary-Resuscitation-DNACPR-Feb-2021.pdf>.
34. **Marie Curie.** Anticipatory medicines in palliative care. [Online] <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/symptom-control/anticipatory-medicines#:~:text=Common%20anticipatory%20medicines%20include%20the,Medicine%20for%20anxiety%20%E2%80%93%20midazolam..>
35. **National Institute for Health and Care Excellence.** Care of dying adults in the last days of life. [Online] 2015. <https://www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-pdf-1837387324357>.
36. **World Health Organization.** Why palliative care is an essential function of primary health care. [Online] 2018. <https://apps.who.int/iris/bitstream/handle/10665/328101/WHO-HIS-SDS-2018.39-eng.pdf>.
37. **Enback, S.** Impact on Workforce Skills, Skills for Health Skills for Health. *COVID-19 insights*. 2020.
38. **World Health Organization.** Health and workforce education and training. [Online] <https://www.who.int/activities/health-workforce-education-and-training> .
39. **Government of Jersey.** Government Plan 2021-24. [Online] 2020. <https://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/ID%20Government%20Plan%202021%20to%202020>.
40. **Government of Jersey - Health and Community Services.** Business Plan - Health and Community Services. [Online] 2021. <https://www.gov.je/SiteCollectionDocuments/Government%20and%20administration/ID%20Business%20Plan%20HCS%202021.pdf>.
41. **Carers Jersey.** Dare to Care from Strategy to Action Road Map for Carers 2022-24. [Online] 2022. <https://carersjersey.je/wpcontent/uploads/2022/02/Carers-Jersey-Strategy.pdf> .
42. **Healthcare Quality Improvement Partnership.** National Audit of Care at the End of Life – Second round of the audit (2019 / 20) report – England and Wales. [Online] 2020. [https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2020/NACEL\\_2019\\_Summary\\_Report\\_Final.pdf](https://s3.eu-west-2.amazonaws.com/nhsbn-static/NACEL/2020/NACEL_2019_Summary_Report_Final.pdf).



43. **NHS Benchmarking Network.** National Audit of Care at the End of Life 2021-22. [Online] 2022. <https://www.pslhub.org/learn/patient-safety-in-health-and-care/patientmanagement/end-of-life-care/national-audit-of-care-at-the-end-of-life-2021-22-12-july-2022-r7190/>.

44. **NHS England — North West.** Electronic Palliative Care Coordinating Systems (EPaCCS). [Online] <https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/for-professionals/electronic-palliative-care-coordinating-systems-epaccs/>.

# Appendix 1. Stakeholder Engagement Event Discussion Summary



**Jersey Hospice Care**  
your care, your choice, your time

## Event Discussions Summary

<b>Event:</b>	End of Life Care Engagement Event – 2 February 2022
---------------	---

Key Quotes	
We're a compassionate island. We've got a huge percentage of Islanders who want to step up and volunteer and help.	They go round the houses, there's a delay and as a consequence there can be quite a lot of anger, patients can be really frustrated and rightly so.
We've got the fastest connectivity in Western Europe, we're not maximising what's available. There's all sorts of technology that we could use to support people in their homes.	There's lots of good partnership working, we've got some really good organisations, fantastically talented people who are very dedicated.
It is so important that we work in partnership, government with all other providers, to serve Islanders and give them the very best care.	What makes a difference in Jersey is the charitable sector, we are so blessed. So many people wanting to contribute.

Task 1	Identifying our enablers and “stones in the shoes” (combined feedback)
Enablers	Stones in the shoes
Compassionate island Effective signposting / coordination of care Excellent end of life care Good civil society and partnership working Multi-agency / partnership cooperation Resilient staffing	Difficulties getting off island Financial issues Inconsistent / inequitable access Limited data sharing (patient care record) Service issues – poor out of hours provision / limited equipment in the community / repetition / inconsistencies / transition amongst services / single point of access Staffing issues – recruitment / retention / immigration / upskilling / limited volunteer collaboration

**Task 2****Separate Themes**

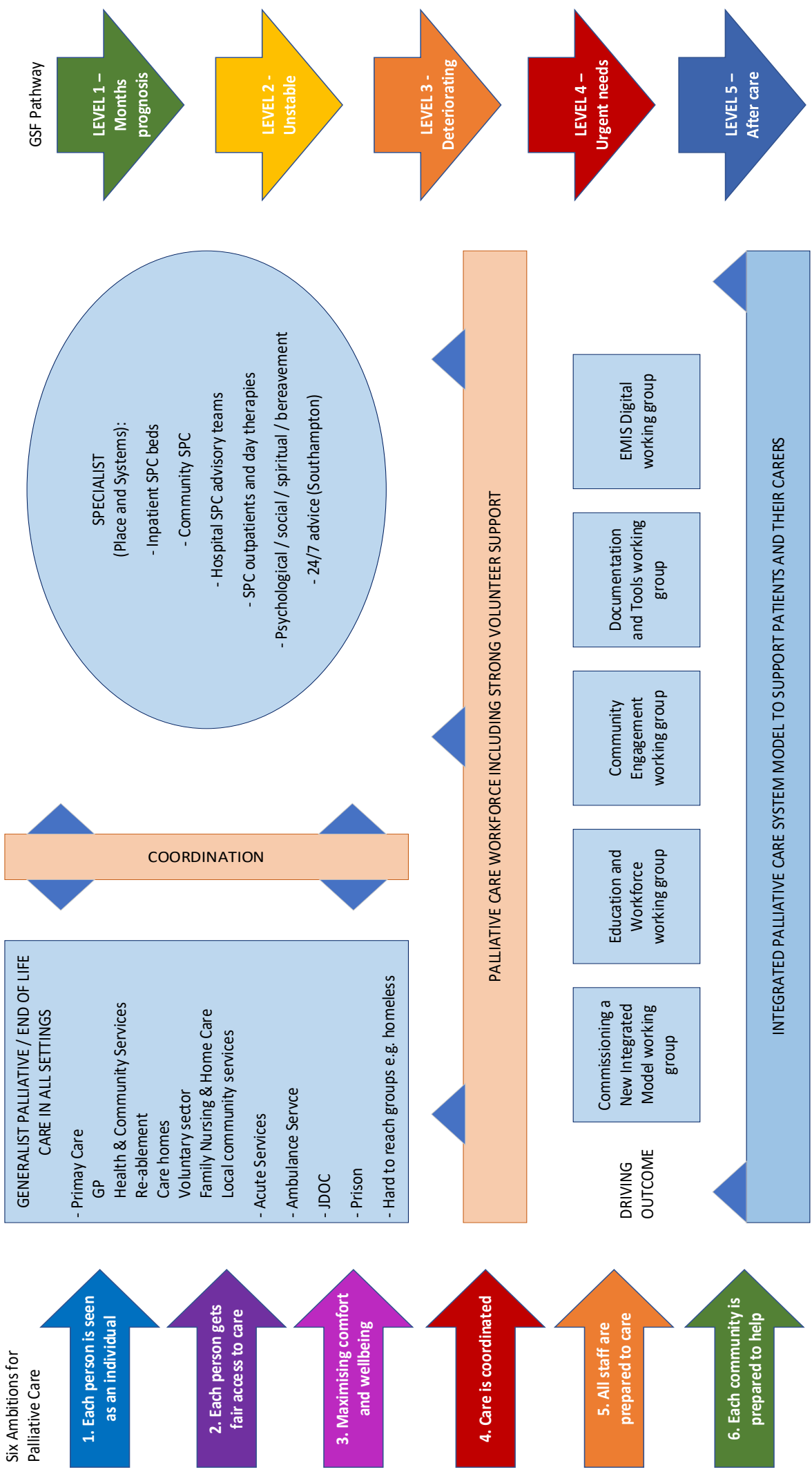
<b>Group 1: How will we know we are getting it right?</b>	<b>Group 2: Integrated care pathways</b>
<p>Need island-wide approach – island-wide strategy / policy; shared pathways; centralise data with information sharing</p> <p>Aging demographic – equitable access for all</p> <p>Competent workforce – succession planning and recruitment</p> <p>Inter-charity / organisation communication and knowledge of services / role</p> <p>Risk management</p>	<p>Service capacity is a key limiting step</p> <p>Need for Care Coordinator – assigned for pathway to signpost / guide patient and act of information source for HCPs.</p> <p>Delays create anger / worsening outcomes – avoid MDT fishing exercises / bouncing between services</p> <p>No central data hub; Ambulance lacks information when attending; disseminating information is limited and challenging</p> <p>Access to care issues verge on rationing – LTC can assist / have flexibility but need to be signposted early</p>
<b>Group 3: Developing the workforce</b>	<b>Group 4: Digital technology and innovations</b>
<p>COVID difficulties – only e-learning continued but face-to-face preferable due to subject matter</p> <p>Recruit / retain challenges, review pay for upskilling, undertake employment survey, promote palliative care nurse role (day in life, opportunities, shadowing), collective recruitment across the sector</p> <p>JHC / HCS liaison very effective – further linkages / blended learning needed to for join up / reduce duplication – Project ECHO, open up Learning Club, masterclasses, use of retail outlets for training</p> <p>Gold / silver / bronze palliative care nurse pathway established – need university link to continue (key gap)</p> <p>Expand training availability within HCS and community partners</p> <p>Online programmes are effective but access limited due to cost</p>	<p>Jersey has the fastest tech in world but lacks innovations – vision shared but devices not coming together</p> <p>New developments – Telecare / Telehealth replacing CAS alarm; EPR by year end; virtual consultations; COVID was a catalyst</p> <p>Issues with accessing resources and data – organisations have to start from scratch on referral</p> <p>Concerns re data sharing – but lack of sharing compromises patient safety – public view should be gained to balance perfection vs progress, sharing vs hiding; public expectation is that organisations talk / share more</p> <p>Central hub would assist access and remove duplication</p> <p>Demographics a risk – aging population</p>



<b>Attendees</b>	
<b>Organisation / Sector</b>	<b>Representatives</b>
Dementia Jersey	Lead Dementia Advisor and Counsellor
Family Nursing & Home Care	Director of Governance and Care Operational Lead – Rapid Response and Reablement Operational Lead – Adult Nursing Service
Funeral Directors	De Gruchy Funeral Care Representative Maillards Funeral Directors Representative
GoJ (Customer and Local Services)	Director of Local Services Long-Term Care Representative
GoJ (Health and Community Services)	Associate Director – Improvement & Innovation Education Representative General Surgical Representative Senior Clinical Auditor Practice Development Sister Senior Change Manager
GoJ (Strategic Policy, Planning and Performance)	Senior Policy Officer
GP / Primary Care Body	GP Representative
Jersey Ambulance Service	Associate Chief Ambulance Officer (Clinical Governance and Risk) Chief Ambulance Officer
Jersey Care Commission	Regulation Officer
Jersey Care Federation	Care Agency Representative
Jersey Hospice Care	Education Manager Director of Palliative Care Services Consultant in Palliative Medicine Senior Nurse – Specialist Palliative Care Team Volunteer Manager Chief Executive Officer Associate Specialist in Palliative Medicine Clinical Nurse Specialist in Palliative Medicine
Macmillan Jersey	Chief Clinical Officer Cancer Support and Wellbeing Practitioner

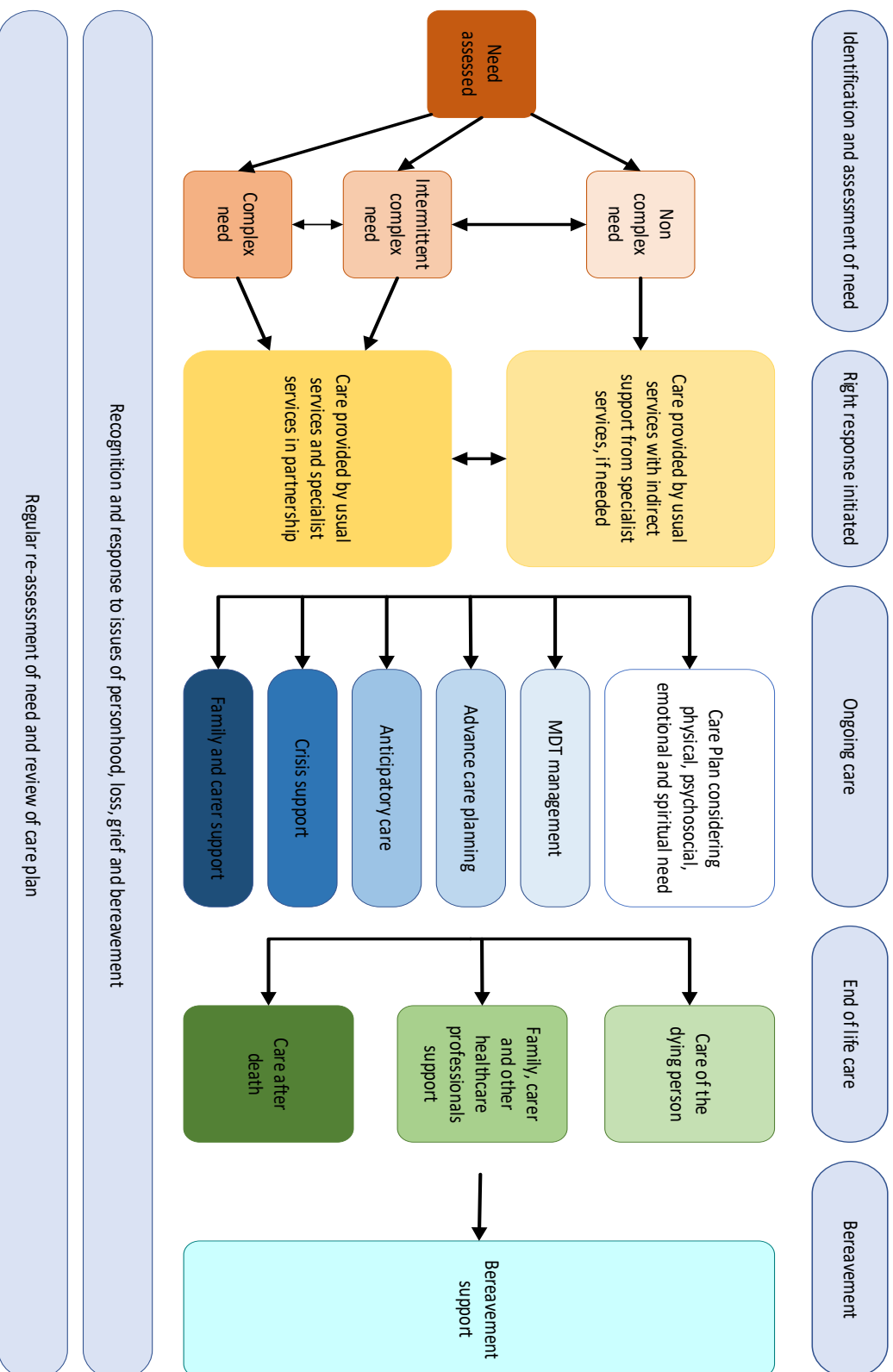
<b>Attendees</b>	
<b>Organisation / Sector</b>	<b>Representatives</b>
Minister for Health	Minister for Health
Scrutiny	Scrutiny Representative Scrutiny Representative Scrutiny Representative

# Appendix 2. Integrated Model of Palliative and End of Life Care

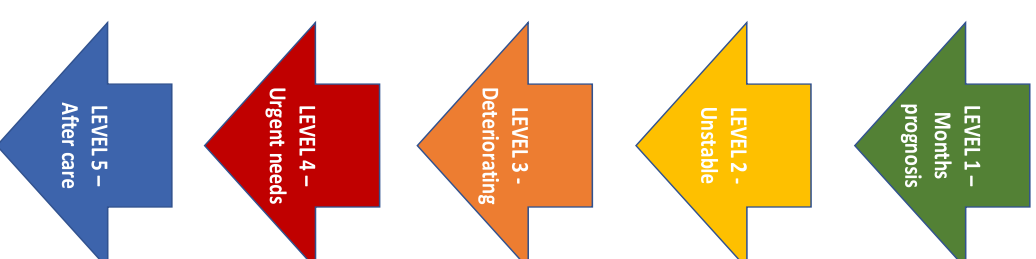


Six Ambitions for Palliative Care

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help



GSF pathway



# Appendix 3. Action Plan

On re-constitution of the End of life Care Partnership Group this Action Plan will require review and agreement.

Key:

Complete	Current / Ongoing	Not Started
----------	-------------------	-------------

	2022				2023				2024				2025				2026				
	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	
Pre-Ratification																					
Draft Document																					
Engagement Event																					
Presentation of strategy to EoLCP																					
Submission of strategy for ratification																					
Post-Ratification	Outcome 1 - People in Jersey who need palliative and / or end of life care will be seen and treated as individuals who are encouraged to make and share advance care plans and to be involved in decision regarding their care																				
Continue the development of GSF across HCPs in the community and hospital																					
Develop a central, integrated IT system (for example EPaCCS in the UK (36)) across health and care professionals to facilitate the																					



sharing of Advance Care Plans and GSF recording and collate outcome performance data																					
<b>Outcome 2 – People in Jersey who need palliative and / or end of life care will have their needs and conditions recognised quickly and be given fair access to services regardless of their background and characteristics</b>																					
Ensure all interested parties who represent patients requiring palliative care have a voice on the EoLCP																					
Design and build a robust 24/7 model of palliative care that is accessible to, and meets the needs of, patients and families at a generalist and specialist level																					
Educate / develop the workforce / volunteers and increase public awareness in relation to palliative care																					
Arrange access to emergency funding for EoL C and to responsive care in the community at EoL either from the Long Term Care Fund or alternative sources																					
Collate PH data across all health care settings using a collaborative approach to IT systems and robust analysis with benchmarking																					



**Outcome 4 – People in Jersey who need palliative and / or end of life care will receive care that is well coordinated**

<p>Ensure the right information is available at the right time to minimise duplication through the development of an integrated IT system across the whole health system in Jersey</p>																				
<p>Expand / realign hospital discharge processes to present the opportunity to enable more people to transfer from inpatient settings to their preferred place of care with the care they require to support them as appropriate</p>																				
<p>Ensure people receive the right care, at the right time, in the place consistent with their wishes and preferences avoiding the disruption of non-value added hospital admissions</p>																				
<p>Develop a single point of access for referrals to help ensure patients have timely access to the most appropriate care in the most efficient way possible</p>																				
<p>Develop an agreed pathway for access to anticipatory medicines / equipment OOH</p>																				
<p>Address care needs to support people to remain in their own home</p>																				

**Outcome 5 - People in Jersey who need palliative and/or end of life care will have their care provided by people who are well trained to do so and are receiving ongoing training to maintain their skills and competencies**

<p>Undertake a needs analysis of the health and care workforce in terms of their knowledge and competence in palliative and end of life care</p>	
<p>Develop an island wide training plan and competency framework to support the entire workforce</p>	
<p>Develop consistent measurable standards and robust evaluation methods for quality education and training and ensure it is delivered by skilled and qualified providers</p>	
<p>Ensure all key staff are able, encouraged and supported to attend training programmes around core principles of palliative and end of life care</p>	
<p>Adopt a system wide approach to the provision of palliative and end of life education. This should include all training providers across the island</p>	
<p>Extend membership of the Morbidity and Mortality Meetings to encourage island-wide attendance</p>	

<p><b>Outcome 6 - People in Jersey who need palliative and/or end of life care will be part of communities that talk about death and dying and that are ready, willing and able to provide the support needed</b></p>												
<p>Ensure everybody's voice is heard through this engagement</p>	<p>To be reviewed and confirmed by Government of Jersey / Health &amp; Community Services</p>											
<p>Develop a proactive approach and plan to galvanise support and spread the message across our communities</p>	<p>To be reviewed and confirmed by Government of Jersey / Health &amp; Community Services</p>											
<p>Develop An island-wide 'Carer Strategy' to ensure we address and meet the needs of these members of our community</p>	<p>To be reviewed and confirmed by Government of Jersey / Health &amp; Community Services (Carer Strategy already in place)</p>											
<p>Undertake a carer assessment in order to establish need</p>	<p>To be reviewed and confirmed by the End of Life Care Partnership</p>											
<p>Develop a strategic approach to utilise the volunteer workforce effectively</p>												
<p>Combine all Third Sector elements to develop a robust, multifaceted model of care delivery which is supported by members of our community who are then reinforcing the need, spreading the message and having the conversations</p>	<p>To be reviewed and confirmed by the End of Life Care Partnership</p>											
<p>Success</p> <p>Baseline assessment against 2019 / 20 National Audit for Care at End of Life (England / Wales)</p>												

75% of patients with an expected death will have documented advance care planning which includes a treatment escalation plan and DNACPR record	100% of health and care professionals working across community, hospital and Hospice will have access to educational sessions around palliative care including GSF and end of life care on a monthly basis	More patients will receive effective care, treatment and symptom control in the community. This will be demonstrated by ensuring that, for those patients who have a PPC within the community and an expected death, less than 30% experience an unplanned hospital admission in the last 90 days of life	Services will be set up to enable more patients to achieve their wishes set put in their advance care plans. 75% of patients will achieve their preferred place of death	75% of patients will achieve their preferred place of care	100% of carers will be supported throughout the palliative care experience of their loved one

