



The Future of Hospice Care in Scotland



Contents

Foreword	5
Executive Summary	7
Introduction	10
About this project	10
What is hospice care?	12
What do people value about hospice care?	16
How has the hospice sector responded to the COVID-19 pandemic?	18
Impact of COVID-19 on death, dying and bereavement	18
How did hospices respond to COVID-19?	18
Beyond the pandemic - how are hospices adapting to and meeting future challenges?	23
Increasing support and partnership working across sectors	23
Reducing pressure on statutory services	25
Increasing care in the community	26
Developing inpatient services to meet needs	28
Tackling inequalities	29
Supporting families and carers	33
Empowering communities	35
Taking forward change	37
Enablers of change	37
Areas for collaboration and further action	41
References	43

About Hospice UK

Hospice UK is the national charity working for those experiencing dying, death and bereavement. We work for the benefit of people affected by death and dying, collaborating with our hospice members and other partners who work in end of life care. Our hospice members influence and guide our work to put people at the centre of all we do. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

For more information

For more information about this work please contact the Policy and Advocacy Team at Hospice UK by emailing policy@hospiceuk.org

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- Marie Curie Hospice Glasgow
- St Andrew's Hospice
- St Columba's Hospice Care
- St Margaret of Scotland Hospice
- St Vincent's Hospice
- Strathcarron Hospice
- The Ayrshire Hospice
- The Prince & Princess of Wales Hospice

Foreword

The COVID-19 pandemic has brought into sharp focus the importance of end of life care and the impact of death, dying and bereavement on families and loved ones. Hospices across Scotland have been at the forefront of Scotland's response to the pandemic, rapidly adapting their services to continue to provide expert, high quality care at a time when their communities needed them most.

As we look towards a future beyond COVID-19, with the need and complexity of palliative care growing, health and social care services under increasing pressure, and major reforms such as a new National Care Service for Scotland on the horizon, now is the perfect opportunity to reflect on the unique contribution of hospice care and its key role as part of the wider health and social care system in responding and adapting to the challenges that lie ahead.

The case studies throughout this report show the incredible creativity and leadership of the Scottish hospice sector and its ability to work in partnership and empower communities. But the report also emphasises the support that needs to be in place to underpin and enable the sector to be a catalyst for long-term change.

This report is shaped by the views and expertise of palliative care staff and partners across Scotland. It forms part of Hospice UK's Future Vision Programme, which aims to drive forward the transformation of hospice and palliative care to meet the growing demand for care and support at the end of life, and work towards a more sustainable future for palliative and end of life care across the UK. We hope that this report stimulates further debate and integrated working in Scotland, and informs the success of the next palliative care strategy and beyond. We look forward to working with and facilitating partners across Scotland to take these conversations forward.



Tracey Bleakley
Chief Executive, Hospice UK

Foreword (continued)

The charitable hospice sector in Scotland is made up of 16 hospices, across the country, who are leaders in palliative care, across all settings. The hospices form one large group – the Scottish Hospice Leadership Group - who are cohesive in their key messages and ethos of care, providing access to the highest quality of services while ensuring that patients’ and families’ wishes and needs remain at the centre of every decision. The hospice sector provides a wealth of experience through strategic leadership and clinical expertise.

The need for palliative care in Scotland is increasing, as is the complexity of care required, and hospices make a significant contribution to the delivery of that care, working in partnership with the wider health and social care system and voluntary sector organisations.

Hospices traditionally deliver their care models flexibly and in response to the communities that they serve, adapting consistently to ensure equitable access to all. The COVID-19 pandemic has accelerated the need to respond rapidly to meet the demands of an evolving healthcare landscape and rising numbers of people requiring end of life care. Throughout this period, hospices have demonstrated an appetite to evolve and grow in response to those societal needs.

Over the years the hospices have developed a resilience based on clinical expertise and business acumen and are a key part of the health and social care system in Scotland, as trusted leaders in the field of palliative care. Moving forward the hospices will continue to work strategically with the Scottish Government and our local healthcare partners to ensure provision of a diverse range of palliative care services, Scotland wide.

The following report describes the importance of hospice care in Scotland during the pandemic and beyond, demonstrating the key position that the hospice sector has in the success of Scotland’s next national palliative care strategy and major reforms to adult social care.



Rhona Baillie
Chair of the Scottish Hospice Leadership Group

Executive Summary

This report sets out the unique contribution of Scottish hospices, the integral role they played in Scotland's response to the COVID-19 pandemic and how the sector is supporting Scotland's recovery and remobilisation. It highlights the opportunities for the hospice sector to work collaboratively with partners to take a whole system, population approach to meeting growing palliative care need. The report is intended as a discussion document to stimulate collaboration and drive forward change.

Hospice care provides vital support to people with a terminal or life-shortening condition, their family and loved ones. Hospices in Scotland support over 22,000 people each year, with over 80% of that care delivered beyond hospice walls, to people in their own homes or in the community¹. Hospices work in partnership with GPs, district nurses, care homes, hospital teams, social care and other services to support people at all levels of palliative care need, across all settings. They deliver training and education, provide specialist clinical expertise and support to other services, and are strategic leaders in palliative and end of life care at a local and national level.

Response to COVID-19

During the COVID-19 pandemic, Scottish hospices rapidly adapted their services to continue providing vital palliative and end of life care and bereavement support in their communities. With the pandemic seeing a sharp increase in the number of people being cared for and dying at home and in care homes, hospices introduced and expanded the support they provided in the community. They established community hubs with other services, provided more support to care homes and community teams, and delivered hospice@home, rapid response and other community services. They embraced technology to provide virtual support to patients and families, where they were unable to see them face to face, increased the bereavement care they delivered across communities and supported health and social care staff to cope with the huge toll they were facing as a workforce.

The pandemic has been a catalyst for strengthening partnership working and collaboration between hospices and other services, particularly care homes, community and primary care services and acute care. It also highlighted hospices' strong leadership role as they worked with the NHS, local authorities and Health and Social Care Partnerships to support local and national planning and the swift development of guidelines.

Future challenges

As Scotland looks towards long-term recovery from COVID-19, health and social care services will need to continue to adapt and respond. Up to 10,000 more people are predicted to need palliative care by 2040², and the complexity of that care is increasing, putting more strain on already stretched services, and on the families and carers of loved ones. This is at a time when the wider health and social care system is under immense pressure, hospital waiting lists are getting longer and Health and Social Care Partnerships face difficult decisions over what to fund while operating in a constantly changing environment with major reforms, including a new National Care Service, on the horizon.

Hospices' strengths in partnership working, their capacity to spark innovation and their ability to empower and mobilise the communities they serve, mean the sector is ideally placed to support and drive change within the wider health and social care system as it responds to the challenges that lie ahead. The cost to NHS Scotland of caring for people in the last year of life is huge, with unscheduled care alone costing nearly £190 million a year³. Hospices reduce the pressure on statutory services, supporting people to stay in their own homes and avoid unnecessary admissions to hospital. Currently only about a third of hospice funding comes from the public purse, yet hospice care offers significant return on investment for every pound of statutory funding spent.

Priorities for change

The hospice sector in Scotland has identified key priorities as it continues to adapt to meet the changing needs of the population. These include expanding how hospices work in partnership with other health and care services, responding to the increasing need and complexity of palliative care in the community, and strengthening the role of the hospice sector in tackling the deep-seated inequalities in palliative and end of life care. The case studies in this report illustrate the many innovative services and initiatives that hospices have already introduced and highlights the areas they are looking to develop further.

Making these changes on a sustainable footing is challenging and the hospice sector needs support from statutory partners and Scottish Government. Palliative care needs to be prioritised at a local and national level through a whole system approach, with hospices valued as equal partners within this. Long-term sustainable funding that meets population need for palliative and end of life care across all settings, including the hospice sector, has to underpin this. The report highlights cross cutting issues that need to be addressed to enable change, including creating the conditions for partnership working, the effective use and sharing of data, maximising the potential of digital solutions and ensuring we have a sustainable and supported workforce that can meet the changing needs of the Scottish population.

The report sets out suggested areas for future discussion, action and collaboration at a national and local level.

Steps to support progress at a national level:

- **Scottish Government, the new national clinical lead for palliative care, integration authorities, hospice leaders, palliative care partners, Hospice UK and the Scottish Partnership for Palliative Care** to take forward the areas identified in this report to inform development and implementation of the new national strategy for palliative care in Scotland
- **The Scottish Hospice Leadership Group and NHS specialist palliative care leaders** to work together to provide strategic leadership and a unified voice for specialist palliative care across the whole of Scotland, working with the **new national clinical lead for palliative care in Scotland and Scottish Government**
- **Hospice leaders, integration authorities and Scottish Government** to continue to engage over a sustainable funding solution for the hospice sector that recognises the increased need for palliative care services, changing models of care, rising costs such as parity with NHS salaries and other priorities identified in this report, as part of broader discussions to ensure funding for palliative care meets population need across all settings

- **Scottish Government, NHS Education for Scotland, hospice and NHS specialist palliative care leaders, professional bodies, workforce regulators and other partners** to work collaboratively around workforce planning, palliative and end of life care education and investment, and strategies to support and retain current staff, to ensure there are sufficient numbers of staff with the right skills to meet people's palliative care needs in the future, including within children's palliative care
- **Healthcare Improvement Scotland and the Care Inspectorate** to discuss how their joint inspections of integration authorities' strategic commissioning processes can encourage a greater focus on the strategic planning of palliative care services to meet population need
- **Hospices, Healthcare Improvement Scotland, research organisations, Scottish Government and other partners** to identify what support is needed to further develop and use the evidence base for hospice and palliative care, evaluate service improvements and support improved patient care
- **Hospice leaders** to work with **NHS Education for Scotland Digital Service** to ensure that hospices are fully involved in developments around the National Digital Platform
- **Hospice leaders and the palliative care sector** to continue discussions with **Scottish Government** on how the sector can best support the upcoming reforms to social care to ensure they work for people with palliative care needs and recognise the contribution of the sector

Steps to support progress at a local level:

Integration authorities, health boards, hospices, local health and social care services across all settings and community groups to work together as equal partners, to discuss and address the areas outlined in this report that they identify as particularly relevant to them, such as:

- Taking time to understand each other's roles, what each partner brings and how best to foster partnership working and shared goals for palliative care locally
- Assessing local population need for palliative care, particularly in the community and out of hours support, and developing services and models of care that are sustainable and meet people's needs
- Understanding unmet need and inequalities in palliative care, prioritising this in local population needs assessments and strategic commissioning plans, and working jointly to understand what matters most to people in all parts of their community and how to reduce barriers and inequalities in palliative care
- Strengthening local partnership working between hospices and other services, in particular district nursing, GPs, social care, out of hours care, acute care and care homes
- Building resilience and capacity within local communities to support people with palliative care needs, their families and carers
- Reviewing local IT systems and working towards integrated systems that allow information to be shared and accessed between hospices, NHS systems and social care
- Expanding the palliative care education and support that hospices deliver to other providers, and ensuring this is resourced and joined up strategically at a local level
- Reviewing local palliative care workforce models to foster more flexible and integrated working both within hospice care and across other settings

Introduction

Scottish hospices have provided leadership in palliative and end of life care in Scotland for more than 40 years and want to continue to support the population of Scotland to have the best end of life care in the world⁴. Scottish hospices provide a powerful partnership between statutory health and social care and civic society, and a funding model which enables rapid innovation and significant added value. Most hospice care is provided at home, but it can also be provided as an inpatient in the hospice, as a day patient visiting a hospice or in another setting, such as a care home.

The COVID-19 pandemic has brought the importance of end of life care into sharp focus. Over 10,000 people died from COVID-19 in Scotland⁵ and the impact this has had on individuals, families, communities, health and social care staff and the wider system has been immense. Access to high quality care at the end of life, where people are treated with respect, dignity and compassion, and are fully involved in decisions about their care, is fundamental to a society based on human rights. Care which goes badly at the end of life can leave people at crisis point, and prolong and complicate the grief of family and loved ones, as well as having a significant impact on the health and social care system and wider society.

Even without COVID-19 the need for palliative care in Scotland is growing. In an average year, nearly 60,000 people in Scotland die and it's estimated between 74% and 95% of them will need palliative care². By 2040, up to 10,000 more people a year are estimated

to need palliative care and the complexity of the care they require is also increasing². Alongside this there has been an ongoing shift, accelerated by the pandemic, in where people are dying, with more people dying at home and in care homes⁶. The number of children with life-shortening conditions is also rising, with the latest data showing that there are 16,700 children in Scotland who may die young⁷.

Throughout the pandemic, hospice care has stepped up - adapting to keep delivering and supporting vital palliative, end of life care and bereavement support in communities across Scotland. As Scotland looks towards a gradual recovery from the pandemic, the health and social care system will have to continue to respond and adapt. Hospices have a key role in supporting the agenda of rebuilding better, as we emerge from the COVID-19 pandemic and beyond.

About this project

This is a collaborative project between Hospice UK and the Scottish Hospice Leadership Group. It sets out the current contribution of the charitable hospice sector in Scotland, demonstrates how the sector has adapted and responded during the COVID-19 pandemic and identifies the opportunities for the sector to further develop to meet the needs of the Scottish population. The report is intended as a discussion document that identifies areas for cross-sector working to explore and develop further in the future.

This work is aligned with the Scottish Partnership for Palliative Care's upcoming report to inform future thinking around a new national strategy for palliative care in Scotland. It also recognises and seeks to work with other significant policy developments, including reforms to social care and the planned new National Care Service for Scotland, the national bereavement charter, the integration of health and social care with its emphasis on anticipatory care, preventative approaches, caring for people closer to home and reducing avoidable hospital admission, and the realistic medicine agenda. In addition, it recognises the developments around Scotland's Digital Health and Care Strategy and the development of a National Digital Platform for Scotland.

The project has been informed by:

- An online survey of hospice and palliative care staff in Scotland (survey responses: 74, run in December 2020)
- Five focus groups with hospice and palliative care staff on: the future of hospice care; hospice care and care homes; children's hospice and palliative care; hospice care in the community; and hospice care in prisons (run in October and November 2020)
- Hospice UK commissioned public polling of 510 people in Scotland (run in April 2021)
- Phone/virtual interviews with key stakeholders across palliative care and the wider health and social care system in Scotland
- An evidence review and collection of case studies

What is hospice care?

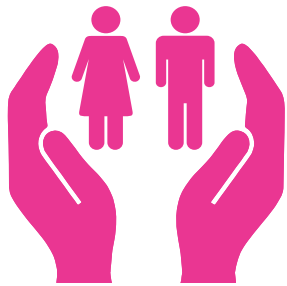
Hospice care: Hospice care aims to affirm life and death. It means working with and within local communities to tailor palliative care around the needs of each adult and child with a terminal or life-shortening condition, whatever that may be, and extends to supporting their carers, friends and family before and after bereavement. Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support that places equal emphasis on someone's clinical, physical, emotional, social and spiritual needs with the understanding that everyone will be different.

Palliative care: The World Health Organisation defines palliative care as 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. Palliative care is explicitly recognised under the human right to health.

Hospices in Scotland support over 22,000 people each year¹, providing expert palliative and end of life care to people in their local community and supporting their families and carers throughout their illness and into bereavement. Hospices support people with any terminal or life-shortening condition, across all ages and from any background. Hospice care is an ethos, rather than something that takes place in a specific building. The majority (81%) of hospice care is delivered to people at home or in the community, through home visits, virtual services, outpatient clinics or day therapy services. Inpatient units provide specialist palliative care to people within the hospice. Hospices also provide services such as drop-in information centres, welfare advice, respite services, bereavement and counselling services and befriending initiatives. Not all hospices offer all services. The services that hospices offer are tailored to meet the needs of their community and to align with local health and care services. On average, just over a third of hospice spend comes from statutory funding, with hospices raising the remaining funds themselves.

There are 14 charitable hospices providing care and support for adults and their families in Scotland. Children's Hospices Across Scotland (CHAS) has two hospices that provide palliative and end of life care for babies, children and young people and respite for the whole family, as well as its CHAS at Home service in the community, virtual hospice service and hospital based teams in every children's hospital in Scotland. The majority of hospices are located around Scotland's central belt and are typically located in more urban areas. Not every health board in Scotland has a charitable hospice, and the NHS and other partners provide specialist palliative care in areas where there isn't a hospice.

Care and support provided by Scottish hospices



22,400

people supported by
Scottish hospices



465

babies, children and young
children received care



19,000

people received
direct/clinical care

81%

of care provided
in the community



2,700

people received
bereavement support



254

inpatient beds

61,400 visits made to people
in their own homes



Hospice care supports people in all settings

Hospices are an integral part of the health and social care system in Scotland. Hospices work in partnership with GPs, district nurses, care homes, hospital teams, social care and other services to support people at all levels of palliative care need, across all settings. As well as working in multi-disciplinary teams to

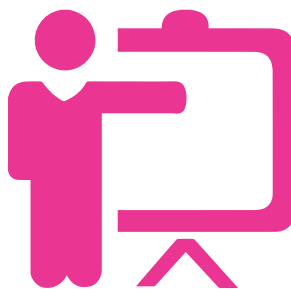
provide direct care, hospices deliver education and training, provide specialist clinical expertise and support, for example through a 24/7 phone service, build capacity within care homes, provide out of hours support, participate in on-call rotas and provide specialist services, such as lymphoedema clinics.

Care and support provided by Scottish hospices



4/5

hospices have an out of hours/crisis service for other clinicians



Over

2/3

provide education and training to other settings



3/4 provide services or support to care homes



4/5

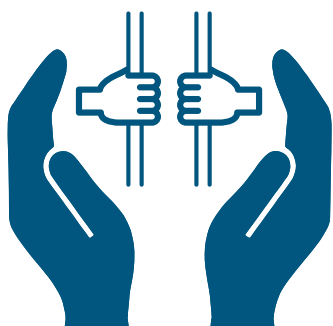
provide services or support to hospitals



Over

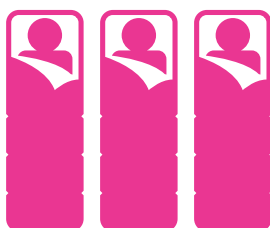
1/2

provide support to learning disability services



2/3

provide support to staff in prisons



Over

1/3

provide services or support to homelessness services

The role and contribution of hospices at each level of palliative care need

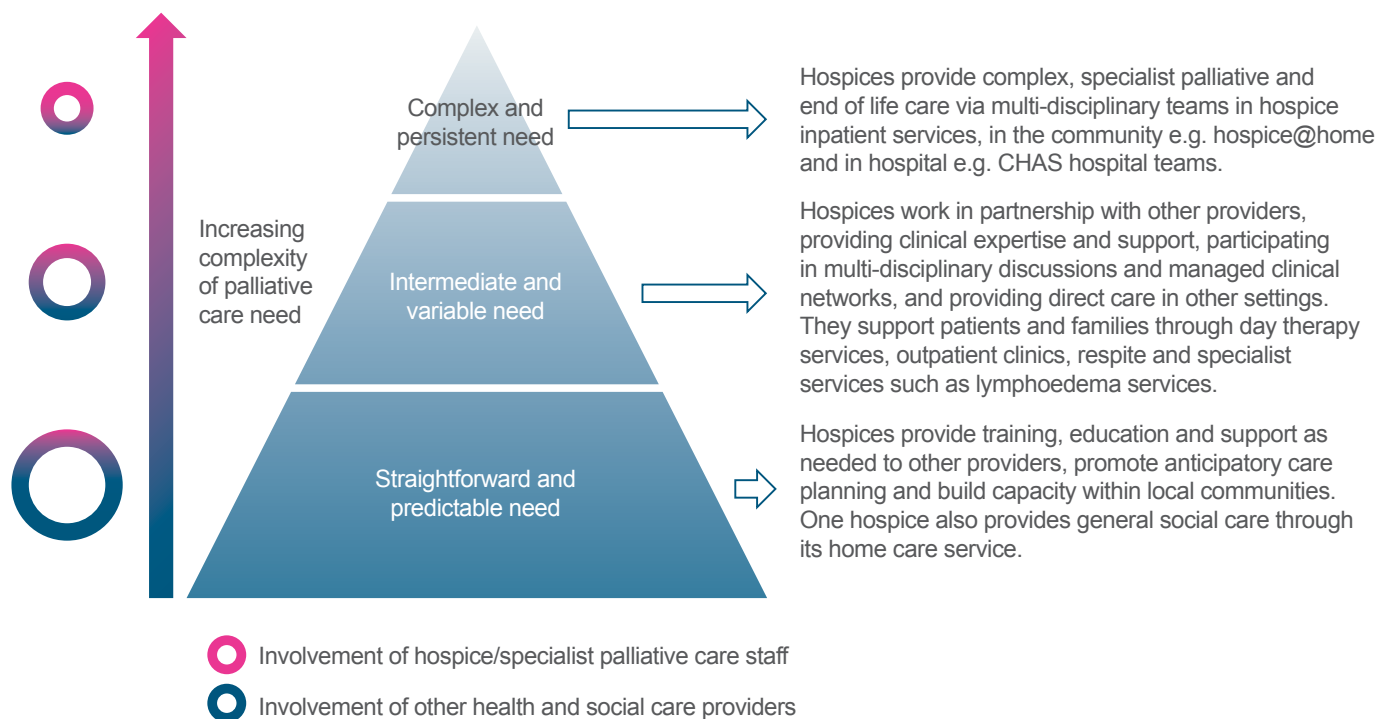


Figure 1: Diagram showing the role of hospice and specialist palliative care staff at different levels of complexity of palliative care need. *Adapted from Palliative Care Australia's figure on alignment of need for palliative care against workforce capability, in its 2018 Palliative Care Service Development Guidelines⁸.*

Many hospices have a strong research function, for example Marie Curie is the largest charitable funder of palliative and end of life care research in the UK. The research leadership and expertise that hospices contribute is vital for building the evidence base and improving care for all people with a terminal or life-shortening condition. Hospices are also involved in, and often lead, local planning groups, local and national quality improvement projects and the development of local and national clinical guidelines.

What do people value about hospice care?

“ I used to think it was a place to come and die - but - as my dad said, it's a place to help him live. ”

Family member

“ Courage to be dealing with difficult times and someone beside you when it counts. ”

Family member

“ For us [CHAS] was an invaluable, and life changing service... giving us some peace in our hearts at least that everything that could have been done for [our son] was done with such love, and such care. ”

Bereaved parent

We know that people value having choice and control over where they die and want to be fully involved in decisions about their care⁹. People want access to high quality care, when and where they need it, delivered by well trained staff. Hospice care achieves this by providing truly holistic, person-centred care for individuals and their loved ones. Research has shown that patients and family members value the specialised knowledge and skills of hospice staff, their ability to develop a close rapport with patients and families and anticipate and respond to their changing needs¹⁰. The availability and flexibility of hospice services, such as phone support, out of hours support and flexible visiting policies, help give individuals and families a sense of security as they approach the end of life¹⁰. People also appreciate the sense of community and opportunities for social engagement offered by hospice services such as day therapy.

Lindsey Currie and her 15 year old son Cody, live in Partick and have been supported by CHAS for over 12 years.

Cody has chronic lung disease, epilepsy and cerebral palsy and has been coming to Robin House for respite care since he was a toddler. CHAS is dedicated to supporting families in the toughest of times, like when Lindsey received the devastating news that she had breast cancer.

Lindsey says: “Life as a single parent with a child with complex needs and a short expected lifespan is very frightening, yet utterly beautiful. CHAS has supported Cody and I through the hard times, but my world came tumbling down when I was diagnosed with breast cancer. CHAS sprang into action.”

When Lindsey went for surgery, Cody was able to stay in Robin House where Lindsey knew he would be safe and surrounded by love. While she was in hospital, Lindsey received photos of Cody and she was able to read Cody a bedtime story every night by video call.

Lindsey says: “When I say I could not have got through this without CHAS – I mean it. I am more grateful than anyone could ever imagine.”

Patient B, a 54yr old lady, was diagnosed with a glioblastoma. Her prognosis was a short number of weeks, and she was referred to the Respite and Response service at Ayrshire Hospice for support to have a rapid and compassionate discharge from hospital. She had expressed to her 26yr old son that she wanted to die at home and he, although fearful of what this would mean for him, wanted to honour her wishes. The team were in place the next day, and quickly able to reassure them both that they would be supported before, during and after her death.

Patient B sadly lost the ability to speak but because the team had expertly identified her wishes immediately they were confident about continuing to ensure that they were able to care for her according to her preferences, and in a person centred way.

A few days after the first visit, Patient B had a seizure and her son contacted the emergency services who said that they could take the lady to hospital for admission. Patient B's son was distressed and contacted the Respite and Response team. He was reassured that his mother's wish to die at home could be fulfilled with continued support with end of life care from the team.

He later expressed that if the Respite and Response team had not been there to support him and his mother it is likely that she would have died in hospital. He felt comforted by the fact that she was able to die at home and that he was empowered to support her.

Grant is 16-years-old and lives in Hillington with his mum, stepdad and brother. In February 2021, his uncle died and the effect on Grant has been long-lasting. Grant found speaking about his feelings almost impossible which in turn caused him great emotional difficulties. He was referred to The Prince & Princess of Wales Hospice's family support services where he began one-to-one sessions with Janette McGarvey, Young Person's Development Worker.

While the initial sessions were difficult, the breakthrough came when Grant was told his beloved dog, Max could come with him to his sessions.

"On my third support session I was told that I could bring my dog Max to the sessions. This really helped me a lot as he was like a comfort teddy. We went for walks in the garden with Max during the sessions. The support has helped me feel more confident about asking my mum difficult questions. This has helped both me and my mum to be able to talk about things more easily."

How has the hospice sector responded to the COVID-19 pandemic?

Impact of COVID-19 on death, dying and bereavement

COVID-19 has highlighted the profound effects of death, dying and bereavement on people's lives. Over 10,000 people in Scotland have died as a result of COVID-19, and there has also been a rise in people dying from other conditions such as cancer, circulatory diseases and dementia⁵. There were over 6,300 excess deaths recorded in 2020 compared to previous years¹¹. The pandemic rapidly accelerated the shift in where people are dying, with the majority of patients with conditions other than COVID-19 being cared for and dying in the community¹². In 2020, nearly a third of all deaths were at home, a steep increase from a quarter in 2015¹³. What is not known is whether these people and their families received the care and support they needed at the end of life, at a time when community services were under immense pressure. The psychological impact of shielding and not having their usual support networks also had a big impact on individuals and their families. In addition, there have been concerns that the pandemic has led to delays in people being diagnosed or accessing treatment for conditions such as cancer.

“ We've had people referred to the hospice who hadn't been seen by a GP for 6 months, in situations which could have been reversible. ”

Hospice member of staff

COVID-19 has also had a profound impact on the way people experience bereavement and the support they need. Restrictions around visiting and attending funerals, and not being

able to spend time with loved ones, are likely to prolong and complicate the grief that people experience^{14,15}.

The restrictions of the pandemic also had a devastating effect on hospices' ability to fundraise. The £27 million emergency funding package allocated to hospices from Scottish Government during the course of the pandemic was strongly welcomed by the sector and provided short-term stability, allowing hospices to continue to provide vital care to people in their communities. However, the pandemic will have a lasting effect on hospices' sustainability, at a time when demand for palliative care is increasing further.

How did hospices respond to COVID-19?

“ Virtual hospice and expanding home-care is something that has been born from the pandemic and has improved what we can now provide for our families. ”

Hospice clinician

Hospices kept going: Hospices innovated and adapted their services, challenging boundaries to continue providing vital, truly person-centred care to individuals, families and communities in exceptionally challenging circumstances. Hospices have provided care to people both with and without COVID-19, supported people to remain in their homes, reducing pressure on hospital services, and have provided bereavement support to families and loved ones. They have provided education and support to the wider health and social care

sectors, particularly care homes and acute care. Pressures on other services have had a knock-on impact on hospices. The CovPall survey of hospice and palliative care services across the UK found that 42% of services in Scotland reported being more busy during the pandemic¹⁶. Community referrals in particular increased because of the rise in people being cared for and dying at home.

Increased care in the community: Many hospices introduced new community-based models of care, quickly redeploying staff and volunteers in order to respond to increased complexity of care and additional need in the community. Hospices introduced or expanded 'Hospice at Home' models to enable more patients to receive treatment and die at home and established rapid response services to quickly assess and support patients. Marie Curie Hospice Glasgow established a virtual ward which enabled up to five patients with particularly complex needs to be cared for at home, with daily input from medical and community clinical nursing teams, Marie Curie Fast Track Service and district nurses to ensure patients and their families received the support they needed. St Margaret of Scotland Hospice rapidly transformed their Edwina Bradley Day Hospice into an outreach blood transfusion and clinical intervention clinic. Hospices also provided wider support to individuals living at home, especially those without other support networks.

“ We pivoted inpatient services into the community very quickly, this would have normally taken months of back and forth and meetings etc. ”

Hospice member of staff

Hospice Hearty Meals

St Andrew's Hospice established 'Hospice Hearty Meals' which provides freshly cooked, nutritious two course meals, three days a week, aimed at patients who are isolated with limited support from family and friends. It delivered 579 meals in its first 12 weeks and all respondents rated the service as being excellent. Feedback from patients and carers found the service to be invaluable. It helped relieve the worry and burden of ensuring they ate well, helping them feel less anxious and more able to cope in uncertain times. Due to the success of the project, St Andrew's Hospice applied for further funding which has allowed them to continue with the service and to date they have provided over 1000 meals to patients and carers across Lanarkshire.

Anne is retired and lives alone. She has Parkinson's disease which has led to reduced mobility and Ataxia. Since lockdown, Anne has received less support and was struggling to make herself fresh, nutritious meals. Since the launch of Hospice Hearty Meals, Anne's sense of wellbeing has improved, "The meals are absolutely lovely! The menu choice is good, with large portions. This service has improved my health greatly by relieving some of the stresses of lockdown."

Marie Curie Edinburgh Rapid Response Service

Marie Curie Hospice Edinburgh established a Rapid Response Service to allow urgent home assessment by a clinical nurse specialist and intervention to assess and support unstable patients on the same day as referral. Hospice doctors were able to prescribe anticipatory medicines for first time to patients at home and able to store medication in the hospice to be used by the medical staff for patients at home. A speciality doctor was assigned to work with community teams and was available to do urgent visits to home or care homes. The Marie Curie Nursing Service also adapted to support an overnight rapid response team of a registered nurse and health care assistant who were able to visit people at home or in a care home whose palliative care needs were urgent.

More virtual support: Hospices rapidly shifted to using virtual technology to continue to provide services and support where this was not possible face to face. Hospices used virtual consultations, moved day therapy services to online support, introduced virtual wellbeing hubs, and counselling and bereavement support via phone and video consultation. Digital technology allowed hospices to expand the reach of their services and reduced travel time for patients and staff. A number of hospices are looking at keeping virtual services, in addition to face to face care, after the pandemic.

Virtual Children's Hospice

CHAS set up the world's first virtual children's hospice service to deliver holistic palliative care to families throughout lockdown – particularly those shielding who did not wish to accept external care into the home. The virtual hospice offered families nursing, medical and pharmacy advice by phone and video; bereavement support; money and benefits advice; and practical advice around coronavirus. The service also offers a storytelling service for children at home; letter writing for children and parents; activity packs and art clubs; and virtual Clowndoctor visits. In its first year, the service reached an average of 170 unique families virtually every month, and all families reported improved quality of life following engagement with the service.

“ The telephone consultations over the last year have been amazing – I have felt so supported and knew that I was never forgotten by you. ”

Individual supported by the Living Well Hub at The Prince & Princess of Wales Hospice

Increased bereavement support: Hospices have responded to the increase in people needing bereavement support by expanding and adapting their bereavement services. Their unique role in their local communities means they have been able to rapidly co-ordinate a community response, increasing the number of bereavement volunteers able to provide one to one advice and recruiting additional volunteer counsellors to respond to the predicted increase in demand. Hospices have also been involved in the development and implementation of Scotland's first national bereavement charter for adults and children.

Renfrewshire Bereavement Network

ACCORD Hospice set up a joint project with Renfrewshire Health and Social Care Partnership to provide a reactive bereavement service for those affected by COVID-19, which included recruiting and training additional volunteers. The Network aims to provide support to people in the Renfrewshire area who are experiencing loss or dealing with grief - by offering access to the most appropriate advice, guidance and counselling available - all from a single point of access. People who need support are able to self-refer by contacting a new helpline where they can discuss the help they need. After an assessment, staff who have been trained to manage calls will aim to make sure they receive the most appropriate support for their individual circumstances. The service is available to adults in the Renfrewshire area, regardless of their gender, social group or location. Following a review of the pilot in February 2021, the service has been extended until March 2022.

Grief Matters Highland

Grief Matters Highland has been established by Highland Hospice as an active regional network with a constellation of around 30 members (as of March 2021) with an interest in delivering the Bereavement Charter for Children and Adults in Scotland. This will provide a learning network and a mechanism to signpost bereaved people to the most appropriate support.

Strengthened partnership working: The pandemic has been a catalyst for developing closer partnership working and collaboration between hospices and other services, particularly care homes, community and primary care services and acute care. Several hospices, including The Prince & Princess of Wales Hospice and Marie Curie Hospice Glasgow, developed community hubs, where patients and health and social care professionals could get advice and support 24 hours a day, and regular briefings were held between hospice, hospital, district nursing and care home liaison staff. This allowed earlier identification of hot spots in the community, improved decision-making and has promoted better partnership working, prompting equipment sharing, support to care homes and multidisciplinary case discussions. Hospices also provided practical support, for example a 24 hour drug courier service to local care homes, an out of hours oxygen delivery service to provide effective symptom management for people in care homes and their own home, and a hospice ambulance service.

Hospice Ambulance Service

At the beginning of the pandemic, St Margaret of Scotland Hospice, in partnership with Marie Curie Hospice Glasgow, established a patient transport service. The service aimed to expedite admissions to hospice from home and hospital, minimise the risk of transmission of COVID-19 for those requiring admission to hospice, reduce the burden on an already overwhelmed Scottish Ambulance Service and support acute and community colleagues by collecting the patient promptly from their care setting following receipt of a second negative COVID-19 PCR swab. Both hospices recruited volunteers to support hospice staff with the safe and timely transfer of patients from either acute care or home to hospice. Volunteers were trained in essential infection prevention and control precautions, moving and

handling, and patient assessment and sensitive communication. St Margaret of Scotland Hospice continues to use the service to support patient transfers to clinic appointments, admission to hospice from acute care or home, and discharge from hospice to home. Patients and family members have been impressed by the “smooth, seamless, compassionate, careful and supportive” service.

Several hospices rapidly developed additional training and education for other providers during the pandemic. Project ECHO (Extension of Community Health Outcomes) is an approach that has been particularly successful in providing support, shared learning and training on palliative and end of life care for staff in care homes and other settings. It is a collaborative, distance learning model of education, where specialist teams and local providers learn from each other by problem solving real-time experiences and sharing best practice via video-conferencing. Highland Hospice rapidly established three COVID-19 knowledge ECHO networks to support out of hours GPs, rural GPs and general GPs during the pandemic. The vast majority of participants reported an increase in clinical knowledge, confidence and skills, and that their daily practice had changed as a result of the programme.

Ayrshire Hospice Care Home ECHO network

In response to the COVID-19 pandemic, Ayrshire Hospice quickly established and implemented a ten-week, live on-line supportive education programme for care homes using Project ECHO. The programme enabled care homes to access specialist palliative care, advice and support. Care homes set the weekly agenda and their identified learning needs were met. It provided

a safe space to share knowledge and experience, and provide peer support, without the need to travel. The network highlighted the challenges faced by care homes and improved links between the hospice, health board, Health and Social Care Partnership and care homes across Ayrshire.

Supported local and national

planning: The swift development of local and national guidelines was vital during the rapidly changing environment of the pandemic. Hospices provided clinical leadership around national COVID-19 guidelines and local protocols, such as symptom control, access to medication and the framework for visiting restrictions. They participated in local and national planning, working in close partnership with the NHS, local authorities and Health and Social Care Partnerships. Hospice research staff also played a key role in the research community’s rapid response to the pandemic.

Supported staff: Health and social care staff across all settings have had to rapidly adapt to deliver complex care in challenging circumstances, whilst coping with the relentless speed of change. For some, experiencing far higher numbers of deaths has taken its toll. Hospices introduced a range of interventions to support their own staff, such as emotional and spiritual support, mindfulness sessions and self-hypnosis sessions. Ardgowan Hospice also expanded the capacity of their Family Support Team and undertook additional training on working with trauma, to provide support to other health and care staff working locally, especially those who had traumatic experiences of deaths as a result of the pandemic.

Beyond the pandemic - how are hospices adapting to and meeting future challenges?

The impact of COVID-19 will be felt for years to come and hospices have a key role to play as Scotland focuses on its long-term recovery. Scotland's National Performance Framework is the wellbeing indicator for the nation, setting out the kind of country Scotland is trying to be. Hospice care makes significant contributions to key parts of the framework, including: supporting communities to be inclusive, empowered and resilient; increasing wellbeing; respecting, protecting and fulfilling human rights; supporting people to realise their full potential and contribute to society; and contributing to an entrepreneurial, inclusive and sustainable economy. Central to the National Performance Framework is the ambition that "We are a society that treats people with kindness, dignity and compassion" – a statement that fully embodies the ethos of hospice care.

As Scotland focuses on recovery and remobilisation following the pandemic, the health and social care system continues to be under immense pressure. Alongside this, Scotland is experiencing a growing need for palliative care and faces stark inequalities in the care that people experience at the end of life. This section outlines how the hospice sector is adapting to meet these challenges, the future priorities it has identified and the opportunities the sector presents to the wider health and social care system and society.

“We have so much potential to do things differently and to do more.”

Hospice senior management team member

Increasing support and partnership working across sectors

By 2040 the number of people predicted to need palliative care in Scotland is expected to increase by between 14 and 20%, with more people dying with multiple conditions². The number of children and young people with life-shortening conditions is also rising¹⁷. Hospices' ability to work in partnership and support other partners to deliver palliative and end of life care is a vital tool in making sure Scotland can meet this increased need and allows limited specialist palliative care resource to be used to best effect. Staff in hospices are often the innovators and catalysts for change who bring other parts of the system along with them. Hospice staff have identified increasing the support they provide to other partners, and building on the collaborative working forged during the pandemic, as a key priority for the sector moving forward.

“A lot of it relies on motivated individuals – in hospice teams there's lots of that, lots of creativity that benefits [other] workers.”

NHS palliative care member of staff

A partnership approach helps to effectively identify people with palliative care needs at an early stage, allowing them to get the support they need and plan ahead for their care at the end of life. Taking a proactive approach to palliative care results in better quality and longevity of life, as well as delivering savings to the wider health and care system¹⁸. There are positive examples of hospices working in partnership with GP practices, district nursing and social care to identify patients to be included in the palliative care register, and of hospices supporting and training care home staff on the use of screening tools and anticipatory care planning.

A growing number of hospices in Scotland are using approaches, such as Project ECHO, to support staff delivering palliative care in care homes, primary care and other organisations such as homelessness services. Hospices also provide specialist clinical expertise and support to other staff, for example through 24/7 phone support. Providing timely advice and support to clinicians in other settings represents significant value for money, being relatively low cost to provide with the potential of avoiding expensive healthcare use. An economic evaluation of the clinical support provided by Highland Hospice to non-specialist clinicians such as GPs showed an impressive return on statutory funding investment of 2939% (see case study on page 26)²⁵.

Hospices work closely with palliative care colleagues and other specialties in NHS settings, for example participating in managed clinical networks such as the Paediatric End of Life Care Network (PELiCaN). There are positive examples of hospice staff and hospital clinicians working closely together to support people with heart failure and in renal services. CHAS also has dedicated teams in all children's hospitals across Scotland.

Hospital-Based Children's Supportive and Palliative Care Team

Around a third of the 16,700 children across Scotland with life-shortening conditions have one or more inpatient stays in hospital during a year, and of those admitted to hospital, approximately 40% are either unstable, deteriorating or dying⁷. Since 2019, CHAS has funded Glasgow's Royal Hospital for Children to establish Scotland's first hospital-based Children's Supportive and Palliative Care team. The team consists of a consultant in paediatric palliative medicine, two clinical nurse specialists and an administrator, who work closely with other professionals within the hospital. The team aims to provide families with seamless and integrated care, and in its first 12 months 86 referrals (Sept 2019-20) were accepted by the team. The parent of a 1-year-old fed back that the team "have completely transformed our experience of the NHS's involvement in our son's life".

Hospices have a lot to gain from working more closely with colleagues from other sectors, such as shared learning and access to NHS resources. Hospice staff value the expertise that colleagues in other settings can provide around diagnoses other than cancer, for example neurological conditions and rare life-shortening conditions in children who are now living longer into adulthood. Care homes also have expertise to offer hospice staff in terms of caring for someone with frailty and advanced dementia.

“Hospices are not the experts at everything. Everyone needs to understand their bit of the jigsaw.”

Hospice clinician

Looking to the future, hospices want to continue to strengthen their relationships with other providers, particularly district nursing, GPs, social care, out of hours services, acute care and care homes. They also want to expand the support and education they provide to other settings, providing this is appropriately resourced.

As services become more integrated, it is important to keep patients and families at the heart of them. Individuals and families want seamless care when and where they need it, supported by the right staff. With multiple agencies involved, it can be a struggle for patients and families to navigate a complex system and this can sometimes lead to gaps in care. Hospices are integral in co-ordinating care and ensuring that the voice of patients and their families are heard.

“ Priority should be patient, and family, foremost! They often seem to get lost as ‘partnerships’ get developed. ”

Hospice clinician and member of senior management team

Reducing pressure on statutory services

People who are approaching the end of life are high users of healthcare. A snapshot of 11,000 hospital inpatients across 25 Scottish hospitals in 2010 showed that almost one third of patients were in their last year of life, with one in 10 dying during their current hospital admission¹⁹. 95% of people in Scotland use NHS unscheduled care services in their last year of life, representing a total cost of nearly £190 million³. People in Scotland typically spend more than a month of their last year of life in hospital, over several admissions, costing an average of £10,134 per person²⁰.

Integration authorities are operating in a challenging environment and face difficult decisions around which services to fund. The integration of health and social care was intended to help shift the balance of care from hospitals to communities, to enable people to receive more anticipatory care closer to home and to avoid people being in hospital unnecessarily, thus reducing demand on hospital services. However, there has been frustration at the slow pace of change²¹, with little difference in health spend going to hospitals in recent years and only a slight rise in community health service spend²². The system is likely to experience further tensions between the backlog of hospital treatments arising from the pandemic and the drive to focus on prevention and community-based interventions. The long-term economic impact of COVID-19 and the impact of a new National Care Service on commissioning processes and local and national structures, will all bring further challenges.

Hospice and wider palliative care services can help integration authorities respond to these challenges. Investing in palliative care services in the community can help make savings and reduce demand on hospitals²³. Evidence from seven European countries also shows that introducing palliative care programmes into care homes significantly reduces costs and prevents lengthy hospitalisations, while maintaining people’s quality of life²⁴. The case studies below demonstrate that hospice care in Scotland provides significant public value for money. It reduces demand on NHS services by reducing emergency admissions, reducing length of stay in hospital and facilitating discharges, and enables preventative investment that is supporting recovery, benefitting our wider public services and providing choice to individuals and their families. It also has wider societal benefits through improving quality of life, mental health and supporting carers to be able to return to work.

Economic Evaluation of Children's Hospice Care

An independent evaluation of CHAS's services concluded that CHAS provides over £49 million in benefit for the £6.8 million that statutory partners invest, demonstrating that CHAS generates £6.24 in public return for every £1 of statutory funding received²⁵. This encompasses the avoided use of NHS and social care services, and wider societal benefits such as adult carers of a child or young person with a life shortening condition being able to work because of the support received from CHAS. The evaluation also highlights the significant benefit that CHAS volunteers bring to the charity in terms of both capacity and value.

Economic Evaluation of Highland Hospice

An independent economic evaluation of services provided by Highland Hospice showed a significant return on investment through avoiding statutory health and social care resource as well as bringing wider societal benefits, in terms of improved mental health and quality of life²⁶. The total return on investment was 395.9%, or £3.96 public benefit for every £1 of statutory funding spent. Some of the returns are considerable, with day therapy, clinical support for palliative care specialists and for non-palliative care clinicians in the community returning the greatest value. For example, the clinical support Highland Hospice provides to non-palliative care clinicians, such as GPs, yields a return on investment of £29.39 for every £1 of statutory funding spent. This reflects the low cost of providing this service and the potentially high value of the alternative healthcare use which may result if the hospice service were not available.

Strathcarron Hospice@Home Service

Strathcarron Hospice's Hospice@Home service in Forth Valley provides high quality personal care to patients at home, as well as practical and emotional support to the patient and their family. It is delivered by a small team of health care assistants with specific experience and training in palliative and end of life care. An independent evaluation showed that patients being cared for by the Hospice@Home service experienced half the number of hospital episodes and on average nine bed days less than those who were not supported by the service – reducing pressure on acute services²⁷. The evaluation also showed very high levels of carer/relative satisfaction and that the service was well integrated into wider health and social care services.

Increasing care in the community

“ We need to meet unmet demand through community based solutions, not expansion of beds. ”

Hospice member of senior management team

Supporting more people to be cared for at home or in a homely setting is a key objective of health and social care integration and Scotland's National Health and Wellbeing Outcomes. COVID-19 has accelerated the trends we have seen in recent years towards more people dying in the community. If current trends continue and community capacity is increased, the proportion of people dying at home or in a care home could rise to two thirds by 2040⁶. The complexity of care in the community is also increasing and this is further complicated by more people living alone or without family and support networks nearby.

Staff providing children's palliative care also report an increase in complexity of need and that more of the families they support are living in poverty or experiencing domestic abuse or addiction issues.

The needs of people in care homes have changed dramatically over the years and care homes now represent a significant level of palliative care need. The average length of stay for people living in care homes for older people is 18 months²⁸ and the majority of people in care homes for older people have palliative care needs.

Recent polling data, commissioned by Hospice UK, suggests that the majority of people in Scotland would prefer to die at home. While 41% of 510 people surveyed don't have a preference or haven't thought about where they want to die, out of those who do have a preference, 82% say that they would want to die at home. Hospices are enabling individuals who wish to be cared for and die at home to do so, through hospice at home and other community services. Research has shown that palliative care at home teams improve patients' and family carers' experience and make them feel more secure when facing life-shortening illnesses at home²⁹.

“ Sometimes it's not about delivering care, just about another human being present. ”

NHS palliative care member of staff

Extension of Community Palliative Care Nurse Specialist Team

The Ayrshire Hospice Community Palliative Care Nurse Specialist (SPCN) team has increased their service, extending to cover 7 days a week. The aim is to provide support and advice for patients, families and other health professionals: improving continuity of care, reducing anxiety for patients and their carers, improve symptom management and avoid crisis situations leading to hospital admission if the patient's preferred place of care or death is home. Early evaluation has shown having input from the SPCN team has avoided crisis situations where previously patients would have been admitted to hospital.

Hospices are adapting and responding to meet increased need in the communities by increasing their community capacity, reviewing their models of care in the community and redeploying and reviewing their workforce, for example through extending their community nurse specialist teams. Prior to the pandemic, Scottish hospices had increased the number of patients they were seeing through outpatient clinics by over 50% in two years¹. Some hospices had also been reviewing their day therapy services, moving from a traditional day care model to services more focused on rehabilitation, wellbeing and self-management. Hospices are expanding the support they provide to other community health and social care staff through training and multi-disciplinary working. Ayrshire Hospice, for example, recently worked on a joint project with NHS Ayrshire and Arran to build capacity and strengthen skill mix around palliative care within community pharmacies³⁰. Highland Hospice has expanded its services more radically in response to community need by establishing a home care service. It is able to capitalise on its strong community links to employ care staff in areas where other

agencies have found difficulties in recruiting staff. Alongside its Helping Hands befriending service it provides an integrated community response to social care needs.

End of Life Care Together

End of Life Care Together is a partnership of Highland organisations with the aim of improving palliative and end of life care for people when it matters most. This is a novel collaboration with organisational lead from Highland Hospice, who are investing £1.5m in service transformation to deliver:

- screening and better identification of those at risk of dying in the next year
- a single electronic plan of care with read and write accessibility across health and social care providers, and with patient / family access
- a coordinated helpline accessible to patients, families, carers and professionals
- an increase in the provision of community care whether this be through structured statutory services or through community and voluntary supports

COVID-19 has hastened the changes that hospices had already been making to increase their community capacity. The sector is now looking at how to sustain successful models of care that have been introduced during the pandemic, such as rapid response services and virtual wards, over the long-term, as well as identifying further priorities such as increasing out of hours support and introducing single point of access. However, a sustained shift to community based care requires extensive collaboration with health and social care partners, alongside more support and funding from statutory partners.

“It’s a massive challenge for hospices resources and funding wise. How can we manage this innovation sustainably? We can’t just switch to this overnight. We’d need support from funders, statutory partners and government”

Hospice member of staff

Developing inpatient services to meet needs

Hospice inpatient services provide high quality, multi-disciplinary specialist palliative care to patients with complex care needs within the hospice. Approximately one third of people admitted to a hospice inpatient bed return home after a period of assessment, treatment or symptom control³¹.

While hospice staff placed a strong emphasis on shifting to more community based services, the majority felt that there would still always be a role for hospice inpatient care. Some hospices have reduced their inpatient beds recently in order to divert resources to community services, while others have increased beds slightly in recent years. Inpatient capacity depends on local need and what other services are available locally. It is important that this is considered across the health and social care system. For example, the two hospices in Edinburgh have participated in a review of beds across all services in Lothian, led by Edinburgh Health and Social Care Partnership.

“We still need beds as a safety net and inpatients are increasingly complex.”

Hospice senior management team member

Hospice staff are seeing an increase in complexity of need of people receiving hospice inpatient care, reflecting the changing demographics of the population. The way hospices are using their inpatient beds is also changing. Hospices are developing their inpatient services to better support people with conditions other than cancer, developing more rehabilitation and respite services to support patients staying for a short time, and developing respite services specifically for young adults and their families. The inpatient unit at Highland Hospice, for example, offers a specialist respiratory rehabilitation service for people with a life-limiting respiratory disease other than cancer, and a rehabilitation programme for people with neurological conditions.

Tackling inequalities

“ We should all have access to the same highly skilled care we receive coming into this world as going out. ”

NHS palliative care member of staff

People with diagnoses other than cancer, those over the age of 85, those that live alone, those from black, Asian and minority ethnic communities, those who identify as LGBTQ+ and those from deprived communities are all less likely to access palliative care^{32,33,34,35}.

We also know that life-shortening conditions in children are more common in South Asian and black families and that children with life-shortening conditions are 50% more likely to live in the most deprived areas of Scotland compared with the least deprived⁷.

Hospices' strong links with their local communities mean they are ideally placed to support the health and social care system to address these wider inequalities in palliative care. Factors such as someone's sexuality, whether they are from a minority ethnic community or living in a deprived or rural area, can all influence how likely it is that that person is identified as having palliative care needs. There are positive examples of

hospices working collaboratively to address this, for example hospice specialist community palliative care nurses working closely with GP practices to effectively reach people who live in more deprived areas.

Working with ethnic minority communities

Govanhill is among Scotland's most deprived and ethnically diverse areas. Fifty-two nationalities live here and 40% of residents belong to an ethnic minority. The area accommodates 3% more Asylum Seekers than the Scottish average. Govanhill sits in The Prince & Princess of Wales Hospice catchment. The hospice recognised the need to improve the referral rate from this community and delivered a needs-led education programme to local community organisations to improve their knowledge and understanding of the hospice and its services and how it can support local communities.

People in prison and people who are experiencing homelessness have complex and significant needs. Some hospices, for example Marie Curie, are supporting the delivery of palliative care to people in the prison population, identifying people who have palliative care needs and providing support to individuals, and to the team of health care and prison officers who work with them. Marie Curie Hospice Edinburgh also works collaboratively with the Edinburgh Access Practice, setting up a regular palliative care review meeting and supporting them to identify people in their care who are experiencing homelessness and who have palliative care needs. This has allowed a small number of individuals to be supported, mainly in the hostel setting. Staff have also been supported as part of a Project ECHO community of learning, led by St Columba's Hospice Care.

Homelessness and Palliative Care ECHO Network

Milestone House in Edinburgh provides short-term residential accommodation for people living with HIV or hepatitis C. At the beginning of the pandemic, it began providing stepdown beds for people experiencing homelessness who have been discharged from hospital, in collaboration with a new in-reach service provided by the Cyrenians. In discussions with St Columba's Hospice Care, managers at Milestone House felt it would be beneficial to staff to have space to discuss issues around death and dying and changes in their service provision. St Columba's Hospice Care established an ECHO network which included staff from Cyrenians and Milestone House, a GP from Edinburgh Access Practice, and staff from Marie Curie and Strathcarron Hospice. The ECHO network provided palliative and end of life care education relevant to homelessness settings, offered advice and support from peers and hospice colleagues, and is beginning to bring services that support people experiencing homelessness together to improve access to palliative care.

A recent report by Marie Curie and Dr Joy Rafferty from Strathcarron Hospice highlighted the significant challenges people experiencing homelessness in Scotland face around palliative and end of life care. The report called for urgent reforms to support better access to care, increased training and more tailored bereavement support³⁶.

Hospice and palliative care staff identified addressing inequalities as a key priority area where they need to go further as a sector to really make a difference. Scotland's last palliative care strategy had as its ambition that access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location³⁷. The survey results in Figure 2 below show that hospice and palliative care staff feel that there are still wide-spread inequities in access to palliative care in Scotland, particularly in relation to someone's geographical location, place of care, level of deprivation, diagnosis and age.

People in Scotland can access palliative and end of life care that meets their needs regardless of their:

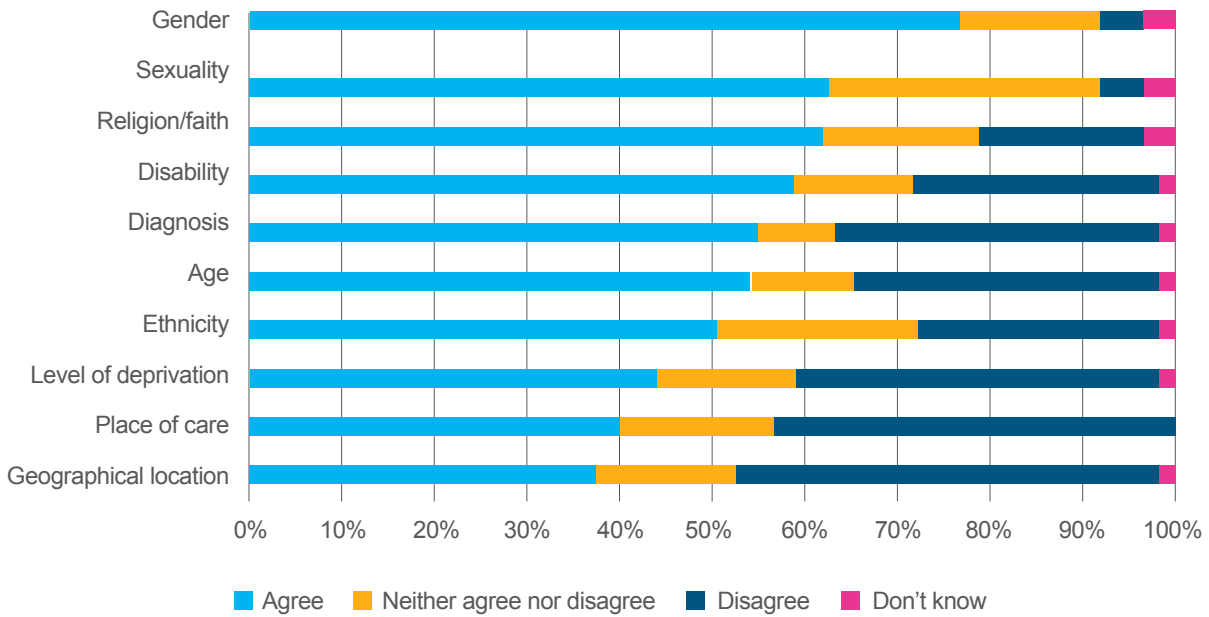


Figure 2: Hospice UK survey responses from hospice and palliative care staff on access to palliative and end of life care in Scotland.

The areas of unmet need that survey respondents identified as the highest priority were geographical variation in the care that people receive, particularly in remote and rural areas of Scotland, care for people with diagnoses other than cancer, including dementia, Motor Neurone Disease, frailty, multiple sclerosis, respiratory diseases, renal and cardiac failure, and care for young people transitioning from children’s services to adult services.

“The care provided to patients and families when their loved one is diagnosed with a terminal illness is purely a postcode lottery.”

Community palliative care member of staff in third sector

People highlighted positive examples of support for young people transitioning to adult services, in particular the support CHAS provides for young people during the transition period and services designed to support young adults at The Prince & Princess of

Wales Hospice. However, this was not felt to be consistent across Scotland. Staff felt that adult hospice and palliative care services do not always meet young people’s needs, that young people need more support through the transitions process, for example having a dedicated transitions lead, and that there needs to be greater collaboration between children’s palliative care and adult services. Developing a national, standard pathway for children with complex medical needs transitioning between child and adult services would be one way to support this.

“I haven’t seen any young people under the age of 20 in our hospice... and I wonder about the reason behind this and whether it’s the complexities of need/conditions that adult hospices are less skilled in.”

Hospice family support team member

Young Adults Transition Clinic

Development of young adult services is a priority for The Prince & Princess of Wales Hospice's future strategy. The hospice has piloted a Young Adult Transition Clinic that has demonstrated that it provides a safe and supportive environment in which young adults feel heard, in control of their wellbeing, and enjoy an improved quality of life. They have been able to demonstrate using the SHANARRI wellbeing indicators (safe, healthy, achieving, nurtured, active, respected, responsible, included) that young adults feel they are healthier, achieving, more responsible and feel more included. One participant commented: "The support of [Doctor] took much pressure off myself in terms of liaising between my different consultants. [Counsellor] saved my life in terms of mental well-being and it wouldn't be possible without [Lead Nurse]. The Physio has always been eager to help also."

Hospice UK recently published a report exploring inequalities in palliative and end of life care across the UK³⁸. As well as highlighting areas of good practice, it looked at common themes, including how the hospice and palliative care sector needs to be more grounded in the experience and wishes of the people it hopes will benefit, in all their diversity; how we need to move away from relying on a few committed individuals within communities, regions or services to see more proactive engagement by palliative care services across all settings; and how we must take an intersectional approach, considering how people are discriminated against and disadvantaged based on a multitude of characteristics, such as race, gender and socioeconomic status to help provide a holistic view of people's experiences.

Staff in Scotland recognised that hospices and their partners need a better understanding of need and unmet need across all parts of the community they serve. Actively going out and developing grassroots collaborations with local organisations and communities will help hospices gain a better understanding of what is stopping people from accessing services and help them develop services that are truly person centred. Compassionate community initiatives, which many hospices have developed to empower and strengthen the support in their local community, are a key opportunity for hospices to expand on their existing community links.

“We're guilty of thinking that one solution fits all, we don't listen to grassroots organisations and what would actually work. We need to truly be partners with these organisations. This hinges on compassionate communities.”

Hospice clinician and senior management team member

Increasing visibility and addressing some of the misconceptions around hospice care is also important. This includes working in partnership with other services to ensure that referrals into the hospice are encompassing everyone who can benefit from hospice services. Hospices are also looking at improving diversity within their own workforce and volunteer base.

“While many hospices may perceive themselves to be 'open to all' and welcoming, they are not aware of the need for deliberate outreach to ethnic/faith communities, so that there are closer links and families know the services which are available to them.”

Hospice family support team member

Supporting families and carers

Families and unpaid carers are incredibly important, providing round the clock care for their loved one, co-ordinating care across multiple agencies and ensuring that the voice of the person being cared for is heard. Carers save the Scottish economy an incredible £10.3 billion - close to the cost of providing NHS services in Scotland³⁹. The impact on people, including young people, caring for someone with a terminal illness is huge, and impacts their physical, mental and financial wellbeing⁴⁰. A lack of support can put both the carer and the cared-for person at risk of reaching crisis point, resulting in a breakdown in care. Timely intervention is crucial to support carers to live well and to carry out their caring role⁴¹.

M is a 69-year old lady, caring for her husband, who is referred to Compassionate Lanarkshire (CLAN) by the Community Liaison team for carer support. CLAN is a partnership project between Kilbryde, St Andrew's and Strathcarron Hospices which aims to support vulnerable and isolated individuals and families in Lanarkshire affected by a life-limiting illnesses.

M explained, "I am just not coping and feeling anxious...I need to speak with someone outside of the family but don't know where and who to ask".

She felt she was unable to share her feelings with her sons and that she had to cope alone. Due to COVID-19 M was not able to visit her husband in hospital and expressed, "I am so upset by this".

M had many questions with regards to the dying process, funeral plans, finances, housing. All were addressed by her support worker. M needed encouragement to share her feelings with her family and allow them to support her. This was achieved after several phone calls of talking and building up

M's strengths. She was then able to see that she would survive and flourish no matter how tough life ahead would be. By engaging in weekly calls M began to feel, "I can face my anxieties now". Her self-esteem returned, and she learnt it was better to confront anxieties and process her feelings to help her through her husband dying.

Case study provided by Kilbryde Hospice

The ethos of hospice care is about providing holistic care and support to an individual and their whole family. Hospice patient and family support teams include social workers, chaplains, counsellors and volunteers who provide a diverse range of support to families and carers including information services, financial advice and support accessing benefits, spiritual care, and counselling and bereavement services. Hospice at home and respite care also play a vital role in supporting and building the confidence of carers to meet the needs of their loved one and enabling people whose wish is to die at home to do so.

Respite and Response Service

Ayrshire Hospice's Respite and Response service is provided by a team of experienced specialist palliative care assistants who visit people at home. It delivers:

- Respite – planned regular visits of 3-4 hours, taking over the role of the family carer, to allow the family carer time to connect with their local community and/or support networks.
- Response – reactive in times of increased need when situations are changing. This could be in relation to end of life care needs or in response to a crisis, supporting people to die at home and caring for family carers who are often plunged into the caring role at a very challenging time.

The hospice is planning to extend this service to provide evening and overnight visits.

Out of hours and overnight care is a key area hospices wish to expand, to provide much needed support and respite for families and loved ones caring for someone 24/7. Overnight care would also support people who are living alone and wish to die at home. However expanding care out of hours and overnight is reliant on appropriate resourcing being in place.

“ Overnight support is the most asked-for from families. ”

Hospice clinician

Care 24 Lothian

CHAS has partnered with NHS Lothian to provide the Care 24 Lothian service, allowing children and their families to access specialist end of life care in their own home at any time. A family who used the service said: “The whole support at home was really amazing. I think it would have been so much more different for me and my grief if [child] died in hospital and we hadn't been given that choice, or in the hospice”. CHAS is keen to work with the Scottish Government, Health Boards, PELiCaN and other partners to consider how a specialist 24/7 at-home service at the end of a child's life can be sustainably resourced and delivered equally across Scotland.

Support in bereavement

Bereavement is a life-changing experience. For most people, the support of family and friends will help them through, but some people need extra help. Between 10 – 20 per cent of bereaved people will experience prolonged and debilitating grief⁴², and the impact of the COVID-19 pandemic means that more people are likely to be experiencing complex grief. Research in 2016 found that a quarter of bereaved people in Scotland who wanted support were unable to access it⁴³. The bereavement services hospices provide is key in addressing this need and the rapid expansion of hospice bereavement services during the pandemic has shown how responsive the sector can be.

Children and Families Support Service

The Children and Families Support service at St Columba's Hospice Care offers specialist support for children and young people (aged 0-16) across Edinburgh and the Lothians who are dealing with the incurable illness of a relative. It provides age-appropriate support, information and resources pre- and post-bereavement, and provides opportunities for families to come together to remember their person who died through a family remembrance day. The service works in collaboration with colleagues from other organisations across Scotland and the UK to improve outcomes for bereaved children, offering training and consultancy for schools and groups who work with children and young people and inputting into strategic developments. In the first two years of providing support, 102 families have been referred. The service recently piloted an online support group for teenagers bereaved of a parent, and all of the young people reported that it helped to lessen isolation in their grief and provided peer support. As one young person fed back: "I was able to open up and felt comfortable to talk about my feelings".

“The support and information we provide has made such a difference already to so many children and young people and families. If this support wasn't available then so many children and young people wouldn't have been afforded the opportunity for "goodbye" with their loved one. So many parents have said, if I hadn't spoken to you and gotten this advice then I would have just left it until after the death to tell them and I see now what a mistake that would have been.”

Family support team worker

“There is unharnessed capacity in the community to provide care and support. If we work with this capacity we can free up professionals to do only the bits they can do.”

Hospice community development staff member

A real strength of hospices is their links with their local community. Volunteers are an integral part of hospice care – supporting all aspects of hospices from fundraising and volunteering in hospice shops, to caring for relatives and patients. Without volunteers hospices would not be able to function. Across Scotland, approximately 8,000 people volunteer at hospices, donating 997,000 hours of their time each year¹. The strength of their volunteer base, and the profile that hospices have within their local communities, mean that hospices can be more responsive to local need and are often seen as hubs of the community. Hospices are well placed to mobilise the community to produce a rapid response when it is called upon. For example during the pandemic, Highland Hospice recruited and trained 60 volunteers to support Highland Home Carers, the largest care at home provider in the Highlands, to provide support if needed.

Volunteering also brings well documented benefits to individuals and communities, and ties into Scotland's National Performance Framework aim that "we live in communities that are inclusive, empowered, resilient and safe". As hospices face increasing social, economic and demographic demands, the need for volunteers is likely to intensify⁴⁴. However, the nature of volunteering is also likely to change significantly in the future, with changing demographics and age profiles of volunteers and shifting patterns around how people volunteer their time⁴⁵. The existing relationships that hospices share with their communities may need to be re-assessed to consider how best to address changes in both society and in volunteering.

Hospices help build capacity and resilience within local communities to support people who are experiencing death, dying and bereavement. The majority of Scottish hospices have compassionate community initiatives, often run in partnership with other community groups, which enable communities to find their own solutions to supporting people at the end of life. These vary from befriending services, to volunteers providing home support and respite for carers, to ensuring no-one dies alone. Ardgowan Hospice's Compassionate Inverclyde initiative, for example, is an award winning social movement that is helping to transform attitudes and everyday practices around loneliness, social isolation, death and bereavement across Inverclyde. The ethos is fundamentally about local people working alongside existing formal services enabling ordinary people to do ordinary things for ordinary people.

“ My father sadly passed away last week after a long stay in [Local Hospital]. During his last few days he and the family were supported by No-one Dies Alone (NODA) volunteers. My brother and I would like to express our gratitude for the help and comfort we were all given during this time. The volunteer companions were understanding and supportive and totally non-judgemental about the amount of time the family were able to spend with my father, allowing us to also spend time at home looking after our mother. ”

Family member

Helping Hands

Highland Hospice's partnership project 'Helping Hands' is a befriending service to help address isolation and loneliness. The service has four objectives: build

community capacity to deal with death and dying; support carers to sustain their caring roles; mitigate impacts of social isolation for clients; support wider health and social care system to cope with increasing demand. The project uses an innovative partnership approach with local communities and in order to extend the service across the whole Highland region it deliberately sought partnerships with small, locally run organisations with a close connection to their community. Local knowledge and contacts support the recruitment of volunteers and helps people feel more comfortable referring to the service.

Empowering and revitalising communities is becoming increasingly important as Scotland recovers from the impact of the COVID-19 pandemic. Hospices' ability to innovate results in a wealth of creative local partnerships within their communities, from social enterprises, partnerships with local colleges and mentoring and apprenticeship schemes for people in the local community.

Beauty with a Conscience

Beauty with a Conscience is an award-winning ethical social enterprise of The Prince & Princess of Wales Hospice. It is the only beauty salon in Glasgow which operates as a commercial venture with all profits going directly to the hospice to help care for patients with terminal or life-limiting illnesses. First established at the end of 2018, the salon also works in partnership with the local campus of Glasgow Clyde College, with beauty students carrying meaningful work experience in a real-life environment. It has been recognised by the SQA in winning the Scottish Qualifications (SQA) Star award for Innovation of the Year 2019 and was highly commended in the category for partnership working.

Taking forward change

Hospices have already significantly adapted and responded to the challenges that Scotland is facing and have prioritised areas for future focus. To sustain these changes and to enable the sector to further develop opportunities that benefit individuals, families, the health and social care system and society as a whole, a number of cross-cutting issues need to be addressed.

Enablers of change

Create the conditions for partnership working:

Partnership working underpins everything and is essential to enable hospices to expand their potential further. To enable collaborative working, there need to be strong relationships, good communication and motivated people. A key part of this is fostering a better understanding of each other's roles and greater recognition of what each service/partner brings.

“ What do our partners need from us and what do we need from them? ”

Hospice senior management team member

Lack of time and capacity was identified as the biggest barrier to partnership working, as well as different IT systems. Facilitating dedicated partnerships or specialist groups from across sectors can help partners to co-design solutions based on a shared understanding and common goal. Funding also needs to be more joined up so it facilitates joint working, and doesn't become a barrier.

“ We need to get away from a place where meetings are inhibited by politics around funding so that we are working together not competing. ”

Hospice clinician

Effective use and sharing of data: Only a third of hospice and palliative care staff surveyed felt that hospice care providers had access to the data they need to inform decisions about services and models of care. Local data about need and unmet need is necessary to inform strategic planning decisions across all partners, including hospices. Multi-disciplinary teams need to be better enabled through technology and the sharing of patient information. Integrated IT systems that allow hospices to have access to NHS held data, and NHS services to be able to access hospice held data, are key, so that patient data can be accessed in a timely way to support the delivery of better care. Some hospices are successfully moving towards this, for example St Columba's Hospice Care has moved onto the TrakCare IT system used by NHS Lothian, while others do not currently have routine access to health board-held patient data.

Integrating IT Systems

In 2020, St Columba's Hospice Care, National Services Scotland and NHS Lothian worked together to integrate hospice electronic patient records within NHS Lothian's TrakCare system aiming to improve patient experience and quality of care. The pandemic led to significant service redesign and as a result, a formal evaluation hasn't been feasible. However, operational evidence shows positive outcomes in enhanced communication and released clinical time, whilst reducing duplication and transcribing risks. Adopting TrakCare required some compromise as the system is not configured exactly for hospice services and requires third party IT support from NHS Lothian to address user issues which can result in delays. However, the significant benefits to patient care have made these compromises worthwhile.

Looking ahead, Scotland's plan for a National Digital Platform is an important opportunity to ensure that patient data and key information on what matters most to an individual is accessible across the health and care system at all times. Hospices need to be included in this development and be able to access, enter and update information within it.

“ An integrated system that everyone can access... a doctor in a hospital could access the info on a child who is in the hospice and vice versa. ”

Hospice clinician

Digital solutions: The pandemic has resulted in unexpected positive developments, such as the shift to more virtual services meaning that hospices have a wider reach and can support people they wouldn't normally have been able to, for example those who live too far from the hospice or were too sick to travel. However digital technology can also exacerbate existing inequalities, for example if people do not have access to appropriate technology or are not comfortable using virtual services. To support a more sustained shift to hospice virtual services, to complement existing face to face services, there needs to be good IT infrastructure and integrated IT systems. Hospice staff and volunteers need support around remote working, so they have the skills and confidence to optimise the technology, and to enable them to maintain the ethos of hospice care while not being physically present with individuals and families. There needs to be continued support for patients and families to use technology and to have access to the equipment they need, to ensure it is an equitable choice for people.

Prioritise palliative care at a local and national level and support a whole system approach: Two thirds of hospice and palliative care staff surveyed felt that palliative care is currently a priority at a local and national level. However the need for palliative care to be a higher priority was consistently raised as an issue during focus groups and interviews with strategic leads of palliative care services. An analysis of integration authorities' strategic commissioning plans found all but two integration authorities made reference to palliative or end of life care, with just over half identifying this as a priority.

Having a planned, population approach to palliative care, with a robust understanding of need and unmet need locally, should be a priority for joint strategic needs assessments and strategic commissioning plans, and involve all stakeholders, including hospices. It should be underpinned by effective use and sharing of data to drive decision-making and the design of services.

Health and Social Care
Partnerships need to undertake local needs assessments involving relevant stakeholders such as hospices, to work together and establish current and future needs for palliative and end of life care. Planning needs to be supported by good quality, accurate local data collections and analysis, which can be shared.

Hospice senior management team member

Palliative care is a cross-cutting issue and where it 'sits' within local planning structures is important. For example, it frequently sits under older people's care, which can result in it being siloed. Strategic leadership within palliative care is vital both locally and nationally. The commitment for a new national clinical lead for palliative care is welcome and hospice leaders look forward to working closely with them. At a strategic level, leaders within the charitable hospice sector have also identified the benefits of working more closely with leaders from NHS specialist palliative care, to represent specialist palliative care providers across the whole of Scotland.

Hospices as equal partners: All partners, including hospices, need to collaborate and be involved from the beginning in the strategic planning, design and delivery of palliative care services. Hospices bring significant funding and expertise to the table and need to be respected and included as equal partners. Only a third of hospice and palliative care staff surveyed felt that hospices were seen as equal partners in the strategic planning of palliative care services. Though relationships varied between different areas, there was a feeling that hospices were "at the table but not yet seen as equal partners". Some hospice staff felt that there is a perception that hospices only "jump in at the end" whereas so much more value is added if hospices are involved

from the beginning. Involving all partners and services equally will ensure that hospices are complementing and not duplicating existing services or left to pick up the gap from other services and risk becoming overstretched.

Everyone somewhat plans their own thing then hopes others will come and be a part of it.

Hospice clinician

We need to be an equal partner when working with others, otherwise we risk just absorbing the lack of other services and plugging an unfillable gap.

Hospice clinician

Sustainable workforce: A sustainable workforce of specialist and generalist staff delivering palliative care across all settings is vital. Only 17% of hospice and palliative care staff felt that there are sufficient number of staff with the right skills to meet people's palliative care needs currently in Scotland. Even fewer, only 8%, felt that there is adequate workforce planning and supply to have sufficient number and skills of staff in the next 10 years. Staff also felt that there needs to be more investment in palliative and end of life care education and training, especially of the generalist workforce, to meet demand and ensure a workforce that is fit for the future and responsive to people's needs.

The top three challenges hospice staff identified relating to their workforce are the difficulty for hospices to match NHS pay and benefits; attracting and recruiting sufficient staff to meet future demand; and retaining current talent. Addressing these requires support from Scottish Government and recognition by integration authorities as part of service level agreement discussions. The need for more investment, especially of the community workforce, was emphasised. Staff suggested

that more collaboration and flexibility of the workforce across settings and sectors would be beneficial, though this needs to be balanced against maintaining specialist staff's expertise. Suggestions included closer working with the NHS in terms of education support, seconded or rotating posts across different settings, more flexible career pathways, closer links between community nursing and hospice at home services, and joint investment and more opportunities for joint learning and development.

“ There needs to be joint investment in a culture of collaboration across the sectors. Partners investing together in education... and linking with the workforce of health and social care to meet a collaborative workforce model of care across sectors. ”

Hospice senior management team member

“ Can we not just pool resources and create a single team that's jointly funded? ”

NHS palliative care staff member

Within children's palliative care there are specific suggestions around specialist training to meet increasing complexity of need of children with life-shortening conditions, including developing a dedicated training programme for paediatric palliative medicine in Scotland and a Specialist Practitioner Qualification, at masters level, for community children's nursing.

Sustainable funding: The funding of palliative and end of life care to meet population need across all settings is a cross-cutting theme that underpins all discussions over the future of hospice care in Scotland. The shift to more community-based care is a key development that hospices felt could not happen in a sustainable way without support from statutory partners and an increase in funding across community palliative care services. If hospices are to expand the support and training they provide to other services such as care homes, then this needs to be recognised as a priority and be appropriately resourced and better co-ordinated at a strategic level locally. Similarly, hospices felt that outreach services needed to be more integrated and part of a properly funded system that reaches out to everyone with palliative care needs.

“ Health and Social Care Partnerships need to invest much more in our health and social care services in the community so that people get the care and support they need not just now, but for the future. ”

Hospice senior management team member

Staff felt that there needed to be a focus on the long-term, sustainable delivery of hospice care, rather than on short-term funding of projects that start and then disappear. On average charitable hospices receive 35% of their funding from statutory sources. Three quarters of hospice and palliative care staff surveyed thought that the current model of charitable hospice funding is unsustainable. While people were less clear on what a different model of funding could look like, the majority (three quarters) felt that there would always be a role for charitable funding and that this allowed hospices to be creative and innovative.

“ Grant funding does allow hospices to be innovative, but we can't continually be innovative without ongoing support. ”

Hospice senior management team member

The question of sustainable funding also raised issues around identity. Hospices are balancing being an active partner in the wider health and social care system with keeping their own identity. Some staff felt that the sector needs to be clearer about the hospice model that we want to be sustaining, with some suggesting that there should be core services that all hospices deliver and then tailored innovative services that individual hospices deliver to their local populations.

“ We need to reflect on our identity. What services can we continue with, what services don't add much value? ”

Hospice member of staff

Areas for collaboration and further action

This report is intended as a discussion document and highlights the opportunities for the hospice sector to work collaboratively with partners to meet the changing needs of their local population and to respond to the wider challenges facing Scotland's health and social care system. Hospice leaders are keen to engage with local health and social care services, community groups, integration authorities, Scottish Government, health boards, improvement bodies and other partners, to take forward the areas identified for future focus. In addition, the proposed new national strategy and national clinical lead for palliative care in Scotland will bring important opportunities to develop these discussions further.

The section below sets out suggested areas for future discussion, action and collaboration at a national and local level.

Steps to support progress at a national level:

- **Scottish Government, the new national clinical lead for palliative care, integration authorities, hospice leaders, palliative care partners, Hospice UK and the Scottish Partnership for Palliative Care** to take forward the areas identified in this report to inform development and implementation of the new national strategy for palliative care in Scotland
- **The Scottish Hospice Leadership Group and NHS specialist palliative care leaders** to work together to provide strategic leadership and a unified voice for specialist palliative care across the whole of Scotland, working with **the new national clinical lead for palliative care in Scotland and Scottish Government**
- **Hospice leaders, integration authorities and Scottish Government** to continue to engage over a sustainable funding solution for the hospice sector that recognises the increased need for palliative care services, changing models of care, rising costs such as parity with NHS salaries and other priorities identified in this report, as part of broader discussions to ensure funding for palliative care meets population need across all settings
- **Scottish Government, NHS Education for Scotland, hospice and NHS specialist palliative care leaders, professional bodies, workforce regulators and other partners** to work collaboratively around workforce planning, palliative and end of life care education and investment, and strategies to support and retain current staff, to ensure there are sufficient numbers of staff with the right skills to meet people's palliative care needs in the future, including within children's palliative care

- **Healthcare Improvement Scotland and the Care Inspectorate** to discuss how their joint inspections of integration authorities' strategic commissioning processes can encourage a greater focus on the strategic planning of palliative care services to meet population need
- **Hospices, Healthcare Improvement Scotland, research organisations, Scottish Government and other partners** to identify what support is needed to further develop and use the evidence base for hospice and palliative care, evaluate service improvements and support improved patient care
- **Hospice leaders** to work with **NHS Education for Scotland Digital Service** to ensure that hospices are fully involved in developments around the National Digital Platform
- **Hospice leaders and the palliative care sector** to continue discussions with **Scottish Government** on how the sector can best support the upcoming reforms to social care to ensure they work for people with palliative care needs and recognise the contribution of the sector
- Understanding unmet need and inequalities in palliative care, prioritising this in local population needs assessments and strategic commissioning plans, and working jointly to understand what matters most to people in all parts of their community and how to reduce barriers and inequalities in palliative care
- Strengthening local partnership working between hospices and other services, in particular district nursing, GPs, social care, out of hours care, acute care and care homes
- Building resilience and capacity within local communities to support people with palliative care needs, their families and carers
- Reviewing local IT systems and working towards integrated systems that allow information to be shared and accessed between hospices, NHS systems and social care
- Expanding the palliative care education and support that hospices deliver to other providers, and ensuring this is resourced and joined up strategically at a local level
- Reviewing local palliative care workforce models to foster more flexible and integrated working both within hospice care and across other settings

Steps to support progress at a local level:

Integration authorities, health boards, hospices, local health and social care services across all settings and community groups to work together as equal partners, to discuss and address the areas outlined in this report that they identify as particularly relevant to them, such as:

- Taking time to understand each other's roles, what each partner brings and how best to foster partnership working and shared goals for palliative care locally
- Assessing local population need for palliative care, particularly in the community and out of hours support, and developing services and models of care that are sustainable and meet people's needs

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