



Future Vision Cymru **Seamless and Sustainable**

Report on engagement discussions
and ways forward

Executive summary

As part of Hospice UK's Future Vision programme, Seamless and Sustainable in Wales engaged health and care professionals working across the spectrum of specialist and generalist palliative care for children and adults, as well as people with lived experience of care, to discuss the future of integrated community palliative care.

As well as capturing examples of effective whole-system or integrated approaches to community palliative care, we heard about the significant challenges and opportunities facing the sector, including the impact of, and responses to, the COVID-19 pandemic.

Emerging as a priority for action was ensuring that children and adults at the end of life have appropriate care available to them overnight. This arose from focused discussions on the 24/7 care agenda and on ensuring coordinated access between families and services that highlighted the particular needs of people during the out of hours period as well the significant variations in approach and provision across Wales.

Targeted work to fill gaps in our knowledge and understanding of the overnight offering of care at home across Wales is needed if the prospect of an equitable whole-system 'Wales offer' of palliative care is to be taken forward in a way that meets the needs of children and adults towards the end of their lives, as well as those of their carers and loved ones.

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Next steps

The National Programme on End of Life Care, hospice and palliative care providers, Welsh Government, NHS Wales and Social Care Wales leads for primary and social care, and Hospice UK should consider our joint roles in taking forward the following recommendations to inform national policy direction and to implement local system change at pace:

- Address gaps in knowledge about the whole system approach to 24/7 care across Wales with a focus on the priority of meeting the overnight needs of children and adults at home at the end of their lives, as well as the needs of their families, carers and loved ones, with the view to providing equitable services across the country.
- Through national direction, explore a consistent approach to meeting the need for a human single point of access for adults in the community at the end of life, in line with the offering in the children's sector.
- Under the National Programme and in conjunction with local partners, take a consistent approach to developing community hospice and palliative care, which provides clarity on the balance of central steer and local implementation.
- Take action to promote formal and informal education and skill-sharing to improve capacity across the palliative and end of life health and care system, for professionals in the social care, primary care or specialist palliative care disciplines.

About this programme

Future Vision is Hospice UK's programme engaging partners in a coordinated way to share current innovation, practice and ideas in order to strengthen the sustainability of palliative and end of life care for the future.

In Wales our work under this programme, Seamless and Sustainable, has brought together professionals working across the health and care system to address the challenges we face in working in a more integrated way to meet the future need for greater palliative and end of life care in the community. At every point we have striven to be informed by what matters most to people with lived experience of care.

We embarked on this work with the aims of:

- Informing the national programme for end of life care, including by involving people with lived experience
- Bringing system partners together
- Identifying and sharing existing models of seamless community care
- Exploring potential 'solutions' and identifying the first steps needed to achieve these, particularly for the areas seen by colleagues as a priority: 24/7 and coordinated care.

About this report

This report summarises the discussions from engagement activities with people with lived experience and professionals from across health and care as part of the first phase of the Future Vision programme in Wales. It does so through sharing examples of existing or developing models of seamless end of life care in Wales with a particular focus on delivering 24/7 care at home and on models of coordinating care. Where not otherwise stated, all quotations are taken from the discussions held in this series.

Published as the National Programme for End of Life Care is being developed, this report offers ways forward at a national level to explore models of collaborative care that will contribute towards an equitable 'Wales offer' of palliative care, no matter what the setting.

Informed by hospices and colleagues from the health and social care sector alike, the examples and ways forward in this report will be of interest to local and national organisations, professionals and service leaders working across community palliative care, whether from a charitable, health or social care background.

Hospice UK will pursue opportunities to act on the ways forward in this report by facilitating openings for national and regional partners to work collaboratively and by drawing on our resource and expertise to fill gaps in knowledge.



“Families are saying ‘we can manage the daytime, it’s the night time’. Services are reduced at that point and you feel a lot more on your own.”

Hospice family support team

Context: the need for seamless and sustainable community palliative care

Health and care systems across the UK are striving to respond to increasing future need with limited financial and workforce resource. Current approaches – or doing the same thing – isn't sustainable. This calls for a transformative approach.

Unmet need and future need

Whilst recognised as amongst the best in the world, palliative and end of life care services as they are currently organised in Wales are not reaching everyone in need. Pre-pandemic, an estimated one in four people were missing out on the right palliative care, which is equivalent to around 6,600 people in Wales each year. Our geography, with swathes of rurality and a varied distribution of palliative care facilities, and our relative deprivation intersect with demographic characteristics and illness profiles with the effect that not all people have the same access to palliative care in their local communities.



Our current approach is not sustainable: to meet future need in line with current trends in individual preference for end of life care, community palliative care and care home capacity will need to double by 2040.²

Projections indicate that our ageing population, with children and adults living longer with more complex needs and multi-morbidities, will contribute to an increase of 25 per cent in palliative care need by 2040.

National policy

A Healthier Wales,³ the Welsh Government's plan for health and care, sets out a transformative vision to meet future need by taking a whole system approach where new models of care are made seamless and delivered as close to home as possible.

Beneath this high level strategy sits the National Clinical Framework,⁴ which sets out the role clinicians across specialist, primary and community care play in the delivery of more integrated clinical pathways. Palliative and end of life care has been recognised in this Framework as a cross-cutting field that would benefit from a more centralised approach through a National End of Life Programme.

The Review of Specialist Palliative Care, or the Stocktake, set against a backdrop of progress made in the field over the past two decades, makes recommendations for the future direction of palliative care in Wales under the National Programme. Recognising the changing landscape of the sector, recommendations about an equitable 'Wales offer' of palliative care, developing the workforce and responding to new flexible models of care are rightly set in the context of the need for a population needs assessments for children and adults.⁵

Integration

While traditionally recognised through financing and strategy as a health priority, the philosophy of palliative care, which cares for the whole person and the people that matter to them, lends itself to an integrated approach. As well as health professionals – both specialist in palliative care and generalists such as community nurses or GPs – people with life limiting or terminal conditions and their loved ones may need support through respite, personal care, appropriate housing, financial support and spiritual care.

As early as 2008, the Sugar Report, which has shaped palliative care improvement in Wales, noted “the patient does not need to know who delivers their care, only that they will follow a seamless care pathway. This strong theme of joint working is vital to the success of palliative care services in Wales and needs to be the driving force for the future.”⁶

Broad input to the National Programme from people with experience of care and a wide circle of professionals beyond specialist care will serve to develop higher value interventions and promote better outcomes for people, in line with the principles of value based health care. An integrated approach and a seamless experience of care will therefore need to be at the heart of a National End of Life Care Programme that delivers on A Healthier Wales’ vision.

This is set within the developing landscape of integration across Wales. Regional Partnership Boards are identified as the Welsh Government’s preferred vehicle for delivering on the transformations needed to achieve the vision of A Healthier Wales. New models of seamless community palliative care will need to form part of the Regional Partnership Board agenda and, as outlined in the Future Vision Discovery Phase,⁷ palliative care providers such as hospices will need to engage as partners in their regional integrated systems if they are to keep pace with change.

COVID-19

As well as highlighting the value and importance of palliative and end of life care amongst the public and decision makers, the COVID-19 pandemic has changed the landscape of palliative care.

37,789 people died in Wales during 2020, a marked increase on previous years with 3,979 ‘excess’ deaths in comparison with the five year average.⁸ Set in context, the COVID-19 pandemic saw palliative and end of life care need increase to the level of demand that was previously predicted to be reached in 2040.⁹ Significant trends emerging since the pandemic include:

- In 2020 deaths in care homes in Wales were 19% higher than the previous five year average¹⁰
- Deaths in hospital from causes other than COVID-19 were markedly lower than in previous years.

32% ↑

Deaths in private homes in Wales were 32% higher in 2020 than the previous five year average, a trend which continued through 2021

COVID-19 has driven rapid developments in integration and greater collaboration between services for the benefit of people at the end of life, as well as fast-track adoption of technology to deliver care. The Welsh Government’s ‘Health and social care in Wales – COVID-19: Looking forward’ highlights the new models of integrated care under the Transformation Fund and the Integrated Care Fund,¹¹ such as rapid discharge from hospital to home and preventing admission, that have been significant contributors to the regional COVID-19 response.

Notably, hospices report greater demand for end of life care in the community and have played a significant role in facilitating rapid discharge from hospital to home, care home or hospice at end of life. The pandemic has also shone a light on the fragility of hospice funding and refocused the Welsh Government’s commitment to reviewing hospice statutory funding based on changing demographic need.¹

Learning from discussions on 24/7 community care and coordinated access for people and families to palliative care services

People with lived experience and professional experience of community palliative care joined us in discussions about the future of seamless community palliative care. Discussions on either the theme of 24/7 community end of life care or coordinated access and communication between services and families demonstrated that no one experiences these issues in isolation and no service exists in a vacuum. Themes, challenges and shared solutions necessarily overlap between the issues, which involve system wide challenges.

“ Families are saying ‘we can manage the daytime, it’s the night time’. Services are reduced at that point and you feel a lot more on your own. ”

Hospice family support team

People’s needs

The needs of children and adults at the end of their lives and their loved ones and carers were central to these discussions. Needs discussed as part of this phase and in our wider engagement with people with lived experience could broadly be separated into the need for:

- Support to navigate a complex system and a variety of organisations and services at a time of emotional strain
- To prioritise relationships and memory making, by being a family or a unit at the end of life, which for some means being at home or in a homely environment

- Urgency and rapidity of response from a person, not a machine, who has the skills and knowledge to react or advise appropriately
- Skills to care, such as the administering of pain relief or medications.

The latter two needs were seen to be of heightened significance during the overnight period.

“ Families don’t always need a nurse at home, but they need a nurse at hand. ”

Palliative care nurse

“ You might have to tell your story to ten different people. Where is that central portal? Why do you have to keep repeating? Central coordination and data. It still doesn’t seem to exist. ”

Family carer

**“Everybody is busy.
There’s an inability
to roll out what
is working well.**

**We need the support
and capacity to
move forwards.”**

“ Waiting on hold for 20 minutes to speak to a healthcare professional can feel like a very long time when you’re witnessing someone you love in pain. ”

Family carer

Overnight care

Overnight care was an area that consistently featured as a priority for people and families as part of this programme, as well as an area recognised as a priority for policy makers in Wales over the past two decades. In 2015, responding to the recommendations set out in the Sugar Report of 2008, Wales was the first country in the UK to provide round the clock consultant advice to clinicians caring for adults and children at the end of their lives.¹²

While there is consistency of consultant advice 24/7 to care providers around Wales,ⁱⁱ it was clear from discussions between professionals and people with experience of care alike that there is considerable variation in the offer and provision of home-based overnight care and support for people at the end of their lives across the country.

Models of overnight care for adults across Wales varied by:

- The hours of operation, with health board out of hours arrangements operating at different hours, some hospices offering different services through the night, some offering extended in-hour services and some open only during traditional working hours.
- The organisations and teams involved: this includes the statutory health providers ranging from specialist palliative care community teams, district nurses and GPs, charitable hospice teams providing either specialist advice, hands on hospice at home care or night sitting services, and domiciliary care workers providing personal care.
- The professional roles, and the skills they bring with them, involved in the care.

For families of children needing overnight end of life care there appears to be greater consistency, with the Paediatric Palliative Care Network taking a Wales-wide central role in driving uniformity of both offer and provision. Variations arise, however, because of the local availability of children’s community nurses skilled in paediatric palliative care and families’ distance from services such as the children’s hospices.

Across both children’s and adults’ services there were questions about workforce capacity, in terms of the numbers of people available to support overnight care and the skill mix needed to deliver appropriate care. This was seen against the backdrop of increasing need and demand for end of life care at home during the COVID-19 pandemic.

While variation in provision is not in and of itself a weakness, the lack of knowledge and understanding about the situation across the country means that we do not know whether the experience of variation is leading to better or poorer outcomes for people in different areas. A significant contributor to the lack of national overview for overnight care across the regions seems to be because the models of care needed are whole system in their approach, involving specialist palliative care, primary care and social care providers, with no one national or local strategy for each of these encompassing the system in its entirety.

Without a Wales-wide overview of the state of overnight care and its impact on people – either through this programme or in existing knowledge bases – we are unable to make judgements about whether experiences are equitable across Wales. It was clear from discussions as part of this programme that further structured exploration and action is needed to understand whether variation is leading to systemic differences in outcomes for people.

A coordinated and comprehensive national approach and overview will be essential if a Wales offer for palliative care is to be forthcoming as part of a future National Programme.

Doing things differently

We heard of several regions or systems working in integrated ways to meet the challenges of providing care overnight. Of these, there is learning and considerations that will be of value to those looking to transform or evolve their overnight end of life care at home offering.

Of the models we heard of, some are designed to enable workforce capacity to flex in response to variable need:

Charity funded Registered Nurses for overnight care

Recognising that there was no equivalent provision from the statutory sector in its area, Magnolia Cancer Charity in Neath was set up to provide out of hours end of life palliative care nursing for local people who wish to spend the last days of their life in their own home.

In the initial trial for this model of care an experienced Registered Nurse was contracted through a nursing agency to provide overnight care in a person's own home for as long as this was needed – from discharge from hospital until the person's death. This ensured wrap around care for the person and their family with in-hour services from the statutory sector so that the person was free from pain and in their preferred place of care and loved ones were fully supported and reassured.

Learning and discussion:

- » The charity took on the responsibility of coordinating agencies to ensure the care was experienced as seamless for the person and their family, highlighting the importance of the coordinator role.

- » Using a nursing agency means that the service is responsive to individual need, including the duration of care, and local population need, such as the number of people who need this care at any given time, without the need for the charity to commit to employing a set number of people or hours.
- » Further work is needed to understand the skills needed by the attending nurse; should this nurse have training in palliative care? What level of skills or experience is needed by the attending nurse – is a Registered Nurse always necessary? What role does specialist palliative care have in this model, whether at the bedside or in an advisory or supervisory role?
- » With projected increases in the number of people requiring end of life care at home there are questions about the sustainability of a model that relies on fundraised income to plug the gaps in statutory provision.

Cross-organisational teams to care for children at home

Responding to family preference for end of life care at home for two children in the Hywel Dda region concurrently, and that during the pandemic, required cross-organisational team working between the Hywel Dda Community Children's Nurses and Tŷ Hafan nurses. Led by the Paediatric Palliative Care Nurse in the region and drawing on the COINS (Children's Outreach In Reach Nursing Service) bank, the pooled workforce meant that appropriately skilled teams were available to care for the children and families for five out of seven nights a week over an extended period.

Learning:

- » Honorary joint contracts can be established rapidly when needed, ensuring good governance with regards cross-organisational working.
- » Working across organisational boundaries and drawing on specialist hospice nurses builds capacity, skill and expertise across the workforce around the family.
- » Pooling, and therefore expanding, the workforce allows greater flexibility and longevity to respond to the uncertain trajectories of some children at the end of life.
- » Despite additional resource, pooling the workforce was still not able to meet the preference of some families to have day and night care seven days a week.
- » For those staff who are part of the COINS bank, there is an ongoing need to maintain education and skills in paediatric palliative care so that staff deployed flexibly are appropriately skilled.

Others take a place-based approach and embody integration within, rather than between, teams:

One team responding to all needs

Select local district nursing teams across Aneurin Bevan University Health Board, Powys Teaching Health Board and Cwm Taf University Health Board were chosen to trial a neighbourhood district nursing approach, where one local team was responsible for the personal care and home health needs of a defined geographic area, based on the Buurtzorg model from the Netherlands. Teams comprised of Registered Nurses with community nursing qualifications, health care support workers and administrators. The pilots were designed to provide a seamless experience of care through the one-team approach and also to encourage greater self-management by people of their conditions. It is not clear how this translated for end of life care or how this was experienced by families.

Learning and discussion:

- » Full evaluation of these pilots has not been possible due to the impact of the COVID-19 pandemic. We do not yet know the extent of the impact of this approach specifically for people and families at the end of life, though the initial evaluation suggests there is scope for further exploration.¹³
- » Continuing Healthcare funding is a potential resource to enable more teams, both statutory, charitable or combined, to explore the one-team approach to end of life care at home that covers social and health care needs.

- » Organisational and governance barriers exist to charitable organisations, including hospices, taking the lead on local area CHC budgets, despite sometimes being in the best position to lead this work. There would be value in exploring how these barriers can be broken down, including looking at examples of this in practice in England.

Alternatively, there are examples where systems are loaded to minimise the need for professional involvement at home overnight:

The non-specialist and the unpaid workforce in rural areas

With no seven day palliative care Clinical Nurse Specialist service and no overnight district nursing service because of the impact of rurality on workforce models, people at the end of life in Powys who need care at home overnight are supported by evening support from domiciliary carers and through the out of hours priority palliative care line provided through ShropDoc. Emphasis is placed on the preparations that can be made in-hours, such as Advance and Future Care Planning through the bespoke 'My life my wishes' document, and through the upskilling of unpaid carers to administer subcutaneous medications through the CARiAD project (carer administration of as-needed subcutaneous medicines for breakthrough symptoms at home).

Learning and discussion:

- » For those people with no carer at home, sometimes home will not be a viable place of care, leading to inequity in the offer in Powys.

- » People in rural areas, where there are smaller but older populations and significant distances from services or hubs, make the reality of an equitable 'Wales offer' difficult in practice. There may be a need to work differently to achieve the same outcomes. Alternatively, there will be some opportunities to combine resources nationally or with bordering health boards.
- » This approach expands the workforce to more formally recognise the roles of unpaid carers and social care providers in the provision of end of life care. This cannot be done without investment in training and support.
- » Again, Continuing Healthcare budgets offer opportunities for truly integrated care.
- » Communities are recognised as an asset in this approach, providing useful learning for the Compassionate Cymru approach to end of life care.

Coordinated communication and care

The role of a key worker or a named coordinator to act as a family liaison and to support navigating the system was cited by contributors as a strong way forward both from professionals and carers alike. There was the view that key working for palliative care should reach across the health and care system, learning from the successes of key working in social care, and could be one way of improving equity in access to care for some groups:

“// Key working works in the social care sector. It’s embraced. An ideal would be to allocate a key worker across agencies, both health and care. There are certain groups that would work well for, including vulnerable adults. //”

Children’s hospices are leading the way with key workers and teams around the child already in place for the families they care for.

Given the broad nature of adult palliative care and the scale of the need drawing on multiple agencies, key working for the adult sector was seen as even more important and potentially more impactful for those needing care.

Despite this, discussions about the key worker role have taken place over many years but programmes have not moved beyond pilots.

The Marie Curie Dying Well in Wales lecture on 23 July 2021 discussed the role of care coordinators within palliative care in comparison with similar roles for specific diseases and conditions. Panellists recommended that a key worker or coordinator for palliative care would need an understanding of the entire patient pathway and a presence within multi-disciplinary team meetings to function effectively.¹⁴

With reference to the limited capacity of statutory services and acknowledgement that key working is, for some, seen as an additional service, the specialist knowledge and involvement in the multi-disciplinary team meeting that hospices can offer were cited as making them “ideally placed to provide that service.”

The hospice-led care coordination role has significant overlap with the coordination of care overnight:

Coordinated out of hours end of life care service across north Wales

Within a few hours of being notified Tŷ Gobaith in partnership with Betsi Cadwaladr University Health Board can provide out of hours end of life care for any child in any location. No organisation was able to do that on their own because of the challenges around resourcing at short notice. Key to the success of the service is the central coordinator, provided by the hospice 24/7, who plugs into nine different local teams to source the right people in the right place to provide the care a family needs.

Learning and discussion:

- » The coordinator of rapid end of life care is in addition to the key worker service, or the Team Around the Child, which every child and family cared for by Tŷ Gobaith is assigned.
- » Making the service work has required each service to relinquish their perceived ‘ownership’ of the child and family and to consciously involve and work alongside other teams, ensuring the family is at the centre.

» Coordination of services needs a person to take on this responsibility – someone who can answer the phone and be a central point of contact between other services. The hospice, as a charity with the ability to flex and be dynamic, was in the best position to be able to create this role.

Alternatives, or supplements, to the key worker to provide coordinated care for families also included a ‘no-wrong door’ policy, where the burden is placed on providers to ensure a person gets the support they need, regardless of whether the contacted provider was the ‘right’ provider from the system’s perspective to deal with the carer query. There was acknowledgement that this is happening to an extent, though in an unplanned and unsustainable way:

“ Families are contacting hospice direct because they can’t contact the district nurses. ”

Priority phone lines, such as the ShropDoc palliative care triage covering Powys, were cited as a positive example of ensuring that families get timely and appropriate communication when they need it, including out of hours, without the formal role of a key worker.

“ You need to get someone on the phone who can help – centralised, who knows all the different services and can help the patient & family have a seamless journey. All the organisations within each health board need to come together – have a centralised access point, don’t have 20-30 different access points/signposts, people and families don’t have time. ”

Providing an access point staffed by an appropriately skilled and knowledgeable workforce was seen as essential for people needing end of life care in the community:

Integrated specialist and generalist out of hours hub in Cardiff and Vale

Piloted pre-pandemic and continuing ever since, the Cardiff and Vale out of hours integrated primary care hub co-locates a palliative care Clinical Nurse Specialist, from City Hospice or Marie Curie Cardiff and Vale, with the primary care team during the daytime each weekend. The CNS is able to advise callers with palliative care needs and their carers with expertise and knowledge and to use clinical judgement to determine what further immediate action, if any, is needed, such as a home visit by the on-call CNS, a GP or to request advice from the on-call palliative care consultant.

Learning and discussion:

- » Co-location of generalists and specialists provides informal education opportunities through skills and expertise sharing.
- » Co-location also has the benefit of encouraging the feeling of integrated working, breaking down cultural barriers.
- » There are already challenges around the seven day working agenda in terms of CNS capacity – this model increases the pressures already felt by the workforce.
- » Families are directed to the right care, taking a prudent approach.

For adult services there were questions about whether a phone service should be provided at a local, regional or national level, with some people suggesting that a Wales wide hub could provide a sustainable solution. Children's palliative care services are already working at a level wider than regional with the two children's hospices offering this service across North and South Wales.



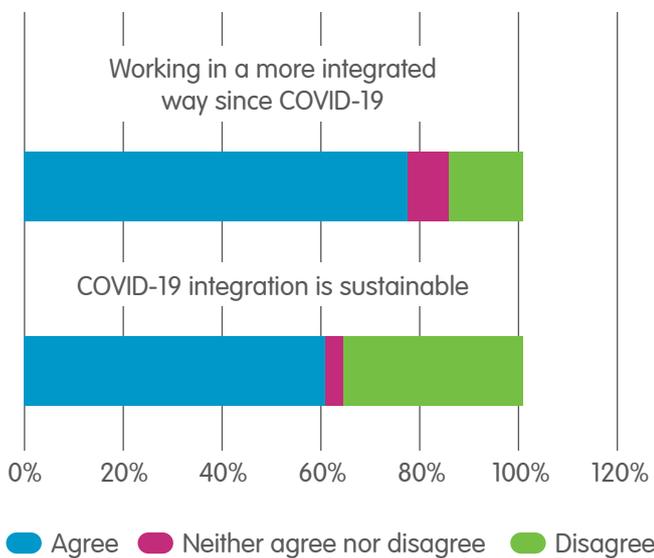
**“There is so much
good practice
throughout Wales -
it needs to be shared
and promoted.”**

Enabling seamless palliative care

Contributors to our discussions explored some of the wider issues and challenges within the system that impact both on the models of seamless overnight care and coordinated care as well as on broader approaches to community palliative care for children and adults.

The COVID-19 pandemic

COVID-19 as a driver for integration and collaboration



The COVID-19 pandemic was strongly seen as a driver for greater integrated working across organisational or sector boundaries, with 77 per cent of respondents agreeing that they work in a more integrated and collaborative way since this pandemic. 61 per cent of respondents agreed that these changes would be sustainable in the longer term, with 37 per cent of people disagreeing.

Can-do attitudes throughout the pandemic have fast-tracked integrated working and approaches to improve the patient journey and the experiences of people at the end of their lives:

Rapid discharge from hospital to home at the end of life

At the height of the pandemic the hospital discharge coordinator, Clinical Nurse Specialists and palliative care teams at South Pembrokeshire and Withybush Hospital worked in partnership with Paul Sartori Hospice at Home to ensure that greater numbers of people approaching the end of life were supported to be discharged rapidly from hospital and cared for at home for their final days. This involved Paul Sartori coordinating with the person's family and carers, ensuring the right equipment is in place in the home and managing a care package that includes overnight respite and occasionally personal care where a care package isn't otherwise in place.

Working across organisational boundaries to support end of life care in care homes

Responding to the rapid decline and high death toll from COVID-19 in the care home sector, St David's Hospice Care flexibly deployed one of their palliative care Clinical Nurse Specialists from the community hospice team to be stationed with care homes in need. This meant that residents sadly dying from COVID-19 were able to access care from a specialist in palliative care and that the care home workers were upskilled in palliative care to be able to care for more people at a time of unprecedented demand.

Despite the COVID-19 pandemic being attributed as the enabler to greater collaboration contributors commented on the impact the pandemic continues to have on their capacity. There was a shared view, supported by data, that demand for care in the community has increased since the pandemic and that services were also picking up additional work where non-statutory services had pulled back. Despite progress for some, others described the pandemic as a period when it has been impossible to take a step back and make strategic changes.

“Everybody is busy. There’s an inability to roll out what is working well. We need the support and capacity to move forwards.”

Stronger central guiding hand

Echoing the recommendations of the Parliamentary Review on Health and Social Care in Wales, there was a shared view that a ‘stronger central guiding hand’ for seamless community palliative care is needed.¹⁵ Within this view is the recognition that palliative care exists as a specialism, on the margins, but transformation requires a central steer to bring it in line and coordinate with transformations in the wider health and care sector.

“What are other groups looking to find solutions, such as district nurses and primary care? We need to join up with other services across Wales. Our part of the system needs to be linked in with those areas.”

Variation was the overwhelming theme across all discussions but there was a desire to see greater oversight and shared knowledge facilitated at a strategic level. Differences in community

hospice and palliative care models were seen as in particular need of strategic direction, having evolved in a fragmented way across Wales in response to local approaches. The lack of strategic direction for specialist community services was interpreted as an undervaluing of the approach, despite its centrality to the realisation of the Welsh Government’s vision to bring care closer to home:

“There has been no national plan to standardise community hospice care. It’s the poor relation.”

The recommendation of a ‘Wales offer’ outlined in the Review of Specialist Palliative Care is an opportunity to strike a balance between equitable offers of care across Wales, enabling the public to have clearer expectations about their rights to palliative care, and the local implementation of this offer.

Participants highlighted the importance of sharing good practice across the country and the value in coming together to learn. It was clear that professionals on the ground in some regions of Wales weren’t aware of the models of seamless care in other regions. There was also a feeling that a national steer is needed to reduce variation and to roll out effective models that have been tried and tested locally. People told us:

“That there is so much good practice throughout Wales - it needs to be shared and promoted.”

“How a more ‘All Wales’ approach is needed to best meet the needs of our palliative and EOL patients.”

A template for a stronger central steer for adult palliative care is already present in the managed clinical network for paediatric palliative care in Wales. There were several examples of the children's sector finding central or 'once for Wales' solutions to seamless community care that warrant further exploration by the adult sector.

A flexible and learning palliative care workforce

“ The workforce response to the population projections needs to be about looking at the models we've got, and it won't be all about an increase in workforce. It will be about how they work differently. ”

As well as the need to increase numbers within the wider palliative care workforce, which was seen as requiring commitment at a strategic level from the Welsh Government, Health Education and Improvement Wales and Social Care Wales, it is seen as necessary to work more flexibly as part of the wider health and care system. There was likewise a frustration that this hasn't happened at pace or at a whole system level.

“ This agenda has not progressed. We have to be able to change. We need to sit down collectively. ”

Implicated in some of the discussions about responding to people's needs, particularly overnight, was a productive questioning of the division between specialist palliative care professionals and those 'generalists', such as GPs, district nurses and domiciliary carers providing hands on care to people at the end of life. These conversations echoed the recommendation for sustainability in the Future Vision Discovery Phase to 'deploy the right people around the patient' without necessarily splitting the workforce rigidly along the lines of specialist and generalist. Instead, some people referred to more fluid divides, intermediate community teams that encompass both specialists and generalists or "palliative care champions" bridging the gap.

The importance of skills and education, formal and otherwise, was raised across all settings. Co-location of the specialist and generalist workforce was cited as a productive way of skills sharing and experiential learning, either with specialists placed in primary care settings or through co-location of specialist community services within hospices:

“ Can hospice be the centre of excellence out of which all NHS services are based? The workforce from the NHS across the region should be part of the hospice team. Welsh Government should put the resource where the specialism is. ”

“This agenda has not progressed. We have to be able to change. We need to sit down collectively.”

Next steps

This programme has so far been concerned with taking a whole system approach to visioning the future of seamless community palliative care. We acknowledge that there are power dynamics at play within the system: various organisations and teams are seen to have a larger or smaller stake in the conversation; the size, constitution or financial strength of organisations affects the roles they can play; and the continuous imbalance of power between people who need care and the services that provide care all lead to challenges in bringing people together as equal partners in a whole system approach.

However, to be transformative, a whole system approach requires coproduction, conversation and shared commitment. In that spirit, we offer the following ways forward as joint challenges for partners to take forward in response to the Seamless and Sustainable programme to inform national policy direction and to implement local system change at pace.

The National Programme on End of Life Care, hospice and palliative care providers, Welsh Government, NHS Wales and Social Care Wales leads for primary and social care, and Hospice UK should:

- Address gaps in knowledge about the whole system approach to 24/7 care across Wales with a focus on the priority of meeting the overnight needs of children and adults at home at the end of their lives, as well as the needs of their families, carers and loved ones, with the view to providing equitable services across the country.
 - » Nationally addressing the significant gaps in knowledge about the whole-system models of overnight care for people at home at the end of their lives across Wales.
 - » Nationally and locally, undertaking research to understand the need for hands-on overnight care at home, both for adults and children, now and into the future based on population projections to enable data-driven decision making.
 - » This will involve building relationships with local systems, involving specialist palliative care, primary care and out of hours care, and social care.
 - » Ensuring that overnight care at home for adults and children at the end of their lives is prioritised in national planning.
- Through national direction, explore a consistent approach to meeting the need for a human single point of access for adults in the community at the end of life, in line with the offering in the children's sector.

This should include:

 - » Prioritising the need for a human response overnight by exploring a priority phone line for people at the end of life staffed 24/7 by a person who is appropriately qualified to manage immediate need or to escalate to clinicians.
 - » Promoting the keyworker or coordinator role in the adult sector for people at home at the end of life, and for adults with additional vulnerabilities, and recognise the value this brings in the children's sector. Charitable hospices are ideally placed to explore this role.

- Under the National Programme and in conjunction with local partners, take a consistent approach to developing community hospice and palliative care, which provides clarity on the balance of central steer and local implementation.

This should involve:

- » As part of a 'Wales offer', developing a shared understanding of what community palliative care services are needed and wanted by the population to ensure local service development is in line with national expectations.
- » Engaging Regional Partnership Boards in the conversation about integrated community palliative care for older people, including within care homes, and disabled children.
- » Nationally and locally exploring the opportunities of developing and expanding the use of Continuing Healthcare funding to develop integrated community palliative care approaches.

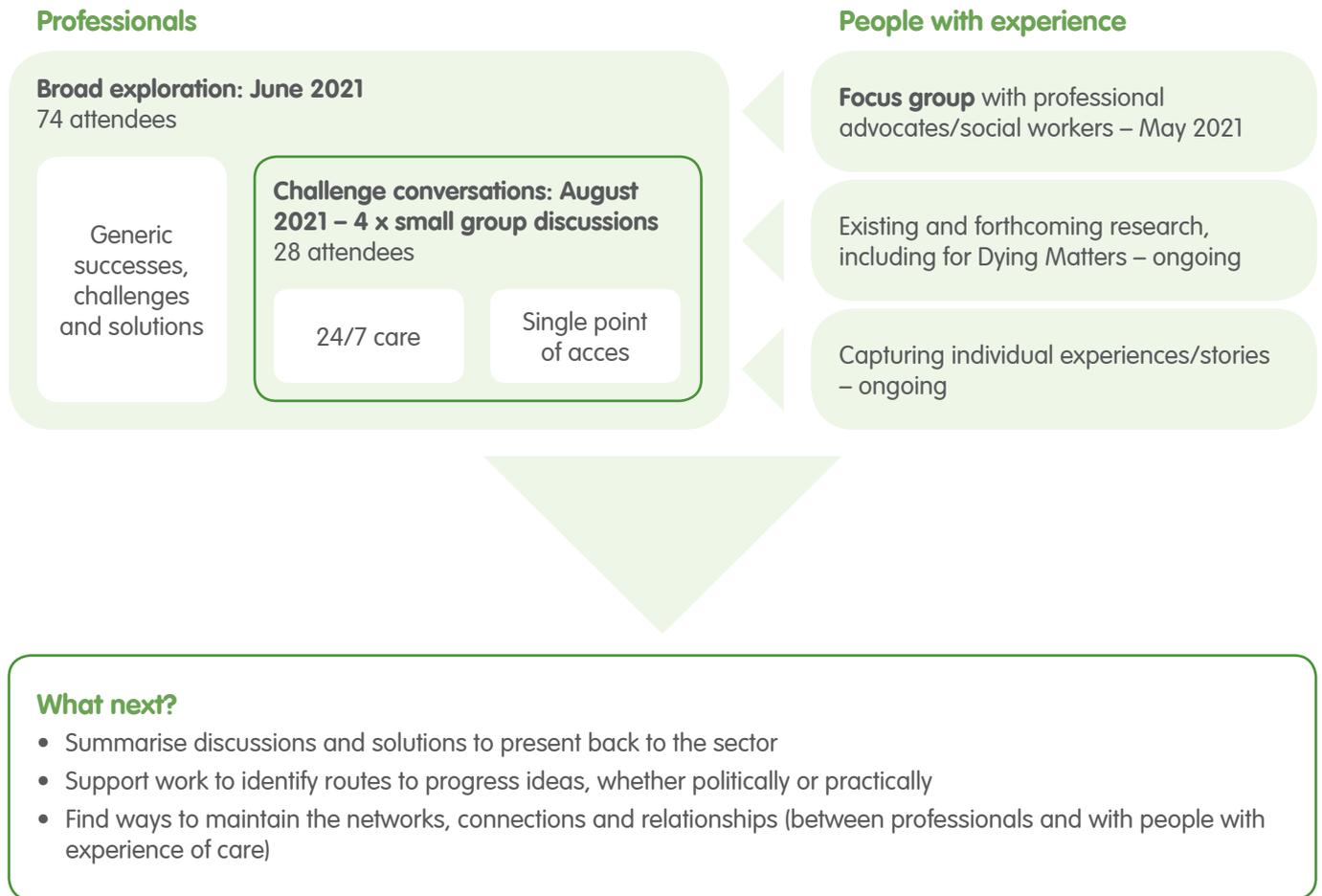
- Take action to promote formal and informal education and skill-sharing to improve capacity across the palliative and end of life health and care system, for professionals in the social care, primary care or specialist palliative care disciplines.

This should involve:

- » Recognising the value of co-location. Hospices are ideally placed to serve as experiential learning sites for all professionals with an interest in improving their skills and the seamless approach to palliative care.
- » Strategic approaches to palliative care education for specialists and generalists, led by Health Education and Improvement Wales and Social Care Wales in conjunction with the National Programme for End of Life Care.
- » Building and maintaining the networks developed in this programme with an interest in improving the experience of seamless community palliative and end of life care, including through exploring options such as developing communities of practice.

Annex

Programme structure



Over Spring and Summer 2021 Hospice UK conducted a series of interactive and participatory sessions with professionals working across specialist palliative care, primary care and social care, and with people with lived experience of care. These were informed by existing research conducted by Hospice UK through the Dying Matters campaign, research undertaken by collaborator organisations working with people with experience of care and through a structured focus group with advocates of people with experience of care. Crucially, we spoke to individuals with experience of caring for a loved one at the end of life at home or in the community to hear their stories, to understand what mattered most, and to learn about what would have made a difference to them and their loved one.

Our sessions with professionals, also attended by people with experience, engaged with more than 80 individuals. Taking a co-productive approach we gave attendees space to talk about the issues that mattered to them and committed to following in the direction, or directions, they identified. From the initial launch and exploration meeting – which covered the models of integrated care participants were proud of, what their greatest challenges are and what changes they had made – we supported 74 individuals, both professional and with experience of care, to further explore two areas of significant interest and challenge. In the second phase, our Challenge Conversations, we dived deeper into the wicked problems of 24/7 care in the community and the need for coordinated services and accessible communication

between families and services. 28 individuals who had expressed their interest were involved in this phase; they were drawn from all regions across Wales, worked with children and adults, had a mix of personal and professional backgrounds from statutory, private and third sector organisations and had roles in specialist and generalist care from medical, nursing, allied health, family support, care home and advocacy.

This report is a summary of the discussions that took place during those meetings and the testimonies we heard from people with experience of care as well as recommendations about the changes needed to drive seamless and sustainable community palliative care in Wales.

Sharing the concerns, ideas and themes from the discussions across the sector and with decision makers is one of the steps Hospice UK will take to further the improvement of seamless and sustainable community palliative care.

Acknowledgements

Hospice UK would like to thank and acknowledge the contributions, conversations and engagements we had with people with lived experience of care to date as part of this programme. We hope your priorities to improve care overnight for people in their own homes is reflected in this report.

We give special thanks to the guidance provided by the Steering Group members who gave direction and focus to this programme.

Finally, we're grateful to all professionals from across health and care who joined our discussions whose interest in, and commitment to, improving the community palliative care for the people they care for was evident in all they shared.

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- i. The Welsh Government’s Programme for Government commits to undertaking a review of hospice funding. The outcome of this review is expected at the time of publication and will form the first phase in a wider review.
 - ii. See the Stocktake for consideration of the sustainability of the 24/7 consultant advice, including for paediatric palliative care.



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