

Palliative and End of Life Support in Place-Based Care in Wales

Report for Marie Curie

October 2022

1 Introduction and summary

This report has been prepared by the Institute of Public Care at Oxford Brookes University following a short study undertaken with and for Marie Curie in May and June 2022.

The purpose of the study was to consider the emerging characteristics of placed-based primary, community and social care in Wales, and the implications of this approach for end of life services across the country. It is hoped that the report captures some of these implications and that it offers a useful contribution to thinking in Wales and beyond about this important subject.

The study involved interviews and focus group meetings with over 70 people from all parts of Wales, including people with lived experience of palliative and end of life care, professionals working in the field and sector leaders. The interviews and meetings were the primary sources for this report, along with a review of national policy and relevant published literature from across the United Kingdom. All of those interviewed were assured of anonymity and gave their time freely. The ideas in this report were generated by the interviewees and we are hugely grateful for their contributions. Of course, we remain responsible for the limitations and any errors.

“Comments from people with lived experience and from professionals are included in the report to illustrate key points and themes. They are included as quotations in boxes like this.”

This is a particularly challenging time for people, professionals and leaders in Wales. The impact of the Covid-19 pandemic is still being felt, and we are facing a difficult economic environment. Health and social care demand and capacity have in some ways never been so unbalanced. A lot of people have been exhausted by the last 2 years. Many services continue to rely heavily on staff good will and additional efforts. We try to recognise these challenges in the report, but not to be frozen by them. Perhaps, despite or even because of these challenging times, there is now an opportunity to explore steps forward that would not have been considered possible in previous decades. It is hoped that this report offers a small contribution to that debate, and that it serves its primary function to stimulate further discussion and action. In summary the report suggests the following:

- The principles of place-based care underpin a key strand of thinking about the future of community-based health, care and wellbeing in Wales.
- Welsh Government remains committed to these place-based care principles as part of its Covid recovery programme, and our interviewees were supportive, seeing them as key in achieving better outcomes and experiences for people at the end of life. The idea of ‘place-based care’ needs to be understood as a continuum of services at different levels from national to regional to local areas.
- Demand for high quality palliative and end of life care is likely to continue growing for the foreseeable future and Welsh Government is committed to continued improvement in this area. There are many people who have experienced exemplary palliative or end of life care and really value the ethos and principles which underpin

them, but not all experiences are positive, and there is more to do to build greater consistency and reliability of care.

- Better place-based community provision is key to supporting people in their own home, and reducing the need for inappropriate hospital care. Primary care clusters may be the starting point for designing local place-based provision. Palliative and end of life care needs to assert itself as part of a whole place-based care local network supporting people with the full range of different needs and this will require wider engagement with other community services.
- There are developments at national, regional, local and provider levels which might help palliative and end of life care services move forward as part of a place-based approach to care in Wales. At a national level this might include common locality service models, encouraging pooled resources, and seamless practice and systems.
- At a regional level this might include rethinking commissioning and partnership arrangements, investing more in community-based care, developing staff and exploring how palliative and end of life services might become more embedded in the wider community offer.
- At a local level this might include agencies working together to develop and pilot more mature partnership arrangements and ensuring that the ethos and skills of palliative and end of life care inform wider practice.
- For palliative and end of life specialist providers this might mean building more effective partnerships with other agencies, and working with commissioners on creative ways of funding services and working together for the benefit of all people in a local area.

2 Place-based care in Wales

2.1 Place-based care in theory

The term 'place-based care' is one of a number of overlapping terms used across health, wellbeing and social services to describe the ambition for more effective seamless local care. It tends to be concerned with local community and primary health services, local voluntary and charitable care services, local authority social care and wellbeing services, and how these promote the health and wellbeing of people, patients and carers of all ages in their local community. Our interviewees broadly agreed that the following principles underpin the idea of place-based care:

- Health, care and wellbeing services planned, managed and delivered together to meet the needs of a local community, town or primary care cluster area.
- Better shared understanding by these services of community needs, aspirations and social capital leading to joint actions and shared resources.
- More joined-up health and care support in people's homes resulting in less need for them to go into hospital, nursing or residential homes or hospices.
- Sufficient professionals with generalist skills and local knowledge to respond effectively to people with a range of different health, care and support needs.
- Multi-disciplinary community teams working together, often based in the same place, taking a holistic view of someone's needs and offering personalised care.
- Shared records and information systems.

- Better digital and technology-based approaches to treatment helping to support people to remain living at home.
- Partnerships with the local community to promote asset-based development and to support people quickly and flexibly when they need help.
- Greater co-production, choice and control over their care for people, patients and carers.

Place-based care is primarily an idea and a set of principles. It is about ways of working and it covers a huge range of different services. It needs to be interpreted and applied locally to be really meaningful. There is no standard blueprint, but the idea does challenge the ways in which health, care and wellbeing services have worked in the past. It tries to address some of these common criticisms:

- Services not thinking hard enough together about how to engage people with lived experience of care, or about how local communities can promote health and wellbeing - leading to separate rather than joint plans to support them.
- Different sources of care and support which are uncoordinated and difficult to access. 'Vertical' alignment of services within different agencies rather than 'horizontal' alignment of services across agencies.
- People spending unnecessary time in hospital, hospice or care homes because there isn't enough support to help them stay at home.
- Professionals with complicated referral arrangements which make support slow and cumbersome.
- Different records systems which undermine effective care co-ordination between professionals.
- Insufficient recognition of the importance of family, voluntary and community care support in promoting people's recovery and longer-term wellbeing.

In practice, of course, what constitutes a 'place' varies according to where you are and according to which services are involved. Some – such as GP practices, local schools, community centres or domiciliary care – may have sufficient frequency to be 'clustered' together within a local town, valley, school catchment or health centre. Others with lower volume or very specialist provision – for example tertiary hospital care, specialist care homes or a hospice - need to be geared towards the needs of people living in a much wider area.

In Wales currently the potential for improving place-based working is being particularly explored at a primary care cluster level. There are 64¹ primary care clusters across Wales and each is different, involving different population needs and strengths, and very different resources. Each 'place', whether based on primary care boundaries or not, needs its own way of working out how services and standards need to develop – perhaps guided by regional and national examples of good practice.

¹ Clusters are sixty four groups of neighbouring GP practices and partner organisations across Wales which provide services for their local populations of between 30,000 and 50,000 people.

“There should be a key individual who knows the patient, who can draw together the different services - be it a nurse, a doctor, or a volunteer - to facilitate communication and arrange an appropriate treatment plan that would work for the patient, whether they’re being cared for at home or wherever.”

2.2 Place-based care in policy

‘Place-based’ principles have been a crucial part of peoples thinking about the future of health, wellbeing and social care for years, and they have underpinned many major policy developments in Scotland², England³ and Wales⁴.



(Diagram above from Welsh Govt ‘A Healthier Wales: our Plan for Health and Social Care’ 2018)

The challenges presented by the Covid-19 pandemic and the subsequent recovery period demands now facing the health and care system have strengthened rather than weakened the resolve of partners in Wales to drive forward more effective local ‘place-based’ primary and community services. So for example in 2021 the Welsh Government reconfirmed its intentions that:

“Primary and community care are at the heart of Wales’ communities and the core of our NHS and the vision for the future. A Healthier Wales sets out the intention to create new models of seamless health and social care. Local cluster primary and community care providers are the foundation for collaboration and innovation.”⁵

In the 2021 NHS Guidance to Local Health Boards in Wales about their priorities for 2022-25 Welsh Government re-affirmed this when it specifically said:

² For example The Scottish Government ‘Health and Social Care Delivery Plan’ (December 2016).

³ For example Department of Health 42 Integrated Care Systems are to be established across England on a statutory basis on 1 July 2022, following Royal assent of the Health and Care Act (2022).

⁴ For example Welsh Government: ‘Social Services and Wellbeing (Wales) Act’ (2014), and Welsh Government ‘A Healthier Wales; Our Plan for Health and Social Care’ (2018).

⁵ Welsh Government ‘Health and Social Care in Wales – COVID-19: Looking Forward’ (March 2021)

“The Primary Care Model for Wales sets out how primary care will work within the whole system to deliver a place based approach... Cluster working is at the core of this as it brings together local health and care services to ensure care is better co-ordinated to promote the wellbeing of individuals and communities. Primary care cluster planning should continue to be taken forward through the multi-disciplinary, multi-agency cluster planning teams and reflect all partner contributions to improving cluster population health and wellbeing.”⁶

The same priorities are reflected in three current initiatives from Welsh Government. Firstly in its 2022 plan to reduce waiting lists Welsh Government states that:

“More care and support will be available from a wider range of local services and healthcare professionals to help you stay well and remain at home. We want to provide local access to diagnostic procedures, with more tests undertaken at the same time, and transform the way we deliver outpatient services to focus on more efficient and effective services – some may be available closer to home.”⁷

Secondly, in its 2022 plan for urgent and emergency care it states that:

“Health and social care organisations should work in collaboration with public service and third sector partners to deliver a coordinated, integrated, responsive health and care service, helping people to stay well longer and receive proactive support, preventative interventions or primary treatment before it becomes urgent or an emergency. People should access appropriate and safe care close to home, and with as much continuity of care, as possible. Admission for ongoing care to an acute hospital bed should only occur if clinically necessary.”⁸

Thirdly, the national Accelerated Cluster Development Programme is concerned with supporting place-based approaches including through Professional Collaboratives and Clusters, whereby GMS practices, Dental practices, Community Pharmacies, Optometry practices, Community Nurses, Allied Health Professions, Social Services and others come together within their profession specific groups across a cluster footprint to consider:

- How they respond to Regional Population Needs Assessments.
- The quality of their service offer.
- How they respond to national strategy and design local solutions based upon their detailed knowledge and expertise.

⁶ Welsh Government ‘NHS Wales Planning Framework 2022 – 2025 (December 2021)

⁷ Welsh Government ‘Our programme for transforming and modernising planned care and reducing waiting lists in Wales’ (April 2022).

⁸ Welsh Government ‘Right Care, Right Place, First Time: Six Goals for Urgent and Emergency Care - A policy handbook 2021–2026. (May 2022)

In summary:

- The principles of place-based care underpin a key strand of thinking about the future of community-based health, care and wellbeing in Wales.
- Welsh Government remains committed to these principles as part of its Covid recovery programme and programme for Government.
- Our interviewees were supportive of the principles of place-based care and viewed them as key in achieving better outcomes and experiences for people at the end of life.

3 Palliative and end of life care in Wales

3.1 Palliative and end of life care provision

The importance of effective palliative and end of life care as part of the panoply of health and care provision cannot be overstated. A few statistics from 2 recent Marie Curie reports give a sense of the need and some of the challenges even before the Covid-19 pandemic⁹:

- Usually, around 34,000 people (1.1% of population) die in Wales each year and at least 75% would benefit from some form of palliative and end of life care. However, for many reasons 25% of these people will not have access to the care that they need to die well.
- By 2040, the number of people needing palliative care is expected to rise by 42%, and in 20 years there will be 100,000 more people dying each year in the UK. Deaths at home are expected to increase by over 88% in Wales and England.
- Just 7% of people expressed a preference for dying in hospital, yet that is where nearly half of all deaths take place.
- Across the UK charitable hospices are the main providers of specialist end of life care. Only around 30% of their income currently comes from government sources. The remainder is raised through community fundraising, charity shops and their own investments.

Services across Wales are, of course, still dealing with additional demands and reduced capacity as a result of the last two years of the Covid-19 pandemic. Palliative and end of life care comprises a wide network of services usually including some combination of the following.

⁹ Marie Curie 'A Place for Everyone - What stops people from choosing where they die?' (2021) and Marie Curie 'Response to Commons Health and Social Care Select Committee Inquiry into DH White Paper (2021)

People concerned with palliative and end of life care as one aspect of their wider role and responsibilities

- Family, friends and local community.
- Local befriending, advice and support.
- Information, assistance and advice from local agencies and national charities.
- General primary and community health services such as GPs, health centres, district nursing, virtual wards, community nursing, therapists, counselling, nursing homes.
- General social care services such as social work, domiciliary care, residential care, direct payments, aids and adaptations.
- General secondary and tertiary health care from specialist hospital departments and community hospitals and health centres.

People with an ongoing specialist role in palliative and end of life care

- Specialist palliative medical, nursing and therapies (including counselling, physiotherapies and OTs).
- Hospice provision and in-patient units.
- Hospice-at-home services including overnight care.
- Community managed specialist palliative care services.
- Bereavement and after death advice and support services.

Palliative and end of life care is by no means the exclusive preserve of specialists who have a prime responsibility in this area. Interviewees for this report were clear throughout that to have an effective network of care and support for people with palliative and end of life care needs requires:

- All professionals involved to share a common understanding of the aims of palliative and end of life care.
- Everyone to have a core set of communication and empathy skills.
- Clear professional responsibilities and good communications between specialists and generalists services.
- Willingness on the part of professionals to see families as primary and equal partners in their work together.
- A level of consistency about the standards of care expected in each local area across Wales.

3.2 Palliative and end of life care policy

Palliative and end of life care is increasingly recognised as an important area for development and improvement in Wales. The Welsh Government has committed to becoming a Compassionate Country and is working with Compassionate Cymru to understand what matters to people and improve how people in Wales care, die and grieve.¹⁰

¹⁰ See <https://compassionate.cymru/>

The Welsh End of Life Care Board Implementation Group finalised its review of Specialist Palliative Care Services in Wales 2010–2021, and made recommendations including a single ‘Wales offer’ for palliative care services across settings and modernising funding arrangements for statutory services and voluntary hospices.¹¹ Subsequently The Welsh Government has committed to focus on end of life care and to review of patient pathway planning and hospice funding in its 2021-26 Programme for Government.¹² Welsh Government is also committed to a National Clinical Framework and underpinning quality statements to guide the development of clinical services in Wales, and the Quality Statement for End of Life Care is expected to be published in the summer of 2022.

In summary:

- Demand for high quality palliative and end of life care is likely to continue growing for the foreseeable future.
- The Welsh Government is committed to continued improvement in palliative and end of life care.
- Many different professionals, particularly in the community, have an important role to play in making sure that high quality palliative and end of

4 Place-based palliative and end of life care

Although there is a very active policy agenda, some important commitments by national government and increasingly clear expectations on services in Wales, the people we talked to for this report described a very challenging environment facing both specialist palliative and end of life support, and community services more widely at the current time. Despite the best efforts of many dedicated and resourceful professionals and leaders they include:

- Very significant staffing capacity and resource issues, including huge difficulties in recruiting and retaining experienced staff across the sector.
- Difficulties in co-ordinating support for people in the community due to staff shortages and additional demands through the Covid-19 pandemic.
- Families finding it hard to get the right information and the right support when it is needed, particularly out-of-hours.
- Too many people having to remain in hospital because the right support is not available in the community.
- Carers not getting access to respite care or support when they need it.
- Families not feeling fully involved in care decisions, and people with lived experience of palliative and end of life care not having sufficient opportunities to inform and guide policy and practice.

¹¹ NHS Wales: Review of Specialist Palliative Care Services in Wales 2010 – 2021’ (July 2021)

¹² Welsh Government ‘Programme for Government – Update’ (December 2021)

- Concerns that some places are far better supported by community-based palliative and end of life care than others, and are able to draw on greater available social capital in their local area.
- Old-fashioned information systems and records which do not enable professionals to share information or take a holistic view of a person's needs.
- Over-heavy reliance on a very high level of contribution by the charitable sector to the cost of core palliative and end of life care.
- A wide range of targeted national funding initiatives which support short-term service development but not long-term sustainability.

“The consultant saw us for about 5 minutes, he was in a hurry and had virtually walked out the door before we left, saying ‘I’m sorry there’s nothing we can do, it’s not worth having any treatment.’ We were in shock afterwards.”

“I’m sure they’re busy and they’ve got rules but they don’t really listen, they come with an agenda and you fit the agenda as opposed to them listening to you and then working out the agenda.”

This is not the whole story. Many people described examples of very high quality care and support, well-timed interventions and effective networks working well together in their local ‘place’. For some people, palliative and end of life support was something very special indeed, and a huge support physically, psychologically and spiritually. The key point though, is that these are inconsistent, with great variation across the country. Some particular concerns cropped up consistently with regard to place-based care:

- Palliative and end of life care does not fit neatly into a simplistic ‘place-based’ model. The spectrum of support ranges from the most intensive and technical health care provision needed by a relatively few people in very specialist facilities, right through to universally available local health and wellbeing support needed in every local community. The idea of ‘place-based care’ therefore needs to be understood as a continuum of services at different levels from national to regional to local areas.
- Local ‘place-based’ care is particularly concerned with the skills, knowledge, systems and capacity to support people in their local community, as provided mainly by ‘generalist’ services. These local places need specialist and intensive support to be wrapped around them, available when they are not able to support people from within their existing resources. If these local place-based services are not invested in sufficiently then demand will inevitably fall upon the specialist and intensive services. Place-based approaches will require palliative and end of life care services to be much more embedded and ‘horizontally aligned’ with other services in local communities.
- Parts of the country are finding it very challenging to build better place-based care in general for their local populations. It is not clear that the policy aspirations of the Welsh Government are being implemented in practice as quickly as it might wish. The demands of the Covid-19 pandemic have had an influence on this but while there is almost universal agreement about the aspiration, many professionals and leaders remain reluctant to make some of the changes needed to deliver community-based care in local areas.

- As demand has increased and services have been stretched, some families have felt unsupported. For some, the quality of support from community-based generalists has not matched that from palliative and end of life specialists.

“It feels pretty much like a two-tier system quite honestly, inhabiting different worlds at times.”

- There is a concern for many people that an unintended consequence of the strong local charity sector involvement in specialist palliative and end of life care is that better-off and more resourceful communities may have far better local palliative and end of life support than poorer, less well-resourced areas. Any emphasis on ‘place-based’ care needs to be balanced by a distribution of resources across the country which recognise different levels of need, and a clear requirement that all local areas will meet consistent national standards of quality and capacity.

“The sense of relief for me of having her somewhere like (the hospice) was huge because I knew she’d be well looked after. You get a sense of community, that everybody involved is pulling together, and trying to do their best.”

- The data and information base which underpins palliative and end of life care, particularly that concerned with the needs and services for people who are supported in the community by non-specialist services is weak, and needs further improvement.

In summary:

- There are many people in Wales who have experienced exemplary palliative or end of life care and really value the ethos and principles which underpin them.
- Not all experiences are positive, and there is more to do to build greater consistency and reliable quality.
- Some community services are really struggling at the current time, due particularly to high recent demands and staff shortages.
- Nevertheless there is an important opportunity to consider how more local, place-based palliative and end of life care can be developed across Wales in the future.

5 Place-based palliative and end of life care in the future

5.1 Is place-based palliative and end of life care the right way forward?

The emphasis that place-based care puts on integrated and seamless support in the community presents a challenge to palliative and end of life care. It emphasises a direction of travel which many people in the sector are enthusiastic about – to equip local communities with the resources to support all people needing care at home and in their local ‘place’. To achieve this requires continued development of palliative and end of life care practice as part of the wider local offer, support to professionals across all

disciplines to develop their skills in this area, fair distribution of resources in response to need across the country, and continued work by partners to engage with local communities on how best to support those nearing the end of life, and to offer greater choice and control in this period.

“It’s so important to have a good death... I’d like to be at home if I can but if not then in a hospice because I know they’ll do their best to facilitate a good death.”

In practical terms this will need local partners in communities across Wales to work together, perhaps at the level of primary care clusters, to ensure that generalist and specialist palliative and end of life care is well embedded and part of the overall local community offer. They will need to be supported by partnerships at local and national level to establish shared common standards for care, ensure resources are distributed fairly in response to need, and build data management, digital and information solutions which can really help to improve people’s care as well as facilitate better knowledge and information-sharing.

“All of a sudden people descended on us from everywhere, had a dietician, speech therapist, district nurses. They came from everywhere. There wasn’t a day when someone wasn’t knocking on the door.”

The strong partnerships built up over years by the public and charitable sectors in the palliative and end of life sector have served it well to date – but partners will need to work even more closely together, and with local communities and the public at large, to ensure the highest standards of palliative and end of life care are part of the offer of every local place-based care partnership in the future.

“They were brilliant because it was a small core of people who came in. They got to know (N) the person as well as (N) the patient. I was thrown out the room while they were having girly chats. Even though she couldn’t talk they would yatter away to her or do her nails ... these things were not in their remit to do... they didn’t have to do it.”

The trends in demand predicted by Marie Curie and others and quoted earlier in the report suggest that service capacity will need to grow steadily over the next few years. If this is not achieved in the community, then it will be increasingly difficult to divert people away from the more expensive and, in many cases, less desirable hospital and long-term care sectors.

5.2 Applying principles in practice

What might people experience in the future as a result of an effective place-based approach? In many ways this should not look too different from the best experiences now – except they should be confident of access to them, and confident that people across the country are able to secure a similar level and type of local support. For example these are some of the key things that our interviewees said they should be able to expect:

- One obvious and accessible place where information, advice and assistance is available and helpful – and every person involved in care able to access it.

- Technology which supports care at home (such as vital signs monitors, reminder software or digital consultations) and which is readily available and easily accessed.
- Quick responses to requests for help, holistic assessments of need and co-ordinated packages of care.
- Enough people to provide direct care and support at the right time to ensure people are cared for in the place of their choice, including in their own home.
- Sufficient resources and capacity to support people well.
- Professionals who are compassionate, knowledgeable and thoughtful about how best to support you, and willing to share responsibility.
- Support for carers which recognises the responsibilities and emotional challenges of caring, and provides a range of flexible ways of helping.
- Kind and compassionate direct care workers.
- Information systems and records that all those involved can have access to.
- No decisions made about a person's care without their involvement and consent.

"I would have to explain the same thing over and over. I felt 'wasn't it possible in this day and age for all the agencies to have the same information?' As a family can't fault the NHS, they were exceptionally good but there was a lack of communication between the specialities, they had to rely on me."

If palliative and end of life services are to fully embrace the opportunities of place-based care, then they will also need to change their ways of working, engage more fully with wider community services, and exert greater influence in the wider system. Place-based care will require partners to start with the holistic needs individuals and of the local population and then work together to support them. This will challenge some of the traditional boundaries between professions and between services. Palliative and end of life services may need specifically to consider:

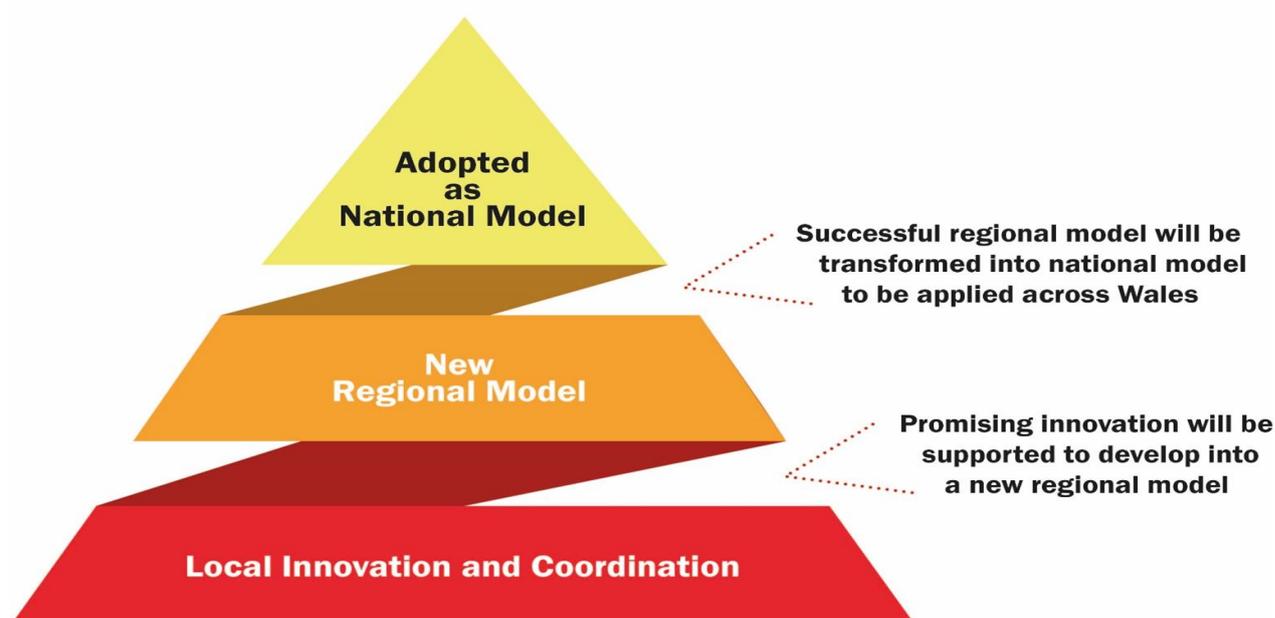
- Working better with partners to understanding local population needs.
- Re-focussing their services to complement other resources and help meet local needs, moving from a separate service to one more embedded with local partners.
- Stronger volunteer and community-based carer services able to meet local home-based needs flexibly and quickly, and stronger involvement of people with lived experience of palliative and end of life services to guide service improvement.
- New contract arrangements promoting long-term partnership and social enterprise models with partners including RPBs, social care, Health Boards, GPs and primary care clusters across Wales, and
- Working with partners to ensure that principles that underpin palliative and end of life care can best inform wider community practice.
- Working more flexibly across professional boundaries and between partners to deliver holistic packages of care, and sharing skills, technologies and best practice with colleagues in the wider community.
- At the same time continuing to improve specialist palliative and end of life care.

In summary:

- Better community-based provision is key to supporting people in their own home, and reducing the need for inappropriate hospital care.
- Primary care clusters may be the starting point for designing local place-based provision.
- Palliative and end of life care will need to be understood as part of a whole place-based care network supporting people with the full range of different needs and this will require wider engagement

6 Discussion – possible ways forward

The Welsh Government is very clear about the approach to service transformation that it wants to see in health and care across Wales. The model below summarises its aspiration for a ‘bottom up’ approach, drawing on local innovation to drive the development and scaling of national models of good practice.¹³



This is based on the experience of managing change over many years. While it is very valuable to have a national framework of good practice as a starting point, effective improvement needs to be focused on different priorities in different places. In the case of the subject of this report this suggests that place-based palliative and end of life care needs to develop in different ways locally and regionally within an overall national framework.

The following sections discuss some ways in which place-based palliative and end of life care might develop, and some of the approaches which might be used to support it. These are not mutually exclusive and they are ideas for discussion, not recommendations.

¹³ Welsh Government ‘A Healthier Wales; Our Plan for Health and Social Care’ (2018).

6.1 National

The national End of Life Strategy Board and Implementation Board have been driving change across Wales for many years, and the national plan¹⁴ developed in 2017 has been very influential. There is the opportunity to continue to build on this work, and focus on common standards and a national model of integrated practice for partners in regions and localities, particularly in terms of the quality of care that should be expected by generalist professionals in the community. Some of the key areas identified by interviewees for this report for these standards included measures of capacity in community, district nurse and other professionals remits, and the need for clear standards about the night time care that people might expect. Beyond this though, there is the opportunity to describe and define the culture and practice of good palliative and end of life care as part of place-based care in Wales, and as a starting point for some of the development and improvement activities discussed below.

Primary care clusters would seem to be an obvious starting point for good community-based practice and there is the opportunity to work with them through the primary care model for Wales, the Accelerated Cluster Development Programme and the Quality Assurance and Improvement Framework for GP practices to encourage and reward best practice in this area.

There may be further opportunities for building on good work by Health Education and Improvement Wales and their partner agencies, particularly to specify common skills and qualities needed by all professionals working with people with palliative and end of life care needs.

'Other than clinical skills, they need communication skills, that's the major one. I used to think empathy was an innate quality in people, but I have realised that's not the case. It can be learnt. They have got to be patient-led. The patient is the person taking the journey. Staff must fit in with their needs not the other way round. They must be flexible - service to one individual isn't necessarily the same as the person next to them.'

Another key area which can only be addressed at a national level is to establish an accurate and sustainable measure of the true cost of palliative and end of life care services, and how much of this is supported through charitable contributions. The level of contribution from charities is much higher for palliative and end of life care than for most other health and care needs and many professionals and people with lived experience were of the opinion that this needs to be rebalanced to enable further investment in this area – perhaps particularly for improving the effectiveness and impact of generalist services in the community. If the recent analysis by Marie Curie¹⁵ and the current concerns about the cost of living crisis this winter are correct, it is likely that many people needing care in Wales will be doing so in poverty, and relying even more on their local services to support them.

"Heating is a worry. People with a terminal illness have limited mobility. People won't put on heating because they are frightened of the bills."

¹⁴ Welsh Government: Palliative and End of Life Care Delivery Plan, (March 2017)

¹⁵ Marie Curie 'Dying in Poverty' (2022). Key facts included 'More than 90,000 people die in poverty in the UK each year. More than one in four terminally ill people of working age spend the end of life in poverty.'

Another area to consider is the use of pooled budgets across services in the community, particularly between health and social care, Continuing Health Care costs and the availability and effectiveness of support for carers. The ability to pool budgets was promoted most recently in the Social Services and Wellbeing (Wales) Act 2014 but has been relatively little used in practice across Wales to date. It may need further legislation or policy guidance in the next few years.

The Welsh Government is committed to drive forward digital health and social care and to improving integrated information systems (including WCCIS) in the future, and TEC Cymru is leading this drive. Place-based palliative and end of life care is an area where a great deal more can be done to support people at home through effective technology, for example in areas such as video consultation, patient alarm and reminder systems, and symptom monitoring technology. It is also an area where shared patient and service-user records in general would make a major difference to the effective co-ordination of care, by ensuring that all professionals share a common information source and are able to maintain shared monitoring of a patient or service user.

“People and carers at end of life need above all to feel safe and comfortable, and we can do much more to ensure they are able to access the technology to help with that.”

In summary, national leaders might want to pursue the following:

- The publication, dissemination and implementation of a national framework for place-based palliative and end of life care which promotes more consistent practice and further investment in community-based services and is supported by people with lived experience of palliative or end of life care.
- Further support for and investment in primary care clusters as the starting point for place-based palliative and end of life care as part of local care systems.
- Further work to develop and apply a framework of common skills and qualities for all professionals working with palliative and end of life care in their local community.
- An analysis of the cost of palliative and end of life care in Wales and how much is paid for by the voluntary sector, an analysis of the potential impact of the cost-of-living crisis on people and their carers at end of life, and an analysis of future resource needs on the basis of population projections.
- Guidance to promote more joint commissioning of palliative and end of life care as part of place-based planning and commissioning by local authorities and Local Health Boards.
- A national strategy to support digital health and care technology roll out which recognises its importance for palliative and end of life care.

6.2 Regional

Regional partnerships between Health Boards, local authorities and their care partners are increasingly significant in Wales. Regional Partnership Boards are playing an important role in building new ways of working, and in ensuring that partners work together to deliver on national aspirations and standards. They play a major role in co-

ordinating the partner agencies involved to direct resources and funds to meet greatest need and to have greatest impact.

There may be an opportunity for regional partners to work together with service providers in Wales to take a different perspective on partnership. Many people have become frustrated by the use of relatively inefficient short-term contracts between public and independent sectors. It may be an opportune time to explore how to move to longer-term, outcome-based commissioning arrangements and alliance arrangements which fully recognise the high proportion of resources that are contributed directly by charities in this area. This might also prompt a move to new models of joint commissioning and pooled budgets between public sector partners in regions. Place-based palliative and end of life care could be a very specific area where new approaches could be tested out. Certainly partners working together in regions should be drawing on the same comprehensive analysis of the future needs of the population to inform them about the future investment needed, and where to focus it.

Our interviewees were clear that greater investment in flexible, high quality home-based 24/7 palliative and end of life care and support is needed as part of local arrangements across Wales to meet needs and improve quality of care. It will be up to regional partners to work through in detail where the resources come from, and where they need to be targeted in their region. Effective regional palliative and end of life care strategy boards or similar will be needed in all parts of Wales to do this work, and they will need to produce clear shared and detailed regional strategies to steer service development. Regional partners will also need to maintain an overview of progress in each of the local communities in their region – so that while services might be different from place to place, the quality of care is of a consistent and high standard.

“We had another appointment with specialist and he said, ‘don’t make plans for your 50th birthday because you’re not going to get there.’ That was her diagnosis that she was terminally ill with motor neurone disease, she was 46. I know it’s a difficult thing but there must be a better way of doing it, giving bad news.”

Many of our respondents described how, over time, they have seen palliative and end of life care tending to be seen as an area of practice separate from wider community-based provision, and how, as a result, opportunities have been missed to integrate these services more effectively into the wider community offer, including social care. There are many people who, while technically not requiring palliative or end of life support, do need the kind of high quality care and support that palliative and end of life services routinely provide. This for example might include some people coming home from hospital, with chronic long-term conditions or with dementia. Health and social care planners and commissioners in regions and local areas across Wales may be missing a trick by not considering how these services might be developed and applied to a wider range of people than currently.

“I feel there are many people who don’t know about the charities like Macmillan, Marie Curie and Cancer Research, it’s not out there for people with cancer.” “I don’t think the NHS is working with them at all to be honest. The NHS is the NHS and the cancer and terminal illnesses charities are another thing.”

Regional partners will also have a role in promoting best professional practice. Regional professional forums giving all staff involved in palliative and end of life care the opportunity to share good practice is one way in which this can be promoted but there are many more including through joint training and development, particularly for generalists in the community. Promoting the use of proven effective tools and resources amongst professionals might also be an important element of an effective regional strategy – for example through promoting effective assessment and care planning practices, sharing good information management practice and digital support tools, and through drawing on the Compassionate Cymru agenda to explore the cultural and communication skills needed in this area.

“When I was working in a nursing home, we did an end of life palliative care course which improved our knowledge as care home trained nurses - they can be left out of the loop sometimes. Doing these courses empowered us to look after our patients at the end of their lives - because if someone is in a nursing home they’re not going to then move to a hospice. Broadening and increasing the skills of health and social care workers is important - they are the “boots on the ground going in to patients”- they need a good foundation and knowledge of what to do and what to look out for at the end of life.”

In summary, regional partners might want to pursue the following:

- New approaches to partnership arrangements between the voluntary and public sectors to deliver place-based palliative and end of life care as part of local place-based provision.
- Comprehensive and systematic analysis of future palliative and end of life care demand, broken down to local place or cluster level.
- Development, dissemination and implementation of a regularly updated place-based regional palliative and end of life strategy informed by those working in the sector and with lived experience of palliative or end of life care.
- Review the distribution of resources between partners across the region with a view to investing more effectively in local place-based care.
- Joint commissioning arrangements enabling partners to explore the potential for specialist providers to flex their services to meet wider local population needs and demands as part of place-based local services.
- Promoting best practice through multi-professional learning and development and regional palliative and end of life practice for all relevant professionals, including with people with lived experience.

6.3 Local

Local partners are the people who really make things work in practice. It is difficult to imagine that there is a single model for local partnerships which can work consistently across the whole of Wales. Circumstances and needs are very different across the country, and people work in different ways. If regional partners need to maintain an overarching framework and a strategy for improvement, and need to ensure that resource are allocated effectively, it is local professional partners who need to make this work for their local community.

Perhaps we could be bolder at the current time – take a leap towards local place-based pilot projects to test out local models of integrated care and provision using combined budgets, a single management structure, co-located staff and common information systems? There might be no shortage of volunteers to try this kind of approach among the 64 primary care clusters across Wales, and palliative and end of life care might be a very important element in this approach

“So when the time came for my mum to need a longer break, like a week, he was willing (at first, he was resistant to going to day therapy) to give it a try. He loved it. He was full of it, it was ‘sister this’ and ‘oh I had a glass of sherry and this for my lunch’. It was just totally not what he expected. That impression still lingers with the general public that you only go into a hospice to die.”

At the very least place-based pilots might encourage much more effective co-ordination, information sharing, key working and assessment and care planning practice. If they are effective in engaging with their local community, in building more capacity through services such as virtual wards or hospice-at-home, then they could make a major contribution to progress in supporting people to live, recover and die safely and comfortably in the place of their choice. A key element of this approach might be more effective and extensive opportunities to engage with people with lived experience of palliative or end of life care.

Similarly, local partners who have experienced high quality end of life services from care providers in their area might want to consider how those services might be supported to expand into other areas of care, bringing the ethos of high quality and compassionate care with them.

“(Carers) are not automatically willing to accept any help because they feel ‘I’m not the person who’s dying, I’ve got to give my all.’” Within a week of my dad being buried my mum had a heart attack, having not been in hospital since she had my brother 50 years ago. That’s an indication that “her needs and anxieties were put on the backburner”. It was partly her doing but I think there could be more services to support carers”

In summary, local partners might want to pursue the following:

- New contracting arrangements with community palliative and end of life care services to support longer-term partnerships, and explore where local services could be more flexible in responding to local population needs.
- Making sure palliative and end of life care specialists are key partners in local primary care partnerships.
- Establishing local advisory groups of people with lived experience of palliative or end of life care as part of representatives of the local community to guide or advise on local priorities.
- Pilot projects to explore how more integrated place-based arrangements, including palliative and end of life care might work in practice.

6.4 Palliative and end of life care providers

“This care package was during the last year of her life and was very stressful. We counted around 30 different carers, they didn’t turn up when they were supposed to, they were an hour or more late, or they didn’t turn up at all and didn’t let you know. I had to phone the company many times. My mother watched how much she drank and timed going to the toilet for when the carers arrived. She got very anxious if they didn’t arrive and relied on me to go round. It really affected my mother; she’d watch the clock and know when they were expected.

Charitable organisations across Wales have led the way in raising standards and capacity in palliative and end of life care for many years. Perhaps as partners across the sector explore what a more effective place-based approach might involve, it is a good time to think about the next areas of influence for them.

This might include working with local partners in regions and in localities to build long-term alliances and partnerships, where staff work much more flexibly and much more closely together to share information, respond to need and ensure good quality care for the whole local population. In the short term this might mean, for example, engaging actively in the national Primary Care Model programme, and exploring how to engage effectively with local primary care cluster leads and local authorities.

Within the palliative and end of life field, providers might continue to expand into much more flexible home-based support through hospice-at-home provision, and virtual ward arrangements, as well as continuing to expand the use of the hospice as the specialist hub to support workers and provide care and support for people at the end of life. As part of this role providers might need to continue to play a major part in the development of national standards of good practice particularly as they apply to generalist support in local communities over the next few years.

As noted above, there is also the potential to widen out the boundaries of services to meet needs in local communities which extend beyond palliative and end of life care. There may be circumstances where the good practice and knowledge built up in this area could be usefully applied to other areas of professional practice – such as, for example, support for people with long-term conditions or disabilities. If partners start from the needs of the individual or the local community it may be that the service solutions will need not to be limited by a palliative or end of life care label. Providers will need to work closely with public service commissioners to explore these opportunities.

Providers will of course need to consider carefully how to use charitable funds to greatest effect, particularly in terms of the communities they support, the impact on needs that they have, and the extent to which mission and remit might allow expansion of activities. While there is no doubt that these are difficult times currently, and many sources of income are from time-limited national grants, providers will need to work closely with local authority and NHS partners to explore how longer-term partnership arrangements can be established, and how contracting arrangements can be developed which allow partners to think about longer-term arrangements and services.

“Charities should be a bonus and add to the care rather than replace it.”

In summary, palliative and end of life care providers might want to pursue the following:

- Seek opportunities to explore wider service boundaries and work with other population groups.
- Seek opportunities to develop these services in collaboration with other providers.
- Engage deeply with colleagues in regional and local partnerships, and promote the skills and principles of palliative and end of life care as relevant to all professionals working in the community.
- Continue to play an active role in influencing partners across Wales to drive forward the quality and consistency of palliative and end of life care in the future.

7 Conclusion

Palliative and end of life care has developed hugely in the last decades. Despite the challenging times we have all experienced in recent years they remain greatly valued and many people consider there is something very special about the quality of care and ethos of these services. They have a great deal to offer to people at end of life and their families. They have also got a great deal to offer colleagues and partners working in local place-based community services more widely. Perhaps now is the time, as well as continuing to improve these services, we can explore how the palliative and end of life approach and ethos of care can be applied more widely across the health and care system for the future.

Professor Keith Moultrie
Institute of Public Care
October 2022

Appendix 1: Interviews with people with lived experience

We spoke with people with expertise through experience of palliative and end of life care. We used the following questions as the basis for semi-structured interviews with individuals.

Questions

- How well do you think services work together in your local area to support people with terminal illnesses, their carers and families - do you recognise this as a place-based approach?
- What should local place-based end-of life care look like in practice in the future?
- What improvements are needed to achieve more effective place-based end of life care in the future?
- What changes in professional skills and practice might be needed to better support end of life care in the future?
- How far should end of life care rely on charitable contributions in the future?

Appendix 2: Interviews with professionals and service leaders

We also spoke with professionals working in community health, wellbeing and care services, specialists in palliative and end of life care and sector leaders. We used the following questions as the basis of semi-structured interviews with individuals and with small groups.

Questions on place-based care for all

- What changes have you seen in the last few years in the way local health, care and wellbeing support is delivered – do you recognise this as a place-based approach?
- What should local place-based care look like in practice?
- What is needed to deliver more effective place-based partnership working in the future?

Questions on end-of life support for all

- What should high quality end of life care look like in the future, and what improvements are needed to achieve this?
- How well do end of life services work as part of an integrated approach to place-based care – what concerns do you have and what successes do you want to recognise?
- How does end of life support need to develop as part of place-based care in the future?

Additional questions for practitioners

- What is needed to enable you to work more effectively as part of a local 'place-based care' system?
- What service changes do you think are needed to help secure more effective local end-of life care in the local community?
- How can you collaborate more effectively with other professionals to deliver end of life care?
- Do you think professionals need to work differently with those with terminal illness, their families and carers in the future – if so, how?

Additional questions for planners

- How far do you think partners across Wales will go in driving forward place-based care in the next few years?
- What changes to skills, staffing, knowledge and culture is needed to ensure end of life care is effective as part of a place-based approach to care?
- What changes to planning, funding and contracting are needed to help improve place-based service provision for the future?
- Do end of life services need to engage differently with local place-based care partners in the future – and if so, how?