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End of Life Care
Implementation Group

Review of Specialist Palliative Care Services in Wales
From
2010 – 2021

Executive Summary

July 2021

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Introduction

Every year around 33,000 people die in Wales, including 200 children, that is around 90 people per day; by 2039 this is predicted to increase by 10% - 15% to around 36,500 (Welsh Gov. 2017)

Alongside the predictions of increased future need for end of life care services - the current Covid-19 Pandemic has brought end of life care into sharp focus. With 5,566 Covid related deaths in Wales in the first year of the pandemic (Public Health Wales, 2021), the collective interest in the provision of high-quality end of life care has never been so widely apparent.

The current End of Life Care Delivery Plan (Welsh Gov. 2017) will reach its term in 2022, alongside the establishment of an NHS Wales Executive and a National Clinical Framework (Welsh Gov. 2021). This is an opportune juncture to conduct a stocktake of the Palliative and End of Life Care (PEOLC) services for the people of Wales.

This report provides an historical narrative of a decade of change in the Welsh Specialist Palliative Care (SPC) workforce and the delivery of care and the systems that support which evolved partly from the Sugar Review (Welsh Consumer Council, 2008) and the Implementation Report (Welsh Gov. 2008). It reviews the developments, improvements, and challenges of the past decade but importantly, it highlights the areas for improvement, change, and the challenges ahead into the next decade.

The report demonstrates that much has been achieved through collaboration and a partnership approach to delivering good end of life care provision; either directly or through the application of education, audit, research and the development of clinical guidance to positively impact on indirect care. This has been achieved primarily with non-recurring investment since 2012. In Wales, specialist palliative care was recognised as paramount to the Covid -19 pandemic response. Crucial to future sustainability and the ability to deliver; will be a recognition of the positive effect of specialist palliative care as part of value-based healthcare system.

Stocktake Report Methods

The service leads for Specialist Palliative Care (SPC) in both clinical and managerial were interviewed in all HB statutory and voluntary organisations between Aug 2020 to April 2021. The interviews were guided by a set of questions based on the Sugar Report and the Specialist Palliative Care Implementation Recommendations (2009). Data was also obtained about the SPC workforce and all Wales data activity for services was retrieved from the Canisc information system palliative care module. The stocktake report relates to both adult, paediatric and transitional services, unless otherwise specified.

Key progress

Strategic:

- The establishment of the End of Life Care Board (EOLB) and the Palliative Care Clinical Groups (paediatric and adult) in 2009 strengthened the 'One Wales' approach.
- Every Health Board in Wales developed an End of Life Delivery Plan as part of the Welsh Government End of Life Strategy. Annual reporting on progress using the outcome indicators identified in the strategy
- Collaboration and engagement between statutory and voluntary services providing specialist palliative care and strategic engagement within Health Boards.
- All services have an identified executive lead and an Advance/Future Care Planning (A/FCP) lead
- There is full participation at the EOLB meetings with attendance between 85-99%.

Clinical Care:

- Clinical leadership is at the forefront of service improvement and the definition of Wales as a small and discreet country ensures those in leadership positions can maintain a dialogue with all services
- All clinical leads participate in the Clinical Group, with medical and nursing representation and wider workforce representation
- The medical and specialist nursing workforce levels align with the 2009 recommendations
- Consultant provision is now available 7-day/24-hour, with consultant support on-call cover 365 days of the year
- The CNS model of 7-day provision has been achieved and sustained in all but one health board
- An all Wales 'Model of Care' has been agreed for paediatric services
- Community palliative care teams have improved links with care homes with a named CNS
- Movement from paper-based to paper-lite with Electronic Systems embedded
- Data demonstrates that we are reaching more people with diverse health conditions
- There has been investment and improved availability of A/FCP
- A Prevalence Study of Children in Wales with life limiting illness is commissioned
- Improved data analytics informing services delivering paediatric services

Stocktake Report High Level Recommendations:

The following recommendations are based on the progress made, the progress not achieved and the changing face of PEOLC recognising new opportunities and ambitions from the decade of learning.

As the Delivery Plans end in 2022, we have the opportunity to look towards a National Programme for End of life Care and this will enable a future with a broader agenda towards 2030, rather than through the prism of the Sugar Report and specialist services. Going forward person-focused end of life care lies in the diversity of our services and diversity in the range of our professionals engaged in our specialist services and with the integration of the wider provision of end-of-life care.

Value based commissioning and funding

- Undertake a population health needs assessment for adult palliative care and develop a clinical pathway which meets the EOLC needs and can be delivered in a local context
- Develop a single 'Wales offer' for palliative care services across settings
- Review and modernise funding arrangements for statutory services and Voluntary hospices
- Support commissioning and service specifications that describe care home provisions in line with the 'Wales offer'
- Define a strategy and provide subsequent investment to deliver Paediatric Hospice at Home

Workforce

- Review the workforce requirements, moving on from the minimum core service levels defined in 2010 to ones based on projected future health population needs
- Plan for succession by creating learning opportunities for health professionals who may consider a career in EOLC
- Develop and support leaders for the future within the current workforce.
- Ensure where SPC services are based within Health Boards that the location allows for integration across secondary, primary/cluster and community services, resulting in resource maximisation, risk management and support of modelling and delivery of seamless care.

Models and collaboration

- Support the development of pro-active, flexible SPC and EOLC models, with access to expertise at every transition in the pathway

- Develop meaningful outcomes of service quality and efficacy – using outcome measures to understand the patient/carer perspective on EOL care provision, such as a Wales patient/family survey
- Improve outcomes for patients and families with protected characteristics at the end of life
- Support the work around the Wales neighbourhood district nurse pilots in respect of EOLC, maximising opportunities for co-production with SPC and hospice at home provision in care delivery
- Develop hospices as experiential learning sites for wider workforce groups
- Maximise opportunities for Wales as a ‘living laboratory’ with continuous reflection and learning and sharing best EOLC models through applied research

Overarching priorities for future work

Equitable provision of high quality PEOLC remains the highest priority. We have quantified progress in some key areas including place of death and support for people with non-cancer diagnoses. The data also shows an increase in referrals and absolute numbers. We need to support innovations that build on and accelerate change because there are still people not reached by services, and the number and complexity of people needing PEOLC will continue to increase in the coming decades.

1. We need to work collaboratively, reassessing actual and perceived boundaries, to deliver integrated services that meet the PEOLC needs of the people of Wales.
2. We need to continue working to build on the principles of Value Based Health Care, including the use of PROMs and PREMs as part of an increasing focus on patients and family’s experiences and outcomes. PEOLC is a complex intervention involving multiple roles; multiple approaches to data collection may therefore be required to understand the impact of service activity on outcomes for patients.
3. We need to support the continuing search for evidence about exactly what it is that works. Building on existing research capacity and activity, rejuvenate plans to convene a Welsh PEOLC research network and consider more systematically what research can be commissioned in and for Wales.
4. We need to support teams to deploy that evidence in the services they develop and operate, including by developing clear specifications for services grounded in the evidence and supported by sustainable models of funding.

5. We need to sustain support for a program of digitisation including for adult PEOLC (WCP, DNACPR, AFCP, CDG), CYP PC, this will support better data for commissioning and needs assessment.
6. Learning from COVID-19
 - a) Putting PEOLC at the heart of future pandemic planning
 - b) Speed of clinical intervention – progression from frail to distressed and dying in a matter of hours
 - c) Speed of innovation and policy
 - d) Co-production of the delivery of care
7. The changing nature of the workforce has become more professionally diverse than the 2009 baseline work covered. Focusing on outcomes and experience will strengthen our analysis of this by understanding how the workforce is aligned to patient and family need

Crosscutting Main Themes

Several crosscutting themes emerged from the stocktake interviews and data collection, these are summarised below:

Workforce

Discussions around the workforce numbers, professional diversity and new and emerging roles cut across Health Board areas, children, and adult services. For example, challenging staffing levels, vacant posts, removal of posts and some at-risk posts emerged as a theme affecting paediatric and adult SPC provision alike.

Through the data provided, it showed some teams have greater diversity of professional roles embedded in their teams. It also appears that some vacant posts are challenging to fill, often due to the working hour commitments.

Many lead nurses reported that the seven-day clinical nurse specialist (CNS) service model left workforce gaps in weekday staffing levels due to the stretching of resource over seven days, with some teams working hi-frequency rotas to fulfil this obligation. Low numbers of CNS staff at weekends and bank holidays was thought by some to lead to inequity in care provision and challenging working environments. Maintaining a pool of staff with the requisite knowledge and skills to work alone at weekends was also reported as a challenge by some teams.

Gaps in medical consultant workforce were reported, with the over-commitment of those in post helping to maintain services. The new 'Shape of Training' (Ass Palliative Medicine, 2015) will take effect from 2022 and some thought that the reduction of time spent in Palliative Medicine could impact on the level of support for out of hours services and

Voluntary Hospices potentially further reducing the resource available, although gaps may be supported by the rotation of internal medicine trainees.

There is a gap in allied health professional (AHP) provision in many specialist palliative care teams. Many statutory teams rely on AHP support from the core HB AHP services or from the voluntary sector services, who often employ their own AHPs and are more likely to have a wider range of specialist therapists than the statutory teams. Where charities have pump-prime funded some Health Board AHP posts, not all posts were successful in achieving permanent funding resulting in the subsequent loss of these posts and the contributions they provide to the Multi-Disciplinary Team (MDT). Collectively, this was thought to contribute to poor availability for career pathways for AHPs in specialist palliative care particularly in the statutory sector.

Workforce future considerations

What do we need now and in the future to deliver all dimensions of PEOLC?

- Agree key indicators of need, potentially at health board level to account of population and geographical characteristics
- The 2009 Implementation Report found that more CNSs would be needed to cover 7 day working. We need to understand *what more we could do*, with more investment to support the workforce and the weekend care provision
- For the medical workforce, how will the imminent next steps in Shape of Training change the landscape further?
- For AHPs we need more definition about the core SPC workforce requirement and how it's changed with probably rising expectations of rehabilitation, with non-cancer, and with the move into earlier supportive care interventions
- We should know more about the access pathways to the wider AHP and support staff for example, Pharmacy, Speech and Language and Chaplaincy and Spiritual care advisors as we have evolved over the decade to understand the wider contributions of roles to the quality of end of life care provision
- We don't know enough about the interface between the specialist and generalist workforce and how this impacts care delivery

Education and training

SPC teams have a huge capacity building role through the education, training and support they provide to generalist staff across Wales. The seven day CNS service offer has extended from providing the traditional clinical support and advice to staff in hospital, community and care homes to training around A/FCPs, supporting *What matters to me* conversations.

While a key recommendation of the Sugar recommendations to achieve an All Wales approach to delivering education was not met, the diversity of opportunities made available has succeeded in improving the knowledge and skills of the generic workforce across all settings. Programmes such as the Six Steps Training for Care Homes, Serious Illness Conversations, Care Decisions, GP Training short course and the formal academic teaching roles are accepted as part of the role of the SPC team, often without dedicated time within job plans.

Services are underpinning the 'out of hours' workforce through weekend and bank holiday support for staff in care homes, hospital and community settings. Few services have dedicated education roles or sessions, which if in place, could improve the educational reach across organisations and between professionals. Where dedicated training roles are in place, these will often be short term, voluntary sector funded positions 'at risk'.

Education and training future considerations:

The Report's focus is on roles in SPCTs where firm conclusions about models, sustainability, and effect are hard to draw. We need fresh consideration, in the spirit of the Sugar recommendation, of what we can do across Wales to pull together the many excellent initiatives and use them to drive equity.

- **Looking out:** The demand for education is set to grow, and consideration needs to be given to how this extra work will be supported; particularly considering the reports of insecure/short term funding for dedicated educational work
- **Looking in:** As service models develop and clinical roles change, additional skills training for the specialist workforce must be considered, such as prescribing and advance practice skills, to support the evolving roles and expectations
- **Coproduction:** Working with HEIW may provide a way forward that was not previously available

Care Homes

We know that communication with care homes has improved over the decade and the 2010 sugar recommendation of a named CNS have been implemented. From the data we have we know that in 'normal' times, access to support for residents is often dependent on referrals from care home staff or other clinicians and success is dependent on the systems and communication pathways that trigger such a referral, this can sometimes result in SPC services being reactive rather than being able to be pro-active.

Some Voluntary Hospice services have been proactive and been able to support Care Homes during Covid-19 to avoid admissions at the end of life, collaborating with care homes to maintain support. This targeted support has helped to manage residents' symptoms and, in some cases, ensure they do not die alone.

We understand from the leads responses that access to specialist AHP care at home, is not guaranteed for care home residents with many care homes only having access to SPC nursing and medical input.

Advanced care planning is recognised as an important means of improving personalised care for care home residents, however, fixed term contracts/funding in some areas have the potential to affect the long-term sustainability of A/FCP support if future resource or is not forthcoming.

Care Home future considerations:

- On care homes, the logical conclusion of what the Stocktake Report presents is to follow the recommendations in the 2018 report (Marie Curie, 2018). These are broadly sympathetic with, and a good update of, the Sugar Report on this point.
- In addition, learning from the Covid-19 pandemic about access and the way in which support can be provided will support this work.

Equality of access

Everyone should have a right to high-quality palliative care when they have a terminal illness regardless of their condition, where they live or their personal circumstances. UK figures suggest one in four people who need palliative care miss out each year.

The information recorded on the Palliative Care Canisc Module, demonstrates that some progress is being made in improving access and reducing inequity, however, inequalities relating to type and place of residence and age emerged through the Stocktake Report. Little is known about other groups with protected characteristics (UK Govt. 2010), such as how individualised care is provided, whether the workforce have skills and knowledge about what affects individuals at the end of life and whether our workforce is representative of the wider population. We know that there are pockets of good practice and we need to consider how to make these apply universally for people at the end of life in Wales.

Reported gaps in workforce will impact on the equality of access for people needing specialist palliative care, for example, Medical Consultant clinical sessions are under pressure to deliver equality of access with more demand to support non-cancer and complex patients with multiple co-morbidities. In addition, continued gaps in the consultant workforce to support children and young people and their families' means service access inequalities exist in north and mid Wales.

Out of hours consultant provision covering large geographical areas can result in inequalities of provision and with different models of delivery being applied. CNS weekend service provision can also be disadvantaged where one individual CNS covering large geographical areas or densely populated areas which can lead to variation in models of delivery and to differences in care received by people. The different out of hours model used in one health

board area means that the population do not have access to a CNS at weekends and bank holidays in line with current recommendations.

Where people live should not affect the care they receive, however, the interviews highlighted that where SPC services based in neighbouring health boards use different boundary criteria to assess eligibility for access to SPC services, patients in these zones potentially experience delays in the delivery of care. Further examples of inequity are that specialist AHPs do not usually reach into care homes as is available to the wider community and do not reach across operational boundaries such as NHS hospice to hospital wards, thus where this is the case, there is an inequity of specialist service access.

Equality of access future considerations:

- On 7-day CNS cover, there is apparent inequity in how many CNSs are available to cover the various services. Six health boards report offering face to face assessment but, access to this also varies. Powys has stopped using this service model, and has alternative arrangements, whether the change leaves unmet need, or whether the same need is now met differently should be kept under review
- On medical cover out of hours, again access to face to face assessment appears to vary and the difference this makes should also be kept under review
- Decisions about better and more equitable 24/7 cover should reflect the Sugar Report's point that 'availability ... is critical to successful patient outcomes...'. We must link this development to the need to measure those outcomes and demonstrate the benefit of what is provided and proposed.

Hospice at Home models and Hospice provision

Hospices provide core care and additional key care that supports the patient and family journey at diagnosis, living with terminal illness and at the end of life. Delivery models are different across Wales and often reflect local need, populations and service gaps. Not all HB areas however, are partnered with voluntary services for all of their community and hospice provision with some HB areas invested in NHS funded hospices or specialist palliative care units, and with different levels and configuration of hospice at home provision.

Care close to home and the need for well-planned support at home will increase service demand in community settings, hospice at homes models will require exploration to best fit local need and subsequent investment to ensure capacity and flexibility to deliver services and meet demand and preferences

Hospice at home future considerations:

- On hospices, the big questions are purpose, service specification, funding, and outcomes, experience and co-production. These important themes will be taken forward in the forthcoming review that is now being commissioned in 2021.

Regulation

Regulation and peer review of services and workforce, which is a theme crossing all care settings, had initially made some progress earlier in the decade. Many third sector services have inspection from HIW and CIW but there are some gaps that have emerged, leaving one voluntary service falling outside of the regulation criteria; in addition, the HB specialist palliative care services are without any targeted regulation around the provision of end of life care services

Regulation future considerations

- Regulation is still piecemeal; explore scope to build on the early collaboration between EOLCB and HIW. At the least, we should note that the Sugar recommendation on this is essentially outstanding. What progress was made on peer review has been largely lost and will need to be included in the new national programme for EOLC

Conclusion

There is evidence in this review that the embryonic specialist palliative care services of ten years ago are now mature services embedded in both secondary and primary/community services and working in co-production with the third sector services, Universities and Research Centres. The specialist paediatric Network, which was the first of its kind in the UK, has been the model for service development in many regions, including Scotland.

A significant achievement over the last ten years has been the level of engagement at senior Health Board and Welsh Government level around End-of-Life Services. All services have an identified executive lead and an ACP lead¹. Each Health Board has a Palliative & EOLC strategic group in place. There is full participation at the End-of-Life Care Board meetings with attendance between 85-99%. All adult clinical teams participate in the Clinical Group, (PCIG), and all paediatric teams participate in the Network, which is led by the Paediatric PCIG and is represented on the EOLCB. In all ages, there is lead medical and nursing and third sector representation.

¹ There is also a separate, well-established all-Wales process for advance care planning in paediatrics that has been led by the paediatric Network.

By way of achievement, the Marie Curie report 'State of the Nations' (2016) – a report into palliative care provision found that Wales was leading the nations and the first country to see specialist palliative care as a core service. As a result of the work initiated by the Sugar Report and taken forward through the PCIB and latterly the EOLB, there has been undeniable progress within the provision of specialist palliative care in Wales;

- Improved access for non-cancer patients and in Transitional Care
- Canisc patient record IT module for statutory and voluntary providers in 2009 and its subsequent replacement in 2021
- The commissioning of an Electronic Advance Care Plan application for NHS Wales
- Paediatric palliative care prevalence study for Wales
- Work to support the All Wales DNACPR roll out
- The evolution of Care Decisions Guidance for the Last days of Life' from 2009-2021
- Development and support for Compassionate Cymru to take forward the work of the Compassionate Cymru charter
- Commissioning a Bereavement review; leading to the work to develop a National Bereavement Framework
- Commissioning a survey of support to adult care homes in Wales: A specialist palliative care provider perspective
- Investment in Leadership programmes for specialist teams
- Investment in an End of Life Care Research Fellow, using research to inform the work programme

These successes must be celebrated alongside recognition that some of the successes have been hard won, and in some cases, progress and service sustainability are thanks to the over commitment of individuals and teams.

Taking an objective view of progress against the 2008 Sugar recommendations, while many achievements have been made against the initial recommendations, many aspects are yet to be fulfilled and require coproduction to succeed e.g., developing a single regulating authority for inspection of all core services. Other recommendations are in progress, for example, achievement of the baseline paediatric service, which impacts on equity of service access in North and Mid-Wales, and the development of a set of Palliative Care Outcomes for use as a benchmark for quality of care and to check if services are achieving their intended goals in Wales is scheduled for completion in 2021.

There is an opportunity for Wales to focus on unique strengths in terms of the way the NHS and specialist palliative care works in Wales. To be curious and questioning about the dynamics of decision-making and systems approaches to care and how the interdependent parts of health and social care might best work and serve the needs of people, young and old, at the end of life.

The Coronavirus Pandemic has made clear that, the delivery of end of life care is everyone's business. Going forward, specialist palliative care will remain imperative to quality end of life care delivery. This may not be through direct intervention, but perhaps by extending the reach through shared expertise and support in all care environments. We should have the ambition to be a 'living laboratory' and look to prospectively capture information on how services are delivered, share elements of good or unsuccessful practice and be UK-leading on how to implement models of care. The lived experience and needs of patients and their loved ones should be central to service development and review.

A Healthier Wales (2018), set out a vision for seamless integrated services that are delivered at home or as close to home as possible. To do this, we need fit for purpose and sustainable services. How services are designed, commissioned and reviewed going forward to 2030 will be key in addressing the equity of access and resilience of our specialist services and the wider service provision of end of life care for the people of Wales.

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