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WALES

Grwp Gweithredu  
Gofal Diwedd Oes  
End of Life Care  
Implementation Group

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

## Foreword

In 2008 the Palliative Care Planning Group set out in the Sugar Report what was needed to make palliative care available to people who needed it across Wales. This stocktake report looks at the progress against those recommendations, at what is outstanding, and at some of the needs that were not yet foreseen in 2008 and anticipates some of the next steps that will need to be taken.

In adult services, there is access to multi-professional teams in all parts of Wales. It is available to people who need it regardless of their diagnosis and in line with clear agreed referral criteria. Dedicated advice & support is provided daily including weekends and bank holiday, by specialist teams in most parts of Wales, and there is 24-hour access to on-call palliative medicine doctors everywhere in Wales. An electronic summary record helps to support a standardised approach to assessment and the sharing of information about patients' care with other clinical teams. A funding formula developed in light of the Sugar Report has supported investment in some parts of the workforce to tackle some of the gaps and reduce some of the inequity.

The UK's first national infrastructure for palliative care in children was founded in response to the Sugar Report. In the years that have followed, the Children's Palliative Care Network has steadily increased its reach and reputation, so that in 2021 there are very few paediatric teams in Wales that remain unfamiliar with the concept of palliative care or are unaware of the existence of a specialist service for children.

This 2021 stocktake reveals, however, that the job is far from finished. There are marked disparities in how easily children in different areas are accessing specialist services. We are not yet able to offer families from some parts of Wales a meaningful choice between home, hospice or hospital as the end of life approaches. The hospices that serve children in Wales are still not securely funded and we cannot yet muster the full range of services a specialist children's team should be able to offer to patients. For adults with palliative care needs there is still variation: in staffing, in effective access to specialists and to some support services across a range of diagnoses, and in support for advance care planning. Inpatient provision of hospice & specialist palliative care is variable. Service specifications, including working arrangements across statutory and voluntary sectors, vary and are not always clear. Services have only partly kept pace with the increasing number of people with palliative care need and particularly with the rapidly increasing complexity of their need. Perhaps most importantly in an era of increasing focus on the principles of value-based health care, we lack adequate systematic measurement of outcomes and of patients' and families' experience.

What follows outlines and, rightly, celebrates over a decade of substantial achievement. But it also lays out some of the challenges for the years ahead, challenges which evolving plans in the NHS and in Welsh Government will need to address.



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## GLOSSARY OF TERMS

<b>ABUHB</b>	Aneurin Bevan University Health Board
<b>AFC</b>	Agenda for Change
<b>AHP</b>	Allied Health Professional
<b>BCUHB</b>	Betsi Cadwaladr University Health Board
<b>CANISC</b>	Cancer Network Information System Cymru
<b>CNS</b>	Clinical Nurse Specialist
<b>CTMUHB</b>	Cwm Taff Morgannwg University Health Board
<b>CVUHB</b>	Cardiff and Vale University Health Board
<b>DGH</b>	District General Hospital
<b>DNACPR</b>	Do not attempt cardiopulmonary resuscitation
<b>EOLC</b>	End of Life Care
<b>EOLB</b>	End of Life Care Board
<b>EOLDP</b>	End of Life Care Delivery Plan
<b>EOLIB</b>	End of Life Care Implementation Board
<b>GP</b>	General Practitioner
<b>HB</b>	Health Board
<b>HDUHB</b>	Hywel Dda University Health Board
<b>HEIW</b>	Health, Education and Improvement Wales
<b>LLC</b>	Life Limiting Conditions
<b>MDT</b>	Multi-Disciplinary Team
<b>OOH</b>	Out of Hours
<b>PAC- Planning</b>	Paediatric Advance Care Planning
<b>PCIG</b>	Palliative Care Clinical Implementation Group
<b>PEOLC</b>	Palliative and End of Life Care
<b>Powys</b>	Powys Teaching Health Board
<b>P-PCIG</b>	Paediatric Palliative Care Clinical Implementation Group
<b>PPM</b>	Paediatric Palliative Medicine
<b>SBUHB</b>	Swansea Bay University Health Board
<b>SPC</b>	Specialist Palliative Care
<b>SPPC</b>	Specialist Paediatric Palliative Care
<b>TYAMDT</b>	Teenage and Young Adolescents Multi-Disciplinary Team
<b>Velindre</b>	Velindre University NHS Trust
<b>WAST</b>	Welsh Ambulance Service Trust
<b>WG</b>	Welsh Government
<b>WTE</b>	Whole Time Equivalent

## Introduction

Every year around 33,000 people die in Wales, including 200 children, equating to approximately 90 people per day. By 2039 this is predicted to increase by 10% - 15% to around 36,500 deaths (Welsh Government 2016).

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 over 5,566 Covid related deaths recorded in Wales in the first year of the pandemic.

Much of end-of-life care during the Covid-19 pandemic, as in normal times, has been provided by non-specialists, carers and families with specialist services supporting and advising with targeted interventions, upskilling, educating and supporting the wider health and social care professionals and families. This current crisis has challenged both adult and paediatric services, with secondary and primary care teams caring for increased number of patients with end-of-life care needs. This stressful and challenging period has also enabled new ways of working together, improving integration and collaboration.

We already know that when services come together to deliver well-coordinated EOL care it achieves more than the sum of its parts: providing patients, families and carers with responsive 'wrap around' or holistic care, supporting choice and preference at the time of need. Going forward, we can build on existing knowledge by learning about the use and distribution of resources for end-of-life care during this crisis, including identifying opportunities for improvements to the infrastructures supporting end of life care, which can be applied in 'normal' times.

The philosophical principles on which palliative care is built are not influenced by patients' age. Each individual is unique in their own right and the premise of equitable access applies. However, the organisation and delivery of services vary between adults, children and adolescents in transition. While cancer patients with end-of-life care needs remain the largest part of specialist caseloads, cancer is relatively unusual in children and young people, and the majority of deaths from life-limiting conditions are from non-malignant conditions such as cerebral palsy, Duchenne Muscular Dystrophy and a vast range of rare metabolic and neurodegenerative conditions. Although the trajectory of support in adults may stretch over many years, a more intensive level of care is usually required during the last phase of life and respite care is not generally acknowledged as a main component of the specialist palliative care intervention. In contrast the trajectory of care for many children will last a whole lifetime and respite care is vital to maintain quality of life for both the child and the family. Children may be referred for palliative care even before they are born (perinatal palliative care) if, for example, a condition is diagnosed antenatally that is incompatible with life beyond a few days.

It will be evident in this report that the delivery of adult and paediatric palliative care services differs; therefore, while the reviews key findings and high-level recommendations encompass all services, adult and paediatric are reported in a way which reflects the service model.

The current Welsh Government Palliative Care and End of Life Care Delivery Plan (2017) will reach its term in 2022, alongside the establishment of an NHS Wales Executive and a National Clinical Plan for End-of-Life Care (WG National Clinical Framework 2021). This would appear an opportune juncture to conduct a review of specialist palliative care.

The report provides a useful historical narrative of a decade of change in the Welsh end of life care infrastructure, looking back on what has been achieved and the challenges ahead through the decade to 2030 for the people of Wales who should benefit from the best care at the end of life and the wellbeing of those who deliver it.

## The Review

**Purpose:** This report summarises the results of a Wales-wide palliative care service review stocktake, undertaken between August 2020 and April 2021.

**Aim:** To provide a clear picture of the current baseline core specialist palliative care service capacity, voluntary hospice provision, and outline areas for consideration to meet future service need.

**Objective:** Review progress against the recommendations of the Wales Palliative Care Planning Review 2008 and the Palliative Care Implementation Board (PCIB) 2009-2014, focusing on specialist services and the historical investment made to progress the core principles of:

- Good end of life and palliative care should be available universally across Wales.
- Fairness of service provision is fundamental to raising the standards of end-of-life care.
- Close integration of services in an area, whether provided by the NHS or by voluntary sector providers, is essential for high standards in care.

**Limitations:** - The following factors have restricted reporting:

- The review has taken place during the Covid-19 pandemic. As a result, interviews and data collecting has been conducted remotely and at a time when services are stretched and under pressure.
- Data reporting has been restricted to posts identified in the original funding formula.

- Service definitions were not agreed by the PCIB at the outset e.g., Hospice at Home appears to be an umbrella term which is delivered in a variety of ways.

In addition, service development and reconfiguration during the last decade have changed boundaries and working practices that would not have been in place during the life of the EOLIB such as:

- Health Board boundary reconfiguration
- Changes in Hospice inpatient units and bed numbers
- The introduction of new services e.g., Advance/Future Care Planning and End of Life Care Facilitator roles

## **Background: Palliative Care in Wales – 2007 - 2009**

- 2007: The Welsh Assembly Government endorsed the principle that, in building a world-class health service, care should be available to everyone, irrespective of who they are or where they live in Wales, at the time of need ('One Wales – A Progressive Agenda for The Government of Wales').
- Substantial evidence to suggest that in palliative care this was not the case. Inequalities in provision of palliative care had been identified as part of the Wales Palliative Care Needs Assessment (Tebbit, 2004) commissioned by the Wales Cancer Networks, where responsibility for redesign of specialist palliative care services existed as a programme of work.
- 2008: Recommendations from a Palliative Care Planning Review commissioned by Welsh Assembly Government - subsequently referred to as the 'Sugar Report' - were published in July.
- 2009: Sugar Report set out the agenda for improvement in palliative care in Wales, with a broad objective to achieve equitable access to services for adults, young people and children, reducing inequalities and raising standards of care.
- Professor the Baroness Finlay of Llandaff appointed to establish the Wales Palliative Care Implementation Board (PCIB) and implement the recommendations of the Sugar Report.
- £6.4 million Welsh Government funding was set aside to support the implementation of the recommendations of the Sugar Report between 2009-2012.



## Palliative Care Implementation Board – Key Objectives 2009 - 2014

- Palliative Care Implementation Board and all-Wales Managed Clinical Network for Paediatric Palliative Care were established to translate the Sugar Report recommendations into actions, incorporating public engagement and facilitating research in improving end of life care.
- Key objectives were set to establish a palliative care service network across Wales that is fair, universal, and fit for the future, both for adults and for children.
- Fairness of provision, as a principle, was a key marker by which the PCIB decided to evaluate their decision-making. One such area of evident need that required a specific focus was that of non-malignant disease. Historically, cross referral rates to palliative care had been low despite an increasing number of patients with life-limiting non-malignant disease, including those with dementia, evidently requiring better end of life care. Building capacity into specialist teams to enable them to provide support outside of the traditional cancer population would be paramount to achieving equitable access.
- A final report on the achievement of the Sugar Report recommendations, the additional objectives laid down by PCIB, and the total funding allocation was produced in 2014. At that juncture the funding was repatriated into Health Board NHS Wales budget allocation, with a proviso that Voluntary sector allocations be ring fenced to 2017.

## Progress: Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014

Fifteen structural and procedural recommendations were set out as short, medium and long-term plans within the Sugar Report. The EOLIB also identified additional key objective Progress against these is described in the table below:

**Table one: Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014**

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
1	<b>Short term (12 months)</b> Establish an All Wales network to co-ordinate existing expertise, including representation from cancer, renal and cardiac networks, and organisations concerned with life limiting conditions for: <ul style="list-style-type: none"> <li>Children and Young People's palliative care</li> <li>Adult palliative care.</li> </ul>		✓	EOL Implementation Board established 2009. Evolved into the End of Life Care Board (EOLB) following the development of the WG Delivery Plans 2014. Adult and Paediatric palliative care clinical groups were set up to provide expert advice (PCIG & PPCIG). Health Boards tend to nominate clinical leads as the EOLB executive representative, which can lead to crossover regarding work stream reporting between EOLB and the clinical groups
2	Identify priority areas for action as arising from the findings of this report.	✓		Areas for action were identified and listed as part of the EOLIB implementation plan. Non-recurring investment by Welsh Government post 2012 focussed on EOLDP objectives. Capacity building in workforce deficits, e.g., AHPs was not addressed.
3	Provide initial investment to achieve a minimum core service level across Wales and across all sectors for both adult and paediatric palliative care.		✓	£6.3million was invested to increase core service level provision in both statutory and voluntary services throughout Wales. Set funding allocated did not take into account full workforce costs in the expansion and

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
				delivery of services such as 7-day CNS services, hospice at home provision.
4	Use the core palliative care service level as a basis for distributing additional funding to the voluntary sector.	✓		A funding formula was applied in 2009, providing equitable funding for core costs e.g. Beds, Consultants, and CNS's. Welsh Government have requested the EOLB review this funding for Hospices in 2021.
5	Strengthen and improve the existing Continuing Healthcare process and ensure the current review of this guidance considers mechanisms for rapid access to funding and more flexible processes for application and renewal of equipment.		✓	PEOLC services worked with HBs and WG to develop a Fast-Track CHC assessment to support timely discharge and allocation/delivery of appropriate care. The national Complex Care Board provides strategic oversight for CHC and the EOLB will continue to offer advice and clinical perspective in relation to EOLC.

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
6	<p>Agree an All-Wales standard guidance for all palliative care services, building on the current Welsh Cancer Standards, that sets out the core service specification with requirements that the core service be established in a set timeframe. Standards that would determine a set of Quality Outcome Measures to ensure the services delivered were fit for purpose and appropriate to the needs of the population.</p>	✓		<p>Standards were agreed by the EOLB 2011 and applied to the Peer Review process and in the development of Quality Markers reported within Canisc. Core service specification above the minimum core level set in 2009 was not developed.</p> <p>Outcome measures are currently progressing (2021), through co-production with the Marie Curie Research Centre and key stakeholders. This work will link to the new National Programme for EOLC work plan in 2021.</p>
7	<p>Undertake an all-Wales review of the templates used for:</p> <ul style="list-style-type: none"> <li>individual care pathways</li> <li>patient pathway through services.</li> </ul>		✓	<p>Work was completed through PCIG and PPCIG in 2013. This work evolved into the Care Decisions Guidance in 2015.</p> <p>Services are working with individual Health Boards to develop local pathways. The National Programme for EOLC will revisit pathways as part of the work plan in 2021</p>
8	<p><b>Medium term (1-3 years)</b></p> <p>Establish a 24-hour secondary and tertiary support service for professionals across the whole of</p>		✓	<p>As capacity was built into the Consultant workforce, a 24/7 service was developed across Wales, whereas prior to the Sugar Report this was only available in South East Wales.</p>

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
	Wales (for both adult and paediatric services) using staff from the specialist palliative care team who have access to an on-call consultant.			Paediatric services have agreed a service model in 2020 to further achieve this recommendation of 24/7 service. Resources to support this model require finalisation.
9	Produce a separate circular for adult palliative care commissioning guidance, including arrangements for: <ul style="list-style-type: none"> <li>• Approval and support of the development of new services.</li> <li>• Agreed service specifications.</li> <li>• Provision of care by the private sector.</li> <li>• Pooled budget arrangements.</li> <li>• Reimbursement for NHS and Local Authority provision .</li> <li>• Reimbursement for voluntary sector provision.</li> </ul>	✓		Work was undertaken to produce core service specification for statutory and commissioned services. This has not been consistently implemented. It is still relevant for this to be considered and should be picked up in the new National Programme for EOLC work in 2021.
10	Develop an All Wales Training and Education Programme with agreed Standards for all palliative care Providers in the following settings: <ul style="list-style-type: none"> <li>a. Primary Care.</li> </ul>	✓		A variety of training programmes have taken place, evaluated feedback is positive. Standards agreed and training packages for specific programmes developed, e.g. <ul style="list-style-type: none"> <li>✓ Care Decisions</li> <li>✓ Serious Illness conversations</li> </ul>

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
	b. Secondary care and community hospitals. c. Nursing and Residential Care Homes.			✓ GP Short course. ✓ Six steps training Programme. However, the 'All Wales' approach was not adopted due to: <ul style="list-style-type: none"> <li>• Inability to acquire mandatory status for training.</li> <li>• Staffing and logistical issues.</li> <li>• One size fit all does not apply .</li> </ul> Requires engagement and co-production at strategic level with HEIW.
11	Nominate a single regulating authority for inspection of all core services and develop inspection regimes for all clinical governance systems with peer review against agreed standards.	✓		Worked collaboratively with Health Inspectorate Wales to establish Peer Review as part of <i>'Doing More Doing Better' 2012-2016</i> . Inspection regulation requires a change in legislation which require negotiation with Welsh government Peer review programme established within NHS Collaborative 2021.
12	Collate all Wales data on patient numbers and conditions to be used to inform commissioning and form a register of need.		✓	A UK minimum dataset was found not to be validated. Data on patients referred to all specialist services are collected on Canisc. The value of an NHS Wales dataset should be considered .

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
13	Develop information for patients, families and carers at a Health Board level, including a directory of services.		✓	Services produced information at a local level and directory of services. Version control and updating of information and service directories is managed at a local level.
14	Develop the current IT systems for adult palliative care and establish an IT system for children's palliative care.		✓	<p>A Palliative Care Module was successfully developed and implemented across the Wales SPC services within Canisc for adult services. A replacement for the Canisc system is part of the Wales digital workstream and the revised SPC patient record will be accessed via WCP, this can be accessed by any NHS Wales team (not just SPC). Work is on-going to support access to Voluntary Hospices (which do not use HB Patient Administration Systems).</p> <p>Challenges remain with cross-border information sharing and logistical problems of access when remote working in a community setting.</p>
15	Conduct further work to identify the specific needs of adolescents and young adults.		✓	<p>Transitional care consultant appointed – first in UK</p> <p>Agreements between Adult and Paediatric hospices on supportive approach for children in transition.</p> <p>Needs assessment commissioned in partnership with the EOLB and Paediatric hospices 2021.</p>
Additional Key objectives set out by the newly established Palliative Care Implementation Board 2009				
	Objective	Progressing	Advanced	Comment

Progress against Sugar Report Recommendations and Palliative Care Implementation Board Key Objectives 2009-2014				
	Recommendation	Progressing	Advanced	Comments
	A funding formula that would determine how to fully fund core, evidence-based services, delivered by both statutory and voluntary sector. organisations that was fair and equitable.		✓	A resource formula was developed and applied to available funding. In line with NHS services, the funding supported core service provision based on the principles of evidence-based care. It was expected that this would result on a minimum level of service on which to build future capacity, not as an optimal level.
	Public engagement, using patient/ carer and public feedback to monitor that services continue to meet the needs of patients, using this information to modify or change services as necessary.		✓	Progress was made on the provision of a patient and family feedback system for Wales using iwantgreatcare which has been available to all statutory and voluntary Specialist Palliative Care services since 2010. This is was decommissioned in 2021 and work is underway to participate in the 'Once for Wales' NHS Survey. It is anticipated that a suite of outcome measures will be in place alongside the survey by 2022.
	Establish a Palliative Care Research Network. Driving up standards of care through evidence, and to provide a focus of enquiry, providing solutions to problems encountered by patients with advanced disease.		✓	This has been achieved through collaboration with the Marie Curie Palliative Care Research Centre, Cardiff.



## End of Life Care Board – End of Life Care Delivery Plan 2014-2017

- The initial three-year term of the EOLIB to oversee the Sugar Report recommendation extended to 2014 and evolved into the EOLB with a remit to develop and oversee the End-of-Life Care Delivery Plan 2014-2017.
- One Million Welsh Government funding was secured to support the Delivery Plan aims and objectives.
- A refreshed Delivery Plan was issued in 2017 with an additional £1million funding that would be available on a recurring basis, for the life of the Delivery Plan.
- The Plan has since been extended and will reach its full-term in March 31<sup>st</sup>, 2022.

There has been undeniable progress within the provision of specialist palliative care in Wales over the last decade, such as improved access to out of hours services for non-cancer and transitional care patients. These successes are to be celebrated, however key aims within the Sugar Report have not been fully achieved and will require reconsideration regarding their appropriateness and value for good end of life care as part of the opportunities for improvements and challenges to overcome in the decade ahead.

## Review Scope

The review had an all-Wales geographic scope and included adult, children's and young people's palliative care. Focussing primarily on the delivery of specialist palliative care in line with the original investment, the scope included services delivered by the public sector and voluntary sectors in the Hospital, Hospice, Home and Community settings; services delivered by community specialist palliative care teams and voluntary hospices to Care Homes. It was not appropriate to apply the same methodology to both adult Children and Young People's services, therefore these are reported separately.

## Adult Specialist Palliative Care

### Methodology

A mixed method approach incorporating interviews and collection of workforce data was used to take stock of adult specialist palliative care services. Analysis of routinely collected (Cancer Network Information System Cymru (Canisc) data was also undertaken to review potential changes in service delivery and/or need over time.

**Quantitative Service Data:** A request for data to inform the report was made to all seven Health Boards, one NHS Trust and 10 Voluntary hospice service providers. Clinical service and managerial leads for Health Boards and Chief Executives and clinical leads of the voluntary hospice services all supplied data as requested.

**Quantitative data Scope:** Service providers (Appendix 1) supplied the following information for specialist service provision:

- **Staffing:** Core staff WTE; additional staffing WTE.
- **Facilities:** including hospital bed numbers, hospice bed numbers, specialist palliative care units, care homes.
- **Deliverables:** – such as integrated services, community and hospital services, hospice at home, education, and clinics.

**Interviews:** Due to the reporting period falling during the Coronavirus Pandemic, data was collected via virtual interviews. Invitations to participate were extended to the lead consultant, the lead nurse and the lead manager for seven Health Boards and one NHS Trust, and to the Chief Executives and clinical leads from the voluntary hospice services.

The interviews were held between September 2020 to February 2021 and all contributions were as follows:

- Twenty-one interviews were held in total and ranged from one to two hours duration.
- The lead managers were able to attend five out of the eight HB interviews, the lead consultants attended in six areas, and in two areas where there is no nominated lead all the local consultants attended; Lead nurses were present for each service.
- One area invited additional staff members (sixteen in total) including representation from therapies, children and young people, community nursing and pharmacy
- The all-Wales lead for Palliative Medicine attended two of the HB interviews.
- The Voluntary Hospice interviews included the Chief Executive and the Lead Nurses.
- All Consultants supporting Voluntary Hospices are employed by Health Boards or NHS Trusts and were represented at the Health Board meetings by the lead clinician.

Each Health Board area and Voluntary Hospice service were sent a set of themed questions (Appendix 2) ahead of the meeting, drawn from the Implementation Plan to guide the interview discussion. Participants were invited to provide any additional information they felt was relevant to the stocktake. The interviews were conducted by the EOLC Co-ordinator and Programme Manager and the National Clinical Lead for Palliative and EOLC. Detailed notes were taken during the interviews for inclusion in the report.

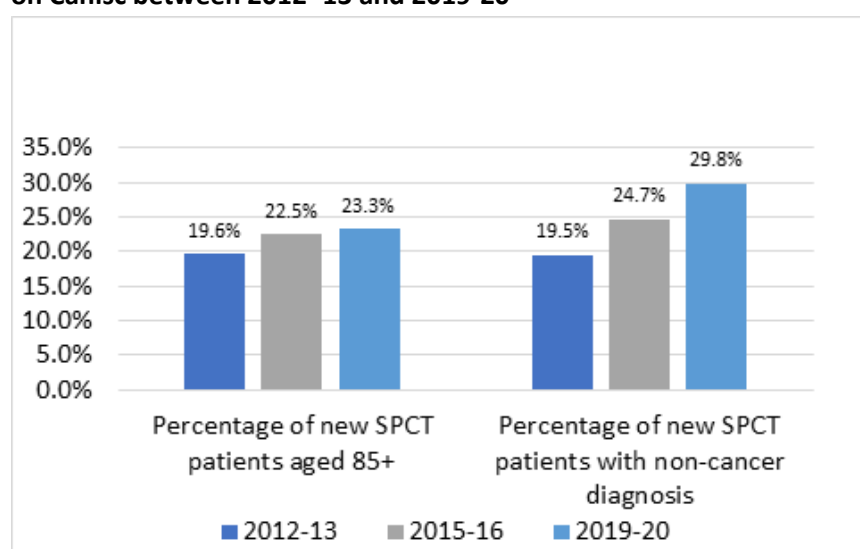
## **Adult Specialist Palliative Care Service Activity Data**

A clear aim of the Sugar Report was to provide equitable access to services, reducing inequalities and raising standards of care for the people of Wales. Capacity built into the specialist teams has created an environment to support those aims. This has been achieved in the face of an increase in the general population of 3.8% in the decade 2009-2019. In 2019 one in five people in Wales were aged 65 or over and estimates suggest this population is growing faster than any other age group (Welsh Government, 2020). This is likely to increase the percentage of patients with more complex, multiple co-morbidities and subsequently lead to increased demand for PEOLC.

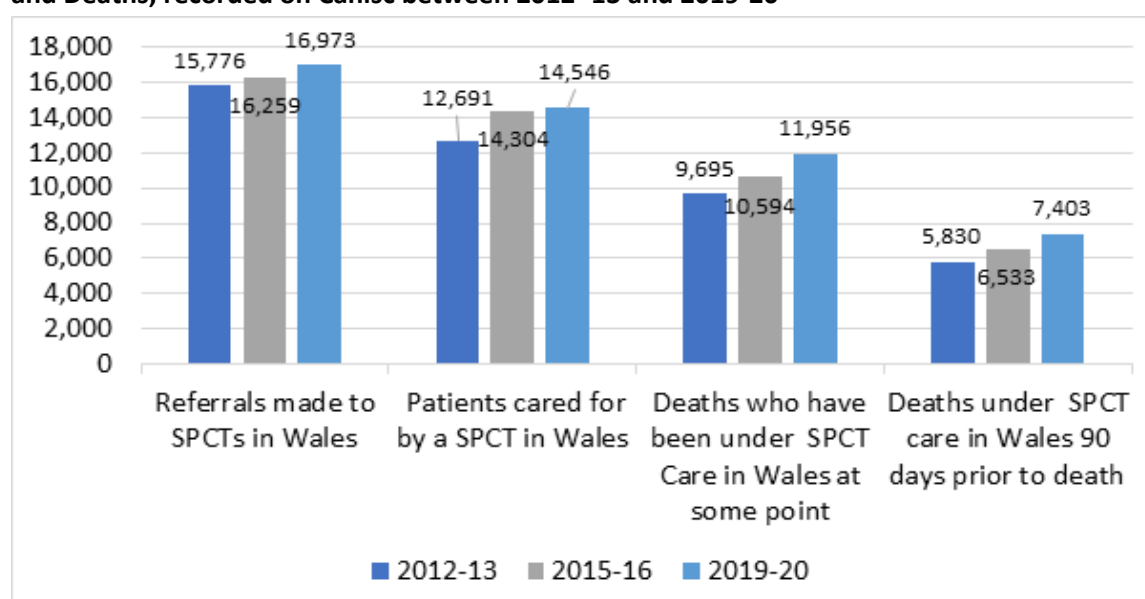
An in-depth exploration of patterns of referral and utilisation of specialist services was outside the scope of the stocktake, however, the information recorded on the Palliative Care Canisc Module, demonstrates that some progress is being made in improving access and reducing inequity and reports an increase in the number of:

- Referrals to SPCT.
- Patients under the care of Specialist Palliative Care Teams at time of death.
- Terminally ill patients who have some contact with a SPCT.
- Patients who had contact with an SPCT within the 90 days prior to death.
- Patients seen by the SPCTs with a non-cancer diagnosis; reflecting the increased recognition of the need for SPC amongst non-cancer patients.
- New patients seen by the SPCTs who are aged 85 years or over.
- People dying at home or in a care home, and a decrease of deaths in hospital.

**Fig 1: Adult Specialist Palliative Care Service Activity Data on age and diagnosis recorded on Canisc between 2012 -13 and 2019-20**



**Fig 2: Adult Specialist Palliative Care Service Activity Data on referrals, patient numbers, and Deaths, recorded on Canisc between 2012 -13 and 2019-20**



Canisc data on clinical support to adults shows an overall growth in activity.

There was a 7.6% increase in referrals to SPCTs between 2012-13 and 2019-20 with almost 17000 referrals being made in 2019-20.

Over 14,500 patients were supported by SPCTs in 2019-20, an increase of 14.6% when compared to data from 2012-13. However, it's important to note that individual patient numbers may mask the true SPCT reach and workload as SPCT support extends beyond individual patients to the wider family and can continue after the death of the referred person.

Between 2012-13 and 2019-20 there was a 27% increase in care provided by SPCTs in the 90 days prior to death, and an overall increase in SPCT input at some point prior to death of 23.3%.

Data on the age and diagnosis of patients supported by SPCTs shows the proportion of patients aged 85 and over has increased over time from 19.6% to 23.3%. The proportion of patients with non-cancer diagnosis being supported by SPCTs has changed significantly - representing almost 30% of the SPCT case load in 2019-20 compared to just under 20% 2012-13.

These data primarily reflect absolute numbers of people referred to specialists, but this is a poor marker of workload. Services describe an increasing complexity of patients referred, requiring more contacts, more non-patient-facing clinical work between contacts (such as liaison with the various clinical disciplines involved) and a greater reliance on specialist involvement. The complexity is often reflected in more 'main diagnoses' per patient; in 2012 the norm was one diagnosis, and people with more than two were rare, but in 2021 it is common to have two and less rare to have several. Partly for this reason, the increasing complexity is probably connected with an increasing proportion of non-cancer patients. This trend is expected to continue and accelerate in coming years: demographic changes mean more people with more concurrent serious illnesses and service developments are likely to mean more demand for specialist palliative care services.

For the future we need to develop and embed the collection and use of data that better reflect need and activity rather than mere headcount. More importantly we need systematic use of measures of outcomes and experience that show how this activity is addressing the need. Work on agreeing and adopting a set of measures has been commenced by the EOLB during 2021.

## Core palliative care service investment and current provision

The funding formula developed by EOLIB focused on the provision of the requisite core palliative care staff and calculated the resource allocation in relation to population figures, hospice and hospital bed numbers as described in tables within each sub-section that follows.

### 1. *Medical Consultant Workforce:*

The Implementation Report (2008) recommended that Specialist Palliative Care services progress to 'Medical Consultant led services' (pg2). The Resource Formula showed that there were significant consultant gaps in services throughout Wales and as a result supported funding of additional Consultant posts and sessions to meet the minimum service requirements.

**Table 2: Medical Consultant resource funding formula**

Setting	Whole Time Equivalent (WTE) Ratio
Community	1 to 300,000 population
Hospice	1 to 20 hospice beds - to also cover those attending for outpatients and for day care treatments, but does not include community care
Hospital	1 to 850 district general hospital beds
	1 to 40 cancer centre beds

*'Each consultant needs support from a matching doctor, either a trainee or staff or staff grade or clinical assistant.'*

*'One associate specialist can be considered as equivalent to 0.7 WTE consultant or one WTE supporting doctor.'*

Funding was made available through the resource formula to raise consultant numbers to a core minimum level across Wales in 2010. All HB's were able to achieve this goal by 2015. Consultant numbers are presented by Health Board area and include Voluntary Hospices.

### **Quantitative data:**

All Health Board/Trusts have a Medical Consultant with whole time equivalents (WTE) ranging from 0.9 to 7.1. Supporting doctors are employed in seven of the eight HB areas where the WTE ranges from 0.6 to 13.2. The total medical consultant/doctor workforce at the time of reporting was 79.05 WTE, see Table 3 which show the medical staff WTE by HB/Trust area. The medical consultant WTE described in table 3 either meets or exceeds the funding formula minimum ratio of 2009

**Table 3: All Wales Core Medical Staff WTE by HB/Trust area**

<b>HB/Trust Area (inc. Voluntary hospice staff)</b>	<b>Palliative Medicine Consultants WTE</b>	<b>Palliative Medicine Supporting Doctors WTE**</b>
ABUHB UHB	4.6	2.8
BCU UHB	6.5	13.2
CTM UHB	4.7	8.25
CVUHB UHB	7.1	10
HD UHB	3.6	3.8
Powys THB	1.1	0
SB UHB	4.9	7
Velindre Trust	0.9	0.6
<b>WALES TOTAL</b>	<b>33.4</b>	<b>45.65</b>

*\*Clinical time includes Supporting Professional Activities (SPA) time*

*\*\*Each consultant needs support from a matching doctor, either a trainee or staff or staff grade or clinical assistant. One associate specialist can be considered as equivalent to 0.7 WTE consultant or one WTE supporting doctor.'*

## Interviews

During the review, interviewees reflected on the consultant workforce challenges during the last decade and commented on the following challenges and opportunities ahead:

- SPC services in three out of seven HBs are undertaking benchmarking reviews of current models of provision to enhance the workforce effectiveness.
- Some HB SPC services are building on co-production with other teams to spread the reach of the specialty, improve patient flow through the systems (including direct admissions), and respond to ultra-complex patients who cannot be transferred from the acute area.
- One service commented on the 'Shape of Training' and the potential impact of this on the level of support available to the out of hours service and Voluntary Hospices.
- The role of the Lead Consultant was not defined in the Sugar Review and some services requested greater clarification and definition of the role and scope.

- Where consultant posts have been created with temporary/short term funding in addition to the core service numbers - three out of seven HB services identified future potential gaps in consultant workforce provision.
- One service identified that during the decade there had been periods of under provision of medical support due to workforce issues .
- One Consultant believed that recent gaps in clinical provision are being supported through the 'over-commitment' of the consultants involved, in order to ensure that the services provide equitable local provision.
- One HB area has chosen to share the leadership role rather than appoint a dedicated lead.

## Discussion

As recommended in the Sugar Report, adult SPC services have evolved to medical led services in Wales. Consultant posts are either hospital, community or hospice based. However many of the posts cross boundaries and are integrated between hospital and community and reach into SPC Units and Voluntary Hospice Units with sessional time to support these areas. Many posts have Health Board contracts, some combined with academic institutes and Voluntary Hospice contracts; all posts have honorary regional contracts with Health Boards to support the out of hour's commitments for 24 hours SPC on-call provision.

There were 33.4 WTE Wales consultant posts and 45.65 WTE supporting doctors making up the medical workforce, the gaps identified a decade ago have been resolved and the medical workforce numbers are also in line with the UK (RCP Census 2019). However, these numbers represent the core minimum of recommended medical workforce outlined in 2010, with some additional, temporary or at risk funded posts over the decade. The Sugar and Implementation Reports recommended that consultants are supported by a matching doctor such as a trainee or SAS doctor. Specialty and associate Specialist (SAS) posts (which replaced the staff grade and associate posts) make up a proportion of the medical workforce supporting Palliative Medicine (see service data).

Wales has eleven Speciality Trainee Registrar 'numbers' available in Palliative Medicine; some of these posts are filled by Less Than Full Time (LTFT) employees, leading to extended training periods and some impact on the availability of workforce sessions. A revised medical trainee programme – the 'Shape of Training' will take effect from 2022. This will now result in Palliative Medicine trainees spending a one-year period in Internal Medicine during their speciality training period. The reduction of time spent in Palliative Medicine will have an 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 (APM 2015).



Although a minimum core workforce has been achieved over the decade, workforce gaps impacting on planning and service delivery to provide equitable services to the population are reported. The way in which the consultant workforce utilise their clinical sessions varies across the services and has evolved over the decade to meet local and increasing demands including the non-cancer demand on services and the trend to supporting patients nearer home; this has included in all areas the development of outpatient clinics, with some services utilising sessions for key joint MDT clinics. Many interviewees described improvement plans for their services and a willingness for co-production to extend the reach of their services. Some interviewees suggested clarity around the scope of end of life clinical leadership roles would be welcomed.

## **2. Clinical Nurse Specialist (CNS) Workforce:**

The CNS workforce is the largest profession engaged in SPC across settings including hospital, community and hospice (see service data). Many early CNS posts worked in isolation within NHS settings, but as services developed these posts became part of consultant led teams and after the Sugar Review all posts were embedded into teams and services. Between 2008 and 2010, funding for additional CNS posts was provided to some Health Board services to align their service levels with the minimum workforce figures shown in table 4 below. However, these numbers represent the core minimum numbers of CNS workforce outlined in 2010. Some voluntary organisations have chosen to employ more CNSs than the minimum numbers suggested for several reasons, including aligning with their model of delivery and meeting the local health population needs.

**Table 4: CNS resource funding formula**

Setting	Whole Time Equivalent (WTE) Ratio
Community	One specialist nurse per 50,000 in the community (this figure will need to be corrected in future years to allow for variations in mortality in the area)
Hospice	One specialist nurse to oversee 7.5 hospice beds, whether inpatient or hospice at home
Hospital	One specialist nurse per 300 district general hospital beds
Cancer Centre	One specialist nurse per 30 cancer centre beds, to also cover those attending for outpatients and for day care treatments

### **Quantitative Data:**

The CNS workforce as reported by services either meets or exceeds the funding formula minimum ratio of 2009 as described below in table 5

**Table 5: All Wales Core Nursing Staff WTE by HB/Trust Area**

<b>HB/Trust Area (inc voluntary hospice staff)</b>	<b>Lead Nurse Band 8</b>	<b>CNS Band 6-7*</b>	<b>Advance Nurse Practitioner Band 7</b>
ABUHB UHB	4.4	38.96	1
BCU UHB	7.91	33.94	2.85
CTM UHB	2	19.1	0
CV UHB	2.8	25.6	0
HD UHB	3	19.1	0
Powys THB	1	6.32	0
SB UHB	1	14.4	1
Velindre University NHS Trust	1	2.8	0
<b>WALES TOTAL</b>	<b>23.11</b>	<b>160.22</b>	<b>4.85</b>

*\*CNS figures for Marie Curie Hospice at Home service not included.*

## Interviews

All the services have clinical lead nurse posts in place. During the interviews, the following points were raised:

- CNS posts had been removed in some Health Boards, resulting in reduced staffing ratio.
- Few CNSs are utilised and engaged in Hospice/SPU units at the bedside.
- Additional CNS posts in most services such as those supporting Heart Failure, Education and Advance Care Planning are on temporary funding.
- Some interviewees are exploring the addition of a range of senior nurse posts in the future such as Advance Nurse Practitioners.
- All services were involved in succession planning for their workforce - three areas identified challenges in filling posts often due to working hours commitments.
- Pressure due to the commitment of providing a 7-day rota and the impact this has on the weekdays.
- Increased travel times over the decade were raised as barriers to efficiency and equality of service provision.
- One HB area is more advanced in training and utilising CNSs as non-medical prescribers; issues including training time and governance challenges were barriers raised by some interviewees.

- In two neighbouring HB areas there were different criteria applied to Health Board boundaries and to access to SPC services that apply to patients in these zones potentially resulting in delays in care.
- The impact on workforce capacity of the need for extra CNS provision from outpatient clinics and tertiary cancer centres.

## Discussion

Between 2008 and 2010, the Resource Formula provided funding for additional CNS posts to some HB services to align their service levels with the above minimum workforce figures. Contractual arrangements vary and CNSs are employed either by Health Boards or Voluntary organisations. CNSs work in the areas in which they have been contracted to work – either community or hospital; however, in a few HB areas the model applied means that the CNS will cross settings between the community and hospital. CNSs are employed at AFC Band 6 or 7, with some of the voluntary organisations CNS salary grades matching AFC salary rates.

Many services are planning to diversify their nursing configuration with Advance Nurse Practitioners posts and some areas already have these roles in place and see the value of their contribution but feel that opportunities for development of these roles are limited by funding opportunities. Learning from areas where non-medical prescribing has been successful will be a useful resource going forward to support further development and service improvements.

Regarding the overall number of CNS posts, the following points need to be considered:

- The Resource Formula did not consider the impact of 7 day working on the CNS workforce numbers during the week and the logistics of delivering services over sparsely populated large geographical areas.
- All hospitals have outpatient clinics for cancer and frequently utilise the CNS posts in those areas which was not accounted for in the original formula.
- Tertiary Cancer Centres based in District General Hospitals act like Cancer Centres with the associated increase in CNS activity due to high demand to support a complexity caseload.

### 3. Allied Health Professional Workforce

The Sugar Review recognised a shortfall in Allied Health Professionals noting a particular shortfall in *physiotherapy and occupational therapy*. The report (Pg11) recommended that:

*'Allied health care professionals, social workers and other members of the multi-professional team are allocated pro rata, estimating that half the number (compared with consultants) are required in the hospice and the district general hospital, but*

more are required in the community, additionally suggesting, 'this requires further work in future years'

**Table 6: AHP resource formula**

Role	Whole Time Equivalent (WTE) Ratio
Physiotherapist	0.3 to 300,000 population
Occupational therapist	0.3 to 300,000 population
Social Worker	0.3 to 3000,000 population
Other	0.1 to 300,000 population

The core specification outlined the AHPs which would form part of the MDT and these included, Occupational Therapists, Physiotherapists, Dieticians, Speech & language therapists, social workers and psychology services. The modelling and resource formula funded a small number of core AHPs for some, but not all services, including Occupational Therapists and Physiotherapists.

#### **Quantitative Data:**

The AHP workforce as reported by services is shown in Table 7 below which show the AHP staff WTE by HB/Trust area and percentage of the all Wales resource.

**Table 7: All Wales Core Allied Health Practitioners WTE by Health Board / Trust Area**

HB/Trust Area (inc. Voluntary hospice staff)	Physio Therapist Band 6-7	Occupational Therapist Band 6-7	Social Worker
ABUHB	2	2.8	4.16
BC UHB	3.64	5.3	3.6
CTM UHB	2.5	2	0
CV UHB	1.6	4.7	2.6
HDUHB	1.8	5.2	0
Powys THB	0	0	0
SB UHB	2	1.85	0
Velindre Trust	0	0	0
<b>WALES TOTAL</b>	<b>13.54</b>	<b>21.85</b>	<b>10.36</b>

#### **Interviews**

The following points raised during the interviews provides additional insight into the AHP configuration:

- Many statutory SPC services link to and utilise generalist AHPs.

- One hospice team described having challenges accessing dietetic advice for new patients.
- One team had experienced the loss of a social work post which had worked directly with their services.
- Some services described how charities such as Macmillan have pump-prime funded some HB AHP posts, with not all posts being successful in achieving permanent funding and resulting in the subsequent loss of these posts.
- One HB area has a therapist managing the SPC service – this is the first example of this in the Wales services.
- All the HB areas included psychology as part of the extended team – although these services were shared with other disciplines and were sometimes disease specific only.
- Very few HBs employ a specialist pharmacist or have dedicated sessions for palliative care in the statutory services but have developed links to named pharmacists.
- Numbers of non-medical prescribers remain low with the exception of one HB area.
- Few statutory SPC services had development plans to increase specialist AHPs in their services.

In addition, there are also supportive roles that have much to contribute; such as art therapies and spiritual care: faith based and non-faith based. Their reach is often determined by access to voluntary hospice providers and religious organisations. The degree of engagement varies widely between actual involvement with SPC MDT's to services still building links to external organisations.

## Discussion

Importantly not all SPC services a decade later have the core AHPs set out in the Sugar modelling as part of their team; the reasons for this may be multi-factorial. Service data and interviews showed that there were gaps in AHP specialists in some services; these services have filled that gap through working in collaboration with the generalist therapists attached to therapy departments or to individual teams such as Acute Support Teams. In addition, some therapists were supported by fixed-term voluntary funding in some HB NHS services and in places this funding had not always been continued with the loss of posts or sessions.

The data and interviews provided insight into how the services vary and an indication of workforce gaps as below:

- Core therapist numbers remain low with little new long-term investment over the decade.
- The third sector employ their own therapists and are more likely to have a wider range of specialist therapists than the statutory teams.

- Therapies staff as part of the SPC hospital teams are generally managed and funded within the therapies department, with few hospital services having core therapists employed, managed and embedded as part of their service.
- Where there are NHS SPC Units with SPC AHPs – these AHPs do not appear to extend their reach into SPC hospital inpatients.

Some of the systems and processes in place could inhibit the way in which the AHP posts are fully utilised, for example some posts are hospice, hospital or community based and do not go into care homes, this may have implications for equality of service access to specialist staff with specialist skills.

#### 4. *Administrative Workforce*

Funding was made available for data entry clerks in each SPC service.

The administrative workforce as reported by services is shown in Table 7 below which shows the administrative staff WTE by HB/Trust area

**Table 8 All Wales Core Administration Support by Health Board/Trust Area**

<b>HB/Trust Area (inc. voluntary hospice staff)</b>	<b>Data Entry and Administrative Support Band 3 –5*</b>
ABUHB UHB	9.6
BCUHB	10.02
CTM UHB	5.49
CV UHB	10.07
HDUHB	4.7
Powys THB	2.53
SB UHB	5.29
Velindre Trust	0.3
<b>WALES TOTAL</b>	<b>48.0</b>

\*Includes 'other' data entry and admin support not defined by service providers.

#### **Discussion:**

All HB areas and commissioned third sector services received funding for a Canisc data clerk. Over time these sessions have merged to form combined administrative support roles for the services. Many of these posts support specialist palliative care MDTs and real-time Canisc data entry. Some of the third sector services have banded these posts at a higher level to reflect the local development of the roles.

## Wales Out of Hours SPC Provision

### **1. All Wales 7 Day Clinical Nurse Specialist (CNS) Palliative Care Services**

Originally the impetus to develop services for 7-day palliative care was provided by NICE (2004), emphasising the need for face-to-face review. The Implementation Report (2008) outlined in its response to the minister, a principal recommendation was,

*‘The move to 24/7 provision should begin immediately, with initially establishing seven day working of specialist providers across Wales.’ (pg2)*

This move was to include a seven-day CNS service, which also supported weekends and bank holidays. Workload analysis was not undertaken due to the perceived urgency of implementation and services did not receive workforce uplifts to support the additional weekend and bank holiday work.

The sum of 137k (10-30k per HB) was invested which supported the payment of the weekend CNS AFC enhancements costs for all the Health Board CNS's. The following point was made in the Implementation Report,

*“a change to seven-day and out of hours working will require more specialist nurses in the rota than had been estimated for in funding models to date” (Pg7)*

As a result of both individual and team commitments all the Health Boards were successful in developing their palliative care services to provide weekend CNS support (apart from Powys, see below) within a short period following the Sugar Recommendation. This meant that Wales was leading the delivery of 7 day working within their services compared to the other nations. Over the decade services have developed and progressed with their weekend provision to a local modified model. For the clinical nurse specialists this involved a shift in systems and service modelling. To adapt to the new service model the following changes and responses were needed:

- The CNSs workforce would provide a weekend 9-5pm and bank holidays 9-5pm service.
- The service would provide face to face CNS reviews.
- Re-organising of the existing CNS workforce including a change in practice with CNSs working alone at weekends, developing good governance for weekend services and supporting the practical and personal changes from a 5-day working culture.
- Developing, negotiating and contracting a weekend service across both hospitals and community areas and in some areas with third sector services.
- Services would engage in all Wales data collection on activity and outcomes based on the previous UK Palliative/Hospice Care Minimum Data collection set.

Table 9 below, shows how the services are broadly set up using the Sugar Review's 7-day service recommendations.



Table 9: CNS Weekend Provision by Health Board/NHT Trust								
Health Board Area	Separate or combined comm & hospital W/E services	Face to face reviews Hospital/comm	Single point of contact	No. of CNSs per day per W/E hospital & comm areas	Accept new referrals	Access to 24/7 consultant advice	Take weekend shift(s) time back in week	Third sector partnerships for weekend service provision
Aneurin Bevan UHB	separate	yes	no	2	yes	yes	yes	yes
Cwm Taf Morgannwg UHB	combined	yes	no	3	yes	yes	yes	no
Cardiff and Vale UHB	separate	yes	yes	4	yes	yes	yes	yes
Swansea Bay UHB	combined	yes	yes	1	yes	yes	yes	no
Hywel Dda UHB	combined	yes	yes	1	yes	yes	yes	no
Betsi Cadwaladr UHB	combined	yes	no	3	yes	yes	yes	no
Velindre University NHS Trust	Hospital only	yes	yes	1	yes	yes	yes	no
Powys Teaching HB	A service review in 2017/18 demonstrated a very small uptake of the service at the weekend and a decision was made to invest the workforce in the working week, anticipating and preparing for the weekends. Consequently, the area is supported by Shrop-doc (GP Service in England which supports the bordering Powys area) to support the out of hours palliative care concerns with access to the 24-hour Palliative Care Consultant Advice Line and the district nurse workforce to support direct interventions. However, the model is kept under review.							

### Interviews:

Great commitment to providing the weekend service was demonstrated, however, the following points were identified:

- Provision of service equity across large geographical areas, densely populated areas or multiple hospital sites is challenging.
- Travel time pressures for both rural and urban areas are difficult for small teams or loan workers at weekends.
- Call management burden and/or the digital challenges of working remotely.
- Concerns about lone working and staff wellbeing were mentioned by some services.
- Maintaining a pool of staff with the knowledge and skills to be able to work alone at weekends is very challenging.
- All services described how workloads have increased over the decade with more demand and increased complexity of the caseloads.
- Some CNS teams report to committing to high frequency weekend rotas in order to ensure weekend provision.
- All services are reporting the impact of service pressure on weekdays from workforce gaps.

### Discussion:

The demand in Wales for 7-day CNS advice was evident from the interviews in all areas. Specialist Palliative Care have been progressive in developing their services to support 7 days, with the exception of Powys which responded to service need using an alternative model (see above).

The weekend CNS provision is a reflection of the local partnerships, for example, where there are partnerships with the third sector – the third sector are providing the community CNS service such as in ABUHB and CVUHB. In other models such as CTMUHB and SBHB where they have no third sector involvement, the NHS CNSs support both hospital and community areas. All community CNSs are working in partnerships with primary/community care and some CNS teams are based alongside OOH's hubs at weekends, including ABHB and CVUHB and HDUHB. Services and teams are committed to the weekend provision and it is firmly embedded in service plans. The different model in Powys means that the population do not have access to a CNS at weekends and bank holidays. While this is not in line with current guidance, the characteristics of Powys: having no district general hospital and the geographical spread of the population requires local solutions to address need.

All SPC CNS seven-day models have developed over the decade and include:

- The availability of face-to-face reviews of the most complex patients.

- Reviewing urgent referrals, particularly for those with a sudden deterioration in condition.
- Providing a key role in sustaining people in their preferred place of care.
- Providing case management continuity.
- Prescribing or advising on medications.
- Providing senior support and advice to generalist staff for example supporting family crisis at the end of life.

There appears to be little evidence of investment in the CNS numbers during the last decade to support demand and growth in the OOH service, although some services have moved extra staff from the week to the weekend to manage demand and support staff welfare. This and many of the other challenges faced by the OOH services were highlighted in the recent in-depth Evaluation of CVUHB 7-day CNS services (Marie Curie Research Centre 2019) which suggests that some of the recommendations made in the report may be transferable to other areas. Overall, there is a perception that more could be achieved at the weekend with more resource e.g. managing complex symptoms at home, thereby avoiding admissions but also sharing of delivery models and good practice would be beneficial.

## ***2. Out of Hours Palliative Care Medical Consultant Service***

The Wales OOH Palliative care medical consultant services fulfil the 7-day, 24 hours service recommendation outlined in the Implementation Plan (2008); although originally covering three areas it has recently been divided into four areas and adapted to local need with variation in models. The out of hours consultant medical cover is provided 24/7 around Wales divided into 4 rotas:

- Aneurin Bevan and Cwm Taf Morgannwg and Powys HBs
- Cardiff and Vale HB and Velindre NHS Trust
- Swansea Bay and Hywel Dda and Powys HBs
- Betsi Cadwaladr HB

The following table outlines the Out of Hours model of delivery in the HB areas.

**Table 10: 24/7 OOH Medical Consultant Weekend Provision by Health Board/NHS Trust**

Consultant OOHs Rota Models	24/7 ROTA	TEL ADVICE	FACE TO FACE REVIEWS	ROTA COMMIT-TMENT	SPC Units/Hospice face to face reviews OOH's
Aneurin Bevan UHB & Cwm Taf Morgannwg UHB	yes	yes	No	1 in 9/10	
Cardiff and Vale UHB & Velindre NHS Trust	yes	yes	yes	1 in 10	✓
Swansea Bay UHB & Hywel Dda UHB & Powys HB	yes	yes	yes	1 in 5.5	✓
Betsi Cadwaladr UHB	yes	yes	No	1 in 8	

#### Interviews:

Stakeholder interviews and data has highlighted the following points:

- All services offer telephone advice to professionals and they support the weekend CNS's services for their geographical areas.
- Some of the services provide weekend face to face reviews at local hospices
- Some are able to provide face to face urgent reviews of complex patients, although this varies across HBs.
- All HB areas have processes in place to discuss with the consultants about any proposed OOH's admissions to the local hospices or palliative care inpatient units.
- Some consultants consider that face to face consultant hospital reviews of complex patients may be possible in some instances in some HB areas.
- All on-call consultants provide supervision and support to middle grade doctors working at weekends in SPC units.
- Opportunities for 'Attend Anywhere' the secure web-based platform for patients with pre-arranged video consultation appointments, was thought to influence modes of service delivery during the Covid-19 Pandemic and will provide more flexible opportunities going forward.

#### Discussion:

The availability of timely consultant advice is critical to successful patient outcomes including relief of suffering and hospital admission avoidance. All areas have well established local regional rotas in place. Rotas have developed in line with local

practices and geographical challenges and therefore, the offers are not the same across Wales.

It was reported during the interviews that there may be inconsistencies in the terms and conditions for the OOHs work, with some contractual differences across the HB regions.

Some areas such as HDUHB, SBUHB and CTMUHB have had the numbers who contribute to their rotas impacted by HB boundary changes. This has made some of the rotas more vulnerable to absence and workforce gaps. Some posts that support rotas are under short term funding arrangements and provide further vulnerability to rotas and pressures on services.

Overall, there were reports of workforce pressure on the OOHs services and rota arrangements; going forward, this may affect the community and hospices more, where 'Shape of Training' may impact the availability of palliative medicine registrars.

## Care Homes

### *Sugar Recommendation: All Care Homes have a named Palliative Care CNS*

All community palliative care services offer support to Care Homes as part of their community provision. Referral to SPC relies on Care Home staff, GPs and district nurses making referrals into SPC services

### Interviews:

It is apparent from the interviews that:

- All teams support Care Homes through their community CNS's as part of their caseload management.
- Care home Residents can be reviewed by the community palliative care consultants or SpRs as they would for any resident in their own home.
- The CNSs are providing clinical support and advice and providing formal or opportunistic educational support on end of life care.
- Some third sector services for example, St David's Hospice Care (ABUHB) offer enhanced support for Care Home residents from registrants, or support to HCSWs particularly for complex patients and to support patients in the last days of life.
- There are many examples of good practice which support improved skills and confidence of Care Home staff and develop pathways to referrals to ensure equal access to SPC , particularly for those with diseases other than cancer – see below.

- BCUHB have a robust delivery model and Bevan Exemplar – Adopt and Spread programme [Adopt and Spread Innovation | Bevan Commission](#) of the Six Steps to success in EOL care for care homes, with adoption commitment from CTMHB and Powys HB.
- Some HB areas have fixed term contract posts for Macmillan AFCP facilitators who support the AFCP/What Matters to Me Agenda for Care Home residents, making these posts insecure.
- SBUHB – have a model of joint working with Older People’s Mental Health colleagues and an MDT for care homes with the Frailty Teams.
- Few areas have their specialist AHPs reaching into Care Homes and this could be for a variety of reasons including resource.

### Discussion:

There were arguably a number of advantages to having a named CNS as proposed by the Sugar recommendations, including to improve recognition of the Care Home communities and to improve co-production around access to referrals and the support and educational needs of the Care Home staff.

The interviews have shown that services are engaged in improving access and knowledge and skills in Care Homes, but access to support residents will be dependent on referrals from Care Home staff or other clinicians and the success of this will be determined by the systems and communication pathways that trigger such a referral.

Ensuring residents have the same access to SPC services is challenging. The teams supporting Care Homes are either from NHS or third sector commissioned SPC community services and all services provide routine and emergency visits. All SPC services will provide consultant and CNS palliative care reviews in hours as is usual for the wider community. However, specialist AHPs do not usually reach into care homes as is available to the wider community, thus where this is the case, there is an inequity of service access to care home residents.

Out of hour’s advice to Care Homes on palliative and end of life care is available through CNSs and consultants in the same way it is available to the wider community. Some Voluntary Hospice services have supported Care Homes during Covid-19 to avoid admissions at the end of life, collaborating with care homes to maintain support services by supplying extra staff. One Hospice service has been providing qualified or HCSWs for symptom support overnight and to ensure people do not die alone.

Advanced care planning is recognised as an important means of improving care planning and provision for Care Home residents, however, with some staff on fixed term contracts in some areas this could affect the long-term sustainability of AACP support if future resource is not forthcoming.

Commissioning contracts held between SPC services and health Boards and Care Homes were not explored, however emphasis on equal access to service provision and levers to incentivise the provision of a better trained workforce, improving recognition of Care Home residents and would influence models of delivery in the light of the impact on Care Homes of the Covid Pandemic.

Care Inspectorate Wales (CIW) inspections and reviews of Care Homes do not separately examine EOLC as part of the review process. Care Quality Commission (CQC) England include a specific question around EOLC in their review process and this requires further exploration for Wales. The recent EOLB commissioned Specialist Palliative Care in Welsh Care homes Review (Newman, 2018) includes recommendations to support effective SPC models in Care Homes going forward and will be further supported by any recommendations resulting from the increased focus on dedicated support to care homes as a result of the recent impact of the Pandemic on Care Home residents and their workforce.

## **Hospice at Home Services**

### ***End of Life Care Board Key Priority 2016:***

Build capacity in Hospice at Home provision, enabling more patients to die in their preferred place of care

### **Interviews**

Comments on the types of hospice at home models provided:

- Multi-visit type service' can provide direct care in collaboration with the District Nurse teams.
- The multi-visit service is flexible and responsive service and can provide single/double calls both day and night.
- Both commissioned Voluntary sector provision and NHS statutory provision capacity will vary, while Care Agencies may support any gaps.
- In some HB areas Care Agency provision can represent a large proportion of the end-of-life care provision which can be affected by high turnover of staff and continuity issues.
- One Voluntary hospice at home provider has supported Care Home workforce where this has been compromised during the Pandemic for

patients at the end of life or with palliative care needs, with the main intention of preventing admission to hospital.

- Hospices report a high percentage of patients known to their services remain in their own homes for end of life care.

**Table 11: Hospice at Home Models**

Providers	Workforce	Models of Care	Place of care
<b>Voluntary Sector 'hospice at home models'</b>	Registered Nurses Health Care Support Workers	Direct core care delivery Sitting service Day service Night service Multi-visit service	At home  Care Homes (some services only)
<b>NHS Statutory Sector 'hospice at home models'</b>	Registered Nurses Health Care Support Workers Care Agency carers	Twilight service Multi-visit service	At home

## Discussion

The Wales hospice at home services support the Healthier Wales (2019) 'closer to home' principle it also seeks to support the aim of 'seamless care' but we are aware that some services are comprised of many different services which can create a challenge to achieving this aim.

The configuration of Hospice at Home services is different around Wales and will be reflected by local need or designed around existing support services. Hospice at Home services provide core care elements to patients in their own homes including direct care interventions for those patients in the end of life care phase of their illness. They do this in collaboration with the primary care services, with the district nurse as the care co-ordinator/clinical care lead.

Investment in Hospice at Home services was included within the original 6.4 million, an additional one million allocated on a pro rata basis to Health Boards to improve access to Hospice at Home having been identified as a key priority in the Palliative & End of Life Delivery Plan (2014-2017).



## Hospice Services

Hospices are part of their health and care communities and work in partnerships to deliver direct care and support – much of which is procured by the NHS in Wales to support the existing services through service level agreements.

The original funding formula used the principle that only core services as defined within the Sugar Report would be commissioned,:

- Provision of hospice inpatient beds.
- Provision of community services - this includes medical, CNS and therapy support to people at home, in care homes or other community settings.
- Provision of hospice at home services - this includes the provision of carer or HCSW and sometimes registered nurses providing direct core care at the end of life (and can include sitter type roles).

### **Quantitative Data:**

The following table shows the Voluntary hospice organisations and the NHS statutory Health Boards providing hospice beds and core palliative care services in Wales. Where statutory hospices exist, these units were originally built with charitable funds and passed back to the NHS to manage. Fundraising committees remain in place to support additional funding for non-core provision. E.g. Ty Olwen Hospice in Swansea Bay Health Board, Ty Bryn Gwyn in Hywel Dda Health Boards

**Table: 12 Voluntary Hospice provision across Wales**

\*Bed numbers may have been subject to change during the pandemic.

<b>Voluntary Hospices across Wales</b>	<b>HOSPICE BEDS (*) In use /total bed numbers</b>	<b>COMMUNITY SPC SERVICES</b>	<b>HOSPICE AT HOME</b>
<b>Aneurin Bevan UHB</b> <ul style="list-style-type: none"> <li>• St David's Hospice (Newport)</li> <li>• Hospice of the Valleys</li> </ul>	15 beds/15 beds	Yes Yes	Yes Yes
<b>Cardiff and Vale UHB</b> <ul style="list-style-type: none"> <li>• C&amp;V Marie Curie Hospice</li> <li>• City Hospice</li> </ul>	28 beds/28 beds	Yes Yes	Yes
<b>Hywel Dda UHB</b> <ul style="list-style-type: none"> <li>• Paul Sartori</li> </ul>	Statutory Provision (See below)	Yes	Yes
<b>Swansea Bay UHB</b> <ul style="list-style-type: none"> <li>• Marie Curie hospice at home</li> </ul>	Statutory Provision (See below)	Statutory Provision (See below)	Yes
<b>Cwm Taf Morgannwg UHB</b> <ul style="list-style-type: none"> <li>• Marie Curie hospice at home</li> </ul>	Statutory Provision (See below)	Statutory Provision (See below)	Yes
<b>Powys Teaching UHB</b> <ul style="list-style-type: none"> <li>• Severn Hospice/St Michaels Hospice</li> <li>• Marie Curie</li> <li>• St David's Hospice Care</li> </ul>	Access to x3 beds	Yes Yes	Yes Yes
<b>Betsi Cadwaladr UHB</b>			

<ul style="list-style-type: none"> <li>• St Kentigern's Hospice</li> <li>• Nightingale Hospice</li> <li>• St David's Hospice Llandudno</li> <li>• Marie Curie hospice at home</li> </ul>	8 beds/12 beds 12 beds/16 beds 16 beds/18 beds	Statutory provision (See below)	Yes
<b>NHS Statutory Hospices across Wales</b>	<b>HOSPICE BEDS (*)- In use /total bed numbers</b>	<b>COMMUNITY SPC SERVICES</b>	<b>HOSPICE AT HOME</b>
<b>Cwm Taf Morgannwg UHB</b> <ul style="list-style-type: none"> <li>• Y Bwthyn Newydd Hospice</li> <li>• Y Bwthyn Hospice</li> <li>• Ward 6 Ysbyty Cwm Cynon</li> </ul>	8 beds/8 beds 8 beds/8 beds 8 beds/8 beds	Yes	Voluntary Hospice provision (See above)
<b>Swansea Bay UHB</b> <ul style="list-style-type: none"> <li>• Ty Olwen Hospice</li> </ul>	10 beds/10 beds	Yes	Voluntary Hospice provision (See above)
<b>Hywel Dda UHB</b> <ul style="list-style-type: none"> <li>• Ty Bryn Gwyn Hospice</li> </ul>	7 beds/7 beds	Voluntary Hospice provision (See above)	Voluntary Hospice provision (See above)
<b>Betsi Cadwaladr UHB</b>	Voluntary Hospice provision (See above)	Yes	Yes
<b>Wales Paediatric Voluntary Hospices</b>			
<ul style="list-style-type: none"> <li>• Ty Hafan (South &amp; mid Wales)</li> <li>• Ty Gobaith (North &amp; mid Wales)</li> </ul>	6 beds/6 beds 5 beds/5 beds	Yes Yes	Yes Yes

### *Welsh adult Voluntary Hospice Services*

Voluntary hospices in Wales provide hospice beds to five out of the seven Health Board areas, with three Health Board areas, Hywel Dda, Cwm Taf Morgannwg and Swansea Bay providing NHS funded specialist palliative care hospice beds.

Ten out of eleven adult hospices are local Voluntary providers with one hospice provider, Marie Curie, being a UK-wide provider. Two of the larger hospice providers Marie Curie and St David's Hospice Newport, provide services for inpatients, community provision and hospice at home provision; they also provide care across more than one HB area.

Voluntary hospices provide in the range of 90 hospice inpatient beds in Wales, with NHS statutory services providing another 47 beds in hospice specialist palliative care units.

Some voluntary hospice services do not provide inpatient beds but focus their delivery model on providing resource and support to people in their own homes through the provision of specialist palliative care or hospice at home services.

### *Funding and Commissioning Arrangements:*

Hospice care is delivered to a local population in partnership with Health Boards.

Services are not fully commissioned, as voluntary sector contracts take the form of service level agreements, based on 'Core' costs within the funding formula. Additional costs are met by the Voluntary Hospices themselves.

Health Boards may also contract additional services, over and above the agreed funding formula e.g., the use of CHC funding to increase Hospice at Home to meet need. Welsh Government funding may also be distributed; by way of the Capital grant process or through the annual EOLB funding allocation.

The impact of the Covid-19 pandemic on third sector income generation brought into sharp relief the fact that delivering a service based on a fund-raising model has a clear element of risk. Acknowledging that without the additional support provided through the Voluntary sector, overall care for end of life patients and their families would be diminished; Welsh Government set out an emergency hospice funding offer which provided nine million pounds during the financial year 2020-2021 to address the deficit in fund raising income

### *'Additional' services provided by Voluntary Hospice Services include for example:*

- Day Therapy Centres
- Complementary Therapies
- Bereavement Support and Anticipatory grief care
- Counselling services

- Extended family support and therapy

#### *Additional staff resources*

- Specialist Allied Health Professionals
- Social workers
- Psychological support
- Spiritual care
- Therapeutic support
- Benefits advisors

Hospice services may also employ additional workforce numbers above those originally identified in the Implementation Report Funding Formula. For example, some hospices employ additional Clinical Nurse Specialists or additional medical sessions or personnel to meet their local models of provision. This increase in workforce exemplifies the Hospice ethos, in ensuring professionals with great expertise are able spend more time at the bedside; listening to the patient, their family and carers.

#### **Interviews:**

The qualitative interview process with Voluntary providers raised the following points:

- All except one Health Board has a commissioning contract and service level agreement for the delivery and monitoring of their services.
- The funding formula calculated the resources required in the delivery of evidence based clinical services; defined as 'core' in end of life care support. Additional services; not considered as 'core' within the commissioning process, play an important role in improving patients and their family's quality of life 'wrap around care'. This type of provision will offer total 'wrap around' care e.g. day-care, transport, complementary therapies are seen as 'key' not 'core' and are provided as part of an holistic service by voluntary hospices.
- The running costs of hospices are met from their voluntary contributions which are not guaranteed and have been seen to fluctuate and placed at extreme risk during the COVID pandemic.
- Some services expressed aspirations for growth of their services, either of existing core services or development to new core services but were unable to move forward without partnership agreements to minimise risk.

#### **Discussion:**

Voluntary Hospices recognise that a team extends wider than the 'core' services detailed within the funding formula and will offer additional support (as above). These resources can be considered 'Key not Core' and are integral to a 'wrap-around' care

model, contributing to quality of life and positively impacting on patient and family wellbeing.

NHS specialist palliative care teams also work to deliver 'wrap around' care and often referrals are made to voluntary organisations to address this holistic need. This is a good example of collaborative working, however as these key services are not included within a commissioning contract, the cost of providing this model of end-of-life support is met by the voluntary sector. Welsh Government have instructed the EOLB to undertake a review of hospice funding during 2021.

## Education and Training

*Sugar Recommendation: Develop an All-Wales Training and Education Programme with agreed Standards for all palliative care Providers in the following settings: Primary Care; Secondary care and community hospitals; Nursing and Residential Care Homes*

All clinicians have an education remit as part of both their professional and operational roles. The intention of the stocktake was not to take an in-depth look at education and training but to look at the reach of that education and explore any dedicated roles. A variety of training programmes have taken place and all have evaluated well. However, an all-Wales training and education programme has not been progressed.

The interviews demonstrated that:

- Many services do not have dedicated education roles.
- Education commitments are embedded in the services strategies and delivery plans
- The educational reach varies across HBs and Voluntary services with some services being able to provide more support with dedicated educational roles.
- A few services identified protected educational time to support and enable high quality learning, resulting in more opportunistic episodes of learning taking place
- Both statutory SPCTs and Voluntary Hospices are supporting a wide workforce in the provision of education.
- Over the decade some services have benefited from third sector short-term investment in educational roles for example, AFCP roles, Care Home education and Care Decision Guidance education/implementation .
- Services expressed challenges in balancing clinical roles and undertaking formal educational opportunities.

### Discussion:

Over the decade there has been progress in the inclusion of end of life care and palliative care into learning at all levels and especially within medicine and nursing training and post-graduate learning.

The all Wales training and education programme approach was not progressed particularly due to the challenges of acquiring mandatory status for EOLC training; going forward, new engagement at strategic level with HEIW may help progress this.

During the review period the approach of supporting different solutions for different areas was adopted which resulted in models and programmes of work which could be scaled up across Wales. Some of these programmes of work have included, for example the Serious Illness Conversations Programme with the Wales Ambulance Service; GP short course; Advance Care Planning and DNACPR programmes of work reaching the wider public; the Care Decision Guidance Programme increasing learning for staff at all levels; The Six-Steps Care Home Communication Programme.

From the interviews there are similarities in the types and range of education being provided across HB areas including medical education, formal study days and teaching on other educational programmes. The statutory service leads in particular, indicated that their resource was usually focussed on direct urgent clinical care and that this impacted on the ability to share learning, develop staff and support the wider workforce to upskill in end of life care provision. Where there were opportunities for development through short-term funding, education outcomes had been achieved but rarely sustained when posts were dissolved, despite a range of different models being promoted.

Staff clinical commitments also had an impact on their own ability to undertake training, for example, Independent Prescribing, MSc level courses, which has implications for personal and professional development and succession planning.

### Regulation and Peer Review of Services

*Sugar Recommendation: Nominate a single regulating authority for inspection of all core services and develop inspection regimes for all clinical governance systems with peer review against agreed standards (sugar recommendation)*

The Sugar Report found that regulation of end-of-life care services was not uniform, and in some circumstances there were services regulated by more than one organisation, yet no regulation was in place for other services. A single regulatory authority was recommended; however this has not been progressed. A change in legislation is

required and therefore was outside of the remit of the EOLB. A Peer Review inspection was undertaken of a voluntary Hospice provider in 2019 on request of a Health Board in lieu of any regulatory process. However, Peer review is a quality assurance programme only and cannot fulfil that of a regulatory function.

**Table 12: Regulation of Palliative Care providers 2010**

Provider	Provision	Regulator	Function
NHS Wales Statutory services	All end of life care provision; NHS Hospices, community services, Continuing Health Care provision	Health Inspectorate Wales	Inspect all aspects of care delivery in all NHS settings
Wales Voluntary Hospices inpatient units	Specialist palliative care inpatient services	Health Inspectorate Wales	Inspect all aspects of care delivery in a clinical setting, in a similar way as private hospitals
Wales Voluntary Hospice at Home	Hospice at Home delivering 'hands on care' in the community as Domiciliary Care Service	Care Inspectorate Wales	Inspect all aspects of domiciliary care delivery the home environment, including care plans, financial stability, training and education
Wales Voluntary Hospice Specialist palliative care community nursing teams	Palliative care support as a clinical nursing specialty (CNS) in the community	Unregulated	Where CNSs are part of a wider Hospice at Home team, CIW will consider as part of the overall service
Wales Voluntary Hospice Day Care	Palliative Care offered as an outpatient day-care facility	Unregulated	Where day-care is provided within an inpatient setting, HIW will inspect as part of the overall service
Voluntary Hospices in England commissioned by CCGs	All end of life care delivered by voluntary hospices, inpatient services, community services, day care	Care Quality Commission	Inspect the services delivered by an organisation in its entirety



### *Peer Review Programme*

As the first step in the plan to having one single regulatory and quality assurance body, The Palliative Care Implementation Board and Healthcare Inspectorate Wales (HIW) started working in collaboration in 2009, to achieve the ambition of developing and implementing a peer review model. Work to research, develop and test peer review approaches with a view to introducing a rolling programme of peer reviews across Wales was undertaken.

A pilot of the End of Life Care Peer Review process with a plan to review three services a year later began in 2013. A thematic approach was developed using the HIW programme: 'Doing More Doing Better'. A programme to review all service providers over five years 2013-2018 was put in place. The End of Life Care Peer Review programme completed reviews between 2013 and 2016.

### **Outcome**

The EOLB began using the Peer Review process with the support of HIW in 2014. The reviews progressed well and there was full and positive engagement by Health Board Specialist Palliative Care MDTs and third sector providers, whose participation in the programme of review was entirely voluntary.

The reviews focussed on MDT working, Care Co-ordination, Achieving Outcomes and the Patient Experience. The services reviewed reflected a variety of providers and settings in which End of Life Care is delivered.

Review teams looked for evidence of:

- Robust Clinical Leadership
- Appropriately trained professionals
- Multi-disciplinary working and recording and sharing of information to improve clinical decision making.

Findings:

- There was evidence of good practice in all areas. Positive patient experience, and innovation.
- To improve patient outcomes and quality at the End of Life was evident in all reviews.
- Following each review, plans were expected to demonstrate action to address any areas requiring improvement.

As of 2020, this work now sits within the NHS Wales Collaborative agreed plan to deliver Peer Review as a component of their Quality and Safety programme.

## Continuing Health Care

*Sugar Recommendation: Strengthen and improve the existing Continuing Health Care (CHC) process and ensure the current review of this guidance considers mechanisms for rapid access to funding and more flexible processes for application and renewal of equipment.*

An individual is deemed to be eligible for CHC when their primary need is a health need: 'the primary health need approach'. This is determined by consideration of the four key characteristics of need: *'nature, intensity, complexity and unpredictability (Welsh Government 2014 pg35).*

During the last decade, improvements have been made in accessing CHC NHS-funded nursing care. The decision around eligibility for end-of-life care was made easier with the addition of the Fast-Track Assessment process. The National Framework for Implementation of Continuing Health Care (2014) outlines the role of fast-track assessments in individuals with a rapidly deteriorating condition who may be entering a terminal phase of their condition.

*"individuals with a rapidly deteriorating condition who may be entering a terminal phase will require 'fast tracking' for immediate provision of CHC so that they can be supported in their preferred place of care without waiting for the full CHC eligibility process to be completed. (p40)"*

**Table 13: Continuing Healthcare Funding**

Continuing Healthcare Funding – Fast Track Assessments for end-of-life care provision	
<p>Fast Track eligibility criteria are determined by healthcare need including, nature, intensity complexity and unpredictability. The assessment should be supported by a prognosis, for example, the following categories will be considered</p> <ul style="list-style-type: none"> <li>• Fast track One - Patients in the last days of life</li> <li>• Fast track Two - Prognosis days to few weeks</li> <li>• Fast track Three - Prognosis up to 12 weeks</li> </ul> <p>*These descriptions of prognosis may vary in HBs</p>	
Process	Comment
<ul style="list-style-type: none"> <li>• Fast Track application completed within 2 days.</li> <li>• CHC team approve eligibility.</li> </ul>	<ul style="list-style-type: none"> <li>• An NHS professional must co-ordinate the fast-track assessment.</li> <li>• Health Boards agree the Fast-Track applications and action immediately.</li> </ul>

<ul style="list-style-type: none"> <li>• Commission Hospice at Home services or Domiciliary Care agency to provide care at home.</li> <li>• Care Home or hospice funded by CHC to provide care.</li> </ul>	<ul style="list-style-type: none"> <li>• Disputes should be resolved outside care delivery.</li> <li>• Hospices with community services, registered with CIW can provide CHC commissioned care.</li> </ul>
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Hospices have been able to work with Health Boards to agree CHC funding in advance which can be drawn down on an individual patient basis. This also applies to the use of Hospice beds for patients meeting the Fast-Track criteria and for respite for patients with life-limiting conditions.

In England a recent Marie Curie Report, suggested that there was inconsistency in the delivery of Fast Track CHC; we do not know whether there are fast track inconsistencies in Wales and this was not part of the review.

## Palliative Care for Children and Young People

*“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.”*

*ACT and the Royal College of Paediatrics and Child Health (RCPCH), 1993*

Children and young people are different from adults in ways that are potentially important to palliative care. Children are constantly changing as they develop through stages of cognition, emotion, physiology and pharmacokinetics that impact on how their physical, psychosocial and spiritual well-being can best be supported. The clinical environments in which Specialist Paediatric Palliative Care (SPPC) must be deliverable include school and home as well as hospital and hospice. Commitment to ‘whole family support’ is a central tenet of children’s palliative care that underlies the ‘wrap-around care’, a model delivered particularly effectively by hospices (fig 3). Families, especially parents, are typically the primary caregivers and the healthcare team must consider their colleagues to include parents, siblings, grandparents and school staff as well as professional health carers. All of them might need education and training as carers as well as professional support as family members. Communication between that informal team of carers is sensitive, especially at the end of life as family and the healthcare team try to establish what interventions are in a child’s interest. Finally, the way in which children are bereaved, as well as the way they die, is different from adults. Some of the risk factors for complex bereavement, such as difficulty articulating grief or a limited opportunity to do so, are universal among children and young people, while access to Child and Adolescent Mental Health Services, and the range of alternative resources available to support bereaved children and young people, are extremely limited in Wales.

There are broadly three observations that must underpin a paediatric palliative care service if it is to meet the distinctive needs of children and young people:

- Specialist medical services for children and young people are centrally organized; palliative care in children and young people is effectively a subspecialty within the specialty of children’s services.
- The way in which children and young people die is highly unpredictable, because the range of life-limiting conditions is extremely wide.
- In children and young people, the need for specialist palliative care is large in proportion to the number of deaths.

Prior to the Sugar Report, statutory provision of specialist palliative care to children in Wales was limited to a single all-Wales consultant and a dedicated children's nurse in Gwent. Children's Hospice care in Wales was provided by three hospices, of which two are located in Wales and one close to the Shropshire border. While a formula was in place to calculate appropriate funding for adult specialist palliative care, it could not, as the EOLIB fully recognises, be applied meaningfully to the paediatric specialty because there had been no assessment of the distinct needs of children. In the absence of such an assessment, it has been difficult to plan a route to parity with the adult service.

The Sugar Report identified a number of important gaps in dedicated medical and nursing provision for children and young people in Wales that required immediate attention. Since its publication in 2008 the Welsh Government's response through the End of Life Board, advised by the all-Wales Network for Paediatric Palliative Medicine Care, has resulted in a number of successes as a significant return on a relatively small investment. They have included:

- Establishment of an all-Wales Network, steered by a Paediatric Palliative Care Implementation Group (PaedPCIG), that brings together statutory and voluntary providers of palliative care to children in Wales.
- A second all-Wales specialist consultant in paediatric palliative medicine (PPM).
- A transitional care lead consultant (the first of its kind in the UK), who also represent a third all-Wales specialist in PPM.
- An out of hours telephone advice service for PPM.
- Sessional commitment and training for a local paediatricians in each HB where there was not already a consultant in PPM, except Powys.
- CNS posts and training in every HB except Powys.
- Purchase of 'Cuddle Cots' in each HB.

### *Childrens Hospices in Wales*

The needs of children and young people are very different from those of adults, and children's palliative care is recognised as a specialist area of practice addressing both the physical issues of children's palliative care and the need to address the psychosocial and spiritual issues of the family as a whole. Although the distinct nature of children, and of the palliative care needs of children, means hospices for children have developed along very different lines, children's hospices share with adult hospices a commitment to holistic and patient-focused care (Hain 2019). The palliative care model for children and adults have some common features which include threat to life, impact of symptoms on activities of daily living, emotional impact, distress to families and the need for a co-ordinated multi-agency approach. The three children's hospices that serve Welsh patients (Tŷ Hafan, Tŷ Gobaith and Hope House) offer a wide range of services and environments to support the child and their family, from the moment an LLC is diagnosed (fig 3). Children with LLC typically require complex support for most of their

life. Criteria for acceptance to a children's hospice varies between organisations but is generally met by the baby, child or young person having a prognosis of not expecting to live beyond early adulthood and may be referred from 24 weeks' gestation. Children with palliative care needs present with a unique array of complex and diverse conditions, leading to illness trajectories that are notoriously difficult to predict. The conditions present with varying prognoses of days to many years, thus resulting in children potentially needing complex support for most of their life. The intensity of palliative care support can change at different stages of the illness trajectory (fig 4).

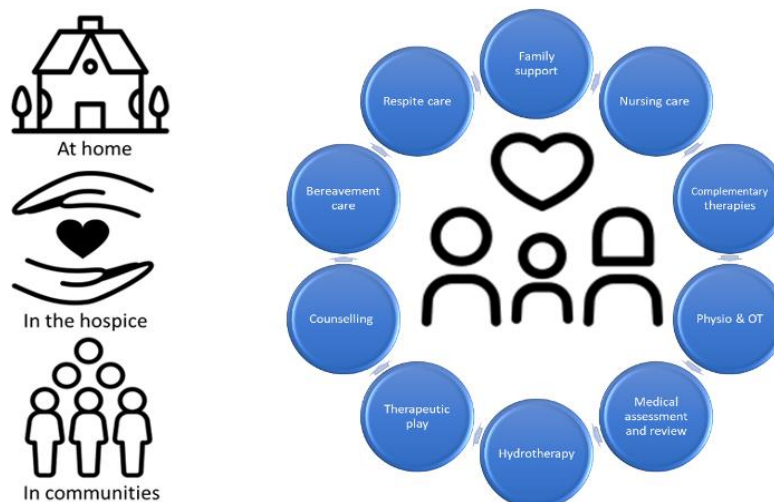
Children's hospices offer many families forms of support and care that are not available through statutory paediatric services. Those can range from play, music and hydrotherapy through respite and support for symptom control, to bereavement support, and the hospices are crucial in delivering the Network's commitment to 'wrap-around' care (fig 3). Most of the responsibility for caring for a child with palliative care needs falls a child's family. In many parts of Wales, rurality makes access to support services and provision of care in the family home challenging, and it is on the children's hospices that many families feel they have to rely on for their care and support needs (Our Lifeline Report 2020). There is evidence of the impact this lifelong caring responsibility has on family life, relationships, finances and the health and mental wellbeing of the child and all family members (Give me a Break Report 2020). Hospices can offer an inpatient clinical environment for children with LLC when that is necessary. Where urgent inpatient symptom control is needed, for example, consultants in PPM can usually arrange for admission to Tŷ Hafan. Just as importantly, the hospices also offer support alongside statutory services for children in other settings as well, particularly in the child's home. Tŷ Gobaith, for example, offers a 24-hour community paediatric nursing team that can provide hands-on care for a child in the last few days of life at home.

The full range of support that hospices can offer to children with LLC is not always reliably available through statutory paediatric services. The Sugar Report recommended that palliative care services for children be centrally commissioned. In 2021, however, Children's Hospices are still supported through nominal grant funding which does not represent parity with the adult hospice model because it does not reflect the service model or the full scope and activity of children's hospices. The services provided by children's hospices in Wales are not centrally commissioned and rely substantially on fundraised income for the provision of core and supportive palliative care services.

**Fig 3: The paediatric palliative care ‘wrap-around’ model**



**Fig 4: Family centred children’s palliative care services that are delivered by children’s hospices in Wales**



### ***Statutory provision of palliative care to children and young people in Wales***

The all-Wales Paediatric Palliative Care Network provides and/or coordinates palliative care for young people in the Principality who are older children or young adults (transitional palliative care) and also for those who are younger children (paediatric palliative care). Thanks to funding for a data manager, in 2020 the Network was able for the first time to begin analysing data in a systematic fashion in order to begin to evaluate its performance against standards set by the EOLB’s Delivery Plans.

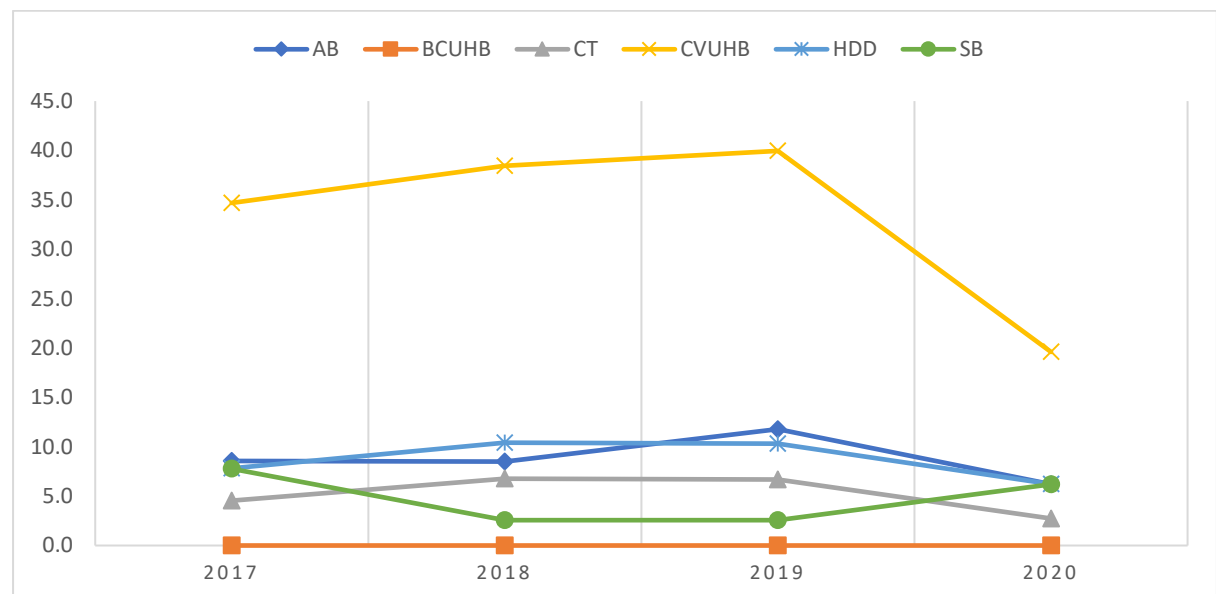
There are currently no data on the current prevalence of LLC in children or young people (CYP) in Wales. The denominators are extrapolated from a reliable epidemiological study in England in 2012, (Fraser et al 2012). Data were not available from Powys as there is currently no local PPC team.

## Young People (Transitional Palliative Care)

The population of young people with LLC is on the increase. The most recent epidemiological study in England has shown an increase in the number of 14-25-year-olds with LLC by 40% over the past years and even higher increase by 53% for those whose diagnosis was made in childhood (before 18), (Fraser et al 2020). The current prevalence of LLC in 18–25-year-olds in England is 44.6 per 10,000 and it expected to rise up to 62.2 per 10,000 by 2023. This translates into an estimate of around 1,500 young adults (Fraser et al 2020) between 18 and 25 in Wales who have LLC and many will require a transition from paediatric to adult palliative care. Provision of palliative care to young adults is becoming an essential part of adult palliative care service.

### Case load:

**Fig 5: Young people known to SPPC (per million population)**



### Notes:

- The Network's role in transition is primarily to facilitate smooth transition of patients between children's and adult services. The Network does offer direct care of patients in transition, but usually only as a temporary measure while substantive arrangements are put in place.
- When the Transitional Consultant was appointed the list of live patient case load stood at 32. Many have since been successfully handed over to adult SPC or other relevant services including GPs for continuing care.
- The current number of young people on the caseload who are between 16 and 25 on the combined PPC and Tŷ Hafan database is 90 and adding this to Tŷ Gobaith/Hope House numbers totals approximately 150.
- For South Wales patients, at least 23 of the 90 have been seen at least once by the adult palliative care team. In North Wales, young adult patients continue to



access children's hospice service until 25 but in the past 18 months, joint work with local adult hospices have begun to jointly provide short breaks/respite stays to these young adults.

#### **Joint working between paediatric and adult palliative care:**

- There was no formal joint working between paediatric and adult palliative care on a regular basis when the Transitional Consultant came into the post in June 2016. By early 2017, a pilot joint clinic was set up between Tŷ Hafan, City Hospice and Marie Curie Hospice for CAVUHB patients between the ages of 16 and 25 who are accessing or have accessed paediatric palliative care service either through Tŷ Hafan or specialist paediatric palliative care or both. 23 patients in this age category were identified and were invited to the clinic, that occurred three monthly over the next 2 years.
- In 2019, Tŷ Hafan secured funding for a quality improvement project from the Improving Transition in Palliative Care Fund from Together for Short Lives. With this funding a Tŷ Hafan nurse was recruited as the transition nurse to co-ordinate Transition Hubs based in adult hospices. The hubs are an expansion of the joint hospice transition clinic, where young people and their carers were able to access information and advice from other professionals such as benefits advisor, further education and career advisors, legal advisor as well as clinical assessment by professionals including physiotherapist, occupational therapist and palliative care doctors and nurses. Complementary therapy was also on offer and there was a social opportunity for the attendees to exchange information and provide peer support.
- Three health boards, C&VUHB, Swansea Bay UHB and ABUHB signed up for the project and in addition to City Hospice and Marie Curie, Y Bwthyn Newydd and St David's Hospice hosted the hubs as well as offering clinical expertise from adult palliative care team. The project was to run over 18-month period but the latter part of it was disrupted by COVID-19 pandemic. Despite the disruption, the hubs and related activities such as skills sharing sessions for the professionals and social activities continued virtually where possible and the project completed with a final virtual skill sharing and feedback session in April 2021, (postponed from June last year). The feedback from the service users and professionals was very positive. The formal evaluation report is currently being prepared.
- Following the Hospice Transition Hub project, the joint clinic (the clinical part of the hub) has continued at City Hospice/Marie Curie and Y Bwthyn Newydd (now only seeing patients from CTMUHB). For the patients from Swansea Bay area who attended that Transition Hub a transition clinic is starting with Tŷ Olwen team, and for the ABUHB patients, St David's Hospice is hoping to continue hosting a joint clinic. A total of 4 joint clinics in 4 different health boards are expected to be running by the end of this year.

#### **Service Gap in palliative care for 16 and 17-year-olds**

- An inconsistency in age criteria between services and health boards has created gaps in service provision for this specific age group.

- A detailed service gap analysis was carried out to identify and address these gaps at local and national levels. C&VUHB and ABUHB has commenced their work to address the gaps jointly between adult and paediatric services.
- PPCIG and PCIG are looking at further ways to streamline the approach to the care of young people in this age category.

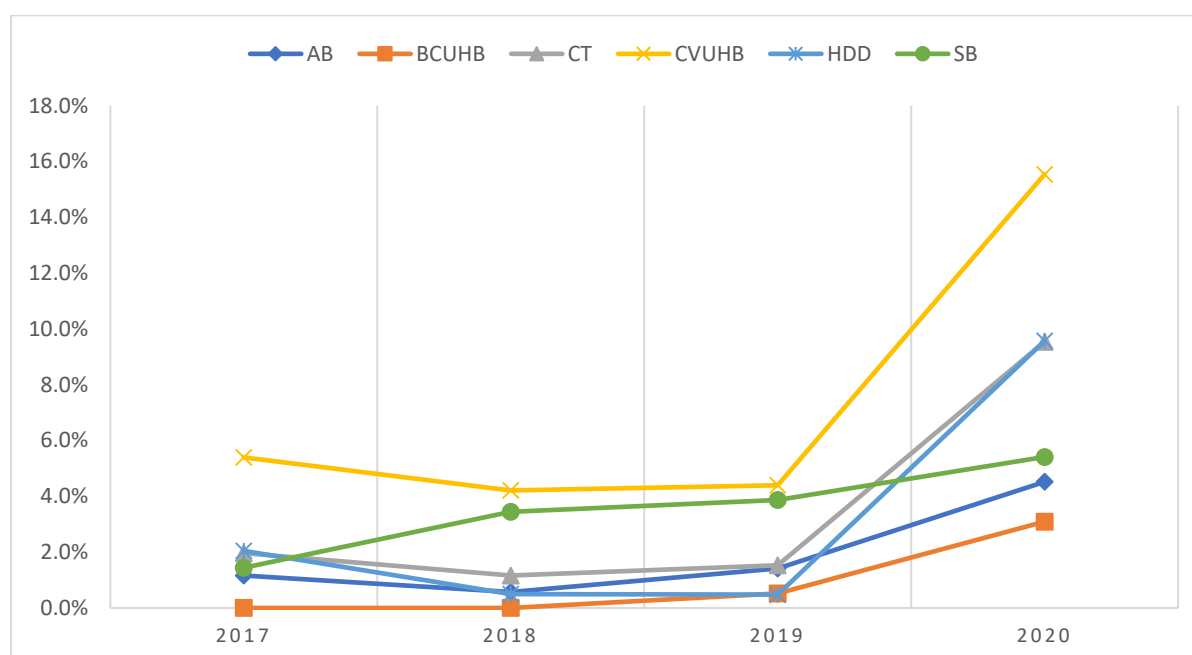
### Oncology TYAMDT

- Transitional palliative care has become an integral part of the teenage and young adult Oncology MDT for South Wales, which promotes early integration of palliative care by the most appropriate team (paediatrics or adult) for the young person.

## Children (Paediatric Palliative Care)

### Proportion of children with LLC that SPPC is currently reaching.

**Fig 6: No. of children who are known to the all-Wales service as a proportion of all the children in Wales with a LLC.**



### Notes:

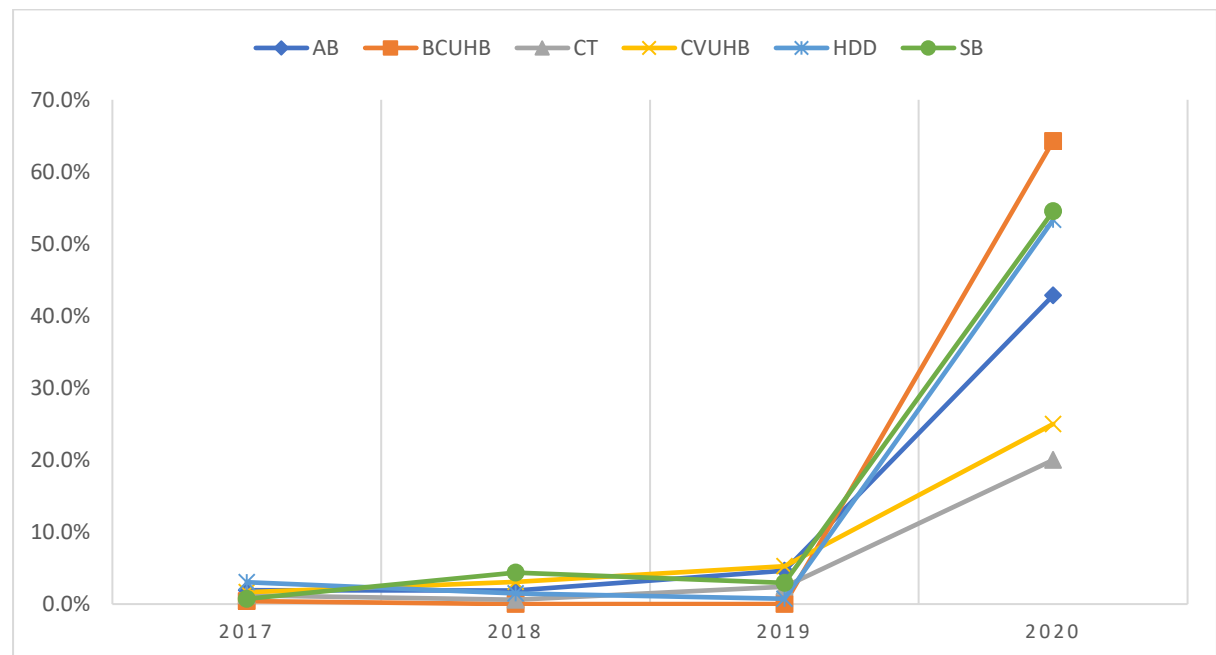
- The target we are aiming at here is not clear. It would not be reasonable to expect every child with a life-limiting condition to be referred to SPPC as soon as the diagnosis is made, so at any one time there will always be some children with LLC who are not known to SPPC. There may even be some who will never need to access SPPC.
- Since it is unlikely the service would accept referrals who should not be seen by SPPC, however, the proportion of children seen in the HB with the greatest

referral rate represents the absolute minimum standard for all HBs. In 2020 that was 16% (CVUHB).

- In most HBs the proportion of children with LLC who were able to access SPPC services was between one eighth and a half of that, suggesting that the profile and benefits of our service remains too low.

### Proportion of children dying with LLC whom SPPC is reaching

**Fig 7: No. of children known to the SPPC service at the time of death, as a proportion of all those with an LLC dying in Wales**



#### Notes:

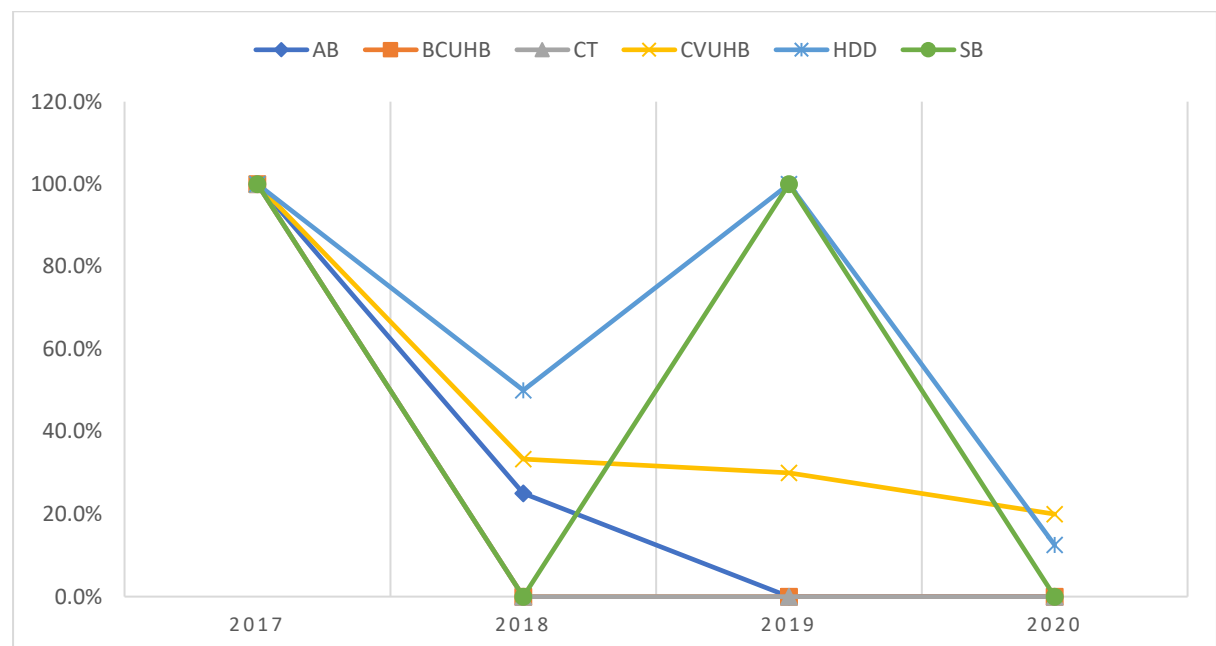
- It seems reasonable to expect that the SPPC team should aim to reach 100% of children in Wales dying from a LLC, though in practice a small number of children might never need to access SPPC (see above) or might die before being able to do so, particularly in the neonatal period.
- The data is hard to interpret because numbers in each HB are small, are approximate and are based on an assumption that on average 50% are caused by a LLC (Hain et al 2013).
- The significant change between 2019 and 2020 is a change in the way data is collected
- The 2020 data, however, offers a good baseline for future comparisons.

### Colours of life

'Colours of life' represent our ability to anticipate that a child is approaching death and so to put into place the necessary measures to ensure a good death in the place of the family's choice, such as alerting the GP that the child should be added to the palliative

care register. Children progress into the amber and red phases when maintaining quality of life takes precedence over curative treatment. It is one proxy measure of the Network's performance against goals for reducing distress at the end of life that are set out in themes 2 and 4 of the EOLB's 2017 refreshed Delivery Plan.

**Fig 8: Children under SPPC who were not considered 'red' or 'amber' at the time of death.**



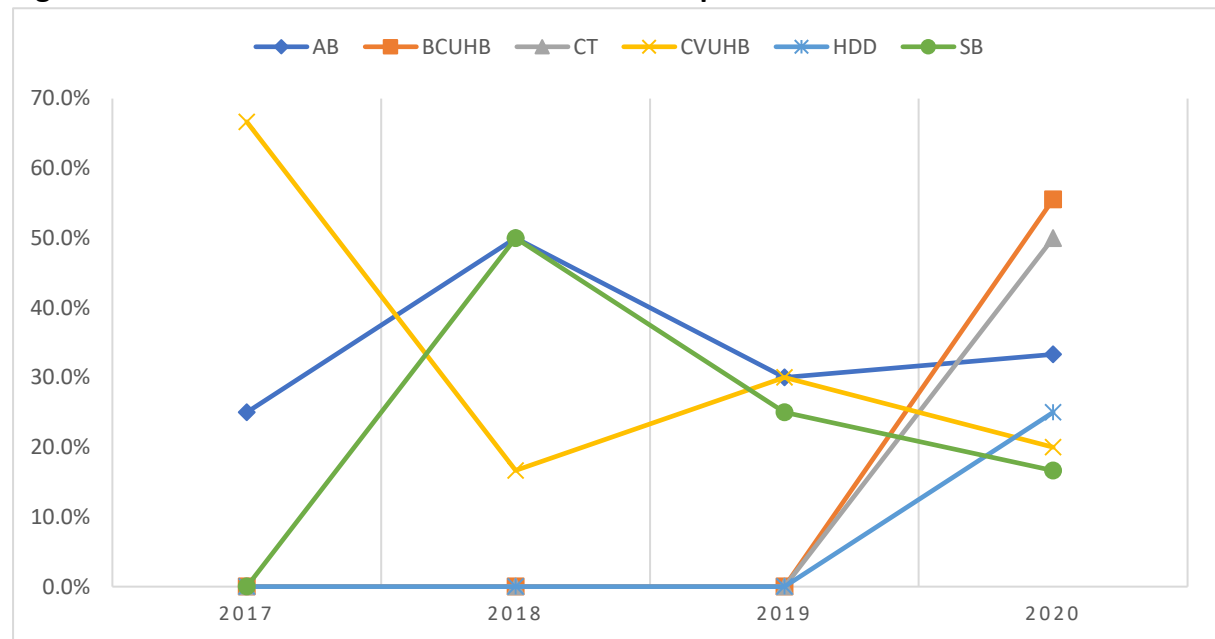
**Notes:**

- The graph represents the proportion of times the SPPC did not recognise that a child who subsequently died was approaching the end of life.
- The target should be 0% but in practice it is unlikely to reach this.
- No patients were coded 'red' or 'amber' in 2017 because the 'colours of life' system was only introduced in 2018.
- It is hard to draw conclusions from previous years but there is some evidence of a trend towards fewer children dying without it being recognised that they are approaching the end of life.
- Again, the 2020 data offers a good baseline for future comparisons.

### PAC-Planning

Paediatric Advance Care Plans (PAC-Plans) represent the extent to which families have been engaged in a timely manner with discussions about what their child's death might look like and what plans and decisions need to be made. The process of PAC-Planning in children with LLC is supported, though not necessarily led, by the Network and is a measure of the Network's performance against goals set out in themes 2, 3, 4 and 7 of the 2017 refreshed Delivery Plan.

**Fig 9: Children under SPPC who had a PAC-Plan completed at the time of death**



**Notes:**

- In 2020, there have been significant changes in the way data about PAC-Planning are captured. The most obvious change has been in the quality of data, with robust data in all six of the HBs with local teams in place becoming available in 2020 for the first time.
- It is not clear what the target should be. It is not 100%, because some families find it intolerable to engage with the process of PAC-Planning, and it would sometimes be unkind and/or counter-productive to force the issue.
- As above, however, the proportion of children in the HB with the greatest number of PAC-Plans can reasonably be taken to represent the absolute minimum standard for all HBs. In 2020 that was 56% (BCUHB).
- Some regional variation would be expected, particularly because of the proportion of oncology children who (at least in the South) have historically not used PAC-Plans.

**What still remains to be done: Gap analysis and the Sugar Shortfall proposal**

As set out in the Sugar Report, the paediatric service model for palliative care takes a Wales-wide network approach to care. The fundamental principles behind the Network are:

- Irrespective of where they are cared for, any child in Wales with a life-limiting condition should have twenty-four-hour access to clinicians with the same degree of specialist palliative care expertise. No family should have to choose between being cared for at or close to home on the one hand and having access to clinicians with specialist palliative care skills on the other.
- The Network's general structure facilitates 'layered' care: at the bedside, local and tertiary:

- Those caring for the child at the bedside are supported by a paediatrician within their HB with post-graduate training (level III) and a sessional commitment to palliative care.
- The level III paediatrician is supported by the all-Wales tertiary palliative care service.
- Specialist support consists of a SPPCN who part of the all-Wales service is; being embedded in the patient's HB alongside the local paediatrician, and a consultant in paediatric palliative medicine (level IV) who may be based at some distance from the patient.
- A fully operationalised model would mean a child anywhere in Wales could always access tertiary expertise, whether they are at home, at school, or in the local hospice or paediatric unit.
- Care at the end of life would represent a collaboration between healthcare professionals who are local to the child but are not always specialists (including doctors working in children's hospices), and those who are tertiary specialists but are not always local.

In 2020, the Clinical Lead for Paediatric Palliative Care in Wales undertook a Gap Analysis, looking at the shortfall in the Sugar Report recommendations in relation to paediatrics. The analysis found that while there has been very significant progress towards the starting point envisaged in the Sugar Report, the baseline has not yet been achieved, resulting in significant inequities particularly in North and Mid-Wales. The Clinical Lead set out a fully costed service model proposal in 2021 which has the support of the EOLB. It is expected that some of the key gaps in the PPC service will be addressed as a result of those proposals, when implemented. This includes, for example:

- Ensuring access to specialist PPC services is the same all over Wales and is not jeopardised by geographical distance from a secondary or tertiary paediatric centre.
- Continuing to improve awareness of the service among families and colleagues so that referrals to specialist PPC are always made when they are needed.
- Improving education and training among professionals caring for children with LLC who are not specialists in PPC.
- Developing a process for timely transition of children to adult services that is seamless and acknowledges the importance of developmental stage.
- Continuing to facilitate and develop the advance care planning process so that parents and paediatric clinicians are supported in making difficult decisions at the end of a child's life.

Other key gaps persist and will require new investment if they are to be filled. Those include (but are not limited to):

- Developing a 'pop-up' palliative care team model that draws on local community children's nurses and can be supported at all times by the all-Wales SPPCN team, allowing children to spend their last few days or weeks at home if they and their families choose.
- Establishing a system of funding for Children's Hospices that acknowledges the distinctive services they offer to families; the support they represent to statutory paediatric services and the particular problems they face around sustainability.
- Expanding the range of disciplines represented on the SPPC team to include (e.g.) psychology, social work and pharmacy.

As part of this work, a paediatric palliative care prevalence study has been commissioned in partnership between the children's hospices in Wales and the EOLCB. This will be undertaken by Professor Lorna Fraser, Director of the Martin House Research Centre, Department of Health Sciences, University of York, UK. Professor Fraser completed a similar analysis for NHS Scotland, this will provide benchmarking opportunities. The study will replicate a previous study undertaken for NHS Scotland and will enable benchmarking to assist with service evaluation and improvement.

## Key Findings

- SPC Services are seeing more patients and reaching more patients with different conditions.
- How we support equality of access and equity of service provision to those with protected characteristics is not always clear.
- Hospice services are providing both core care and diverse patient focused care with their delivery models.
- Statutory SPC services have embedded and matured over the last decade.
- SPC Services are seeking to do more with less – through co-production and reviews of their traditional models of delivery considering for example, shared care type models and SPC beds in acute hospitals.
- Perceptions of workforce gaps exist despite meeting minimum core staffing levels in medical and nursing groups.
- Actual gaps in some areas exist for Specialist AHPs with potentially few career opportunities for AHPs within the specialty.
- New roles in SPC teams such as Advance Nurse Practitioners are progressing slowly reportedly due to few funding opportunities.
- Health boundaries which determine access to SPC services need to be clarified to ensure equitable and timely patient access.
- Assurances are needed about equal access to skilled and trained SPC staff in care homes through the models of delivery in place.
- Assurances are needed about the impact on patients and families around Hospice at Home service models that include multi-provider models to ensure consistency of care provision.
- We need assurance that organisational and professional boundaries and models do not inhibit patient experience and health and wellbeing outcomes.
- 7-day CNS services are embedded but the model of delivery impacts on the delivery of the weekday service and on the reach of the service at weekends.
- Workforce recruitment development and retention is challenging in some Health board areas and for some professions.
- There is a need for the workforce to be supported to fully understand the leadership role and to nurture those who wish to be future leaders.
- Paediatric services shortfall of clinical posts prevents delivery of an equitable service



## Key Recommendations

The following recommendations are based on the progress made, areas of 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 all settings.
- Review and modernise funding arrangements for statutory SPC 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 for 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.

## Review 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 AFCP lead<sup>1</sup>. 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.

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 'Last days of Life' guidance from 2009-2021.
- 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.

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

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 work 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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## Appendices

### Appendix 1: Health Board area lead contributors to review and areas they represented.

	NHS HOSPITALS	HOSPICES (Independent, third sector and NHS provision)	HOSPICE AT HOME (Voluntary sector provision)	COMMUNITY (NHS, third sector provision)
<b>ABUHB</b> SPC Medical and nursing leads Voluntary Hospice CEO/ Director of nursing	Royal Gwent Hospital Neville Hall The Grange Hospital Ysbyty Ystrad Fawr Ysbyty Aneurin Bevan (plus, community hospitals)	St David's Hospice	St David's Hospice Care Hospice of the Valleys	St David's Hospice Care (community service) Hospice of the Valleys (community service)
<b>CTMUHB</b> SPC Medical/Nursing leads Lead palliative Care manager	Princess of Wales hospital Royal Glamorgan Hospital Prince Charles hospital (plus, community hospitals)	Ysbyty Cwm Cynon unit Y Bwthyn Unit Y Bwthyn Newydd	Marie Curie hospice at home	Statutory community services
<b>CVUHB</b> SPC Medical/Nursing leads Lead palliative Care manager Third sector Managers, clinical Hospice Leads	University hospital of Wales University Hospital of Llandough (plus community hospitals)	Cardiff & Vale Marie Curie hospice	Marie Curie hospice at home	City Hospice (community service) Marie Curie (community service)
<b>VELINDRE</b> Medical and nursing leads	Velindre Cancer Centre	Not applicable Regional service for SEW Wales	Not applicable Regional service for SEW Wales	Not applicable Regional service for SEW Wales
<b>SBUHB</b> SPC Medical/Nursing leads	Morriston Hospital Singleton Hospital Neath Port Talbot hospital (plus community hospitals)	Ty Olwen Hospice	Marie Curie Hospice at home	Statutory services
<b>HDUHB</b> SPC Medical/Nursing leads Lead palliative Care manager Voluntary Hospice management leads	Bronglais hospital Withybush Hospital Glangwili Hospital  (plus, community hospitals)	Ty Bryn Gwyn	Paul Sartori	Paul Sartori plus Statutory services



	<b>NHS HOSPITALS</b>	<b>HOSPICES</b> (Independent, third sector and NHS provision)	<b>HOSPICE AT HOME</b> (Voluntary sector provision)	<b>COMMUNITY</b> (NHS, third sector provision)
<b>POWYS</b> SPC Medical/Nursing leads	Bronllys Hospital (plus, community hospitals)	Severn Hospice St Michael's Hospice (Hereford)	Marie Curie Hospice at home Severn Hospice St David's Hospice	Statutory services
<b>BCUHB</b> SPC Medical/Nursing leads Voluntary Hospice CEO's & clinical leads	Glan Clwyd Hospital Wrexham Maelor Ysbyty Gwynedd	St David's Hospice St Kentigern Hospice Nightingale House	Marie curie Hospice at Home Gwynedd Hospice at home NHS Hospice at home	Statutory Services

## Appendix 2: INTERVIEW QUESTION THEMES

Interview question areas drawn from the Implementation Plan and the End-of-Life Delivery Plan:

- *Service model*
- *Core team composition*
- *Funding of posts*
- *7-day services*
- *Out of Hours provision*
- *Hospice inpatient units*
- *Hospice at home*
- *Advance care planning*
- *Evidenced based tools*
- *Pharmacy model*
- *Education*
- *Care homes*
- *Non-medical prescribing*
- *Service user feedback*
- *Future modelling/plans*

## Appendix 3: Population estimates 2019:

Mid-year population estimates 2019 by Welsh health boards, all ages.

Health Board	Population
Betsi Cadwaladr University Health Board	699,559
Powys Teaching Health Board	132,435

Hywel Dda University Health Board	387,284
Swansea Bay University Health Board	390,308
Cwm Taf Morgannwg University Health Board	448,639
Aneurin Bevan University Health Board	594,164
Cardiff and Vale University Health Board	500,490