



Six Month Report up to 31st August 2023



Wessex Children's and Young Adults' Palliative Care Network

6 Month Update to 31st August 2023

Jayden's Story by Dr Tim Warlow (patient name has been changed to protect identity)

Jayden was the cheekiest lad you ever did meet. He had the most wonderful smile and loved nothing more than grabbing my stethoscope from around my neck every time I got close, and giving one of his siblings a playful prod and grinning from ear to ear when they caught him.

Jayden had significant disabilities from a young age due to a condition which prevents the fluid that bathes the brain from flowing properly. He had stiff muscles that were painful at times and required feeding through a tube into his stomach. He struggled to communicate, to swallow his secretions and required a wheelchair to move around. His muscle tightness led to his bones twisting out of shape, especially his spine which made breathing hard and caused him to be sick, sometimes several times per day.

He was well supported by a large, loving family, a team of dedicated schoolteachers, school and community nurses, a community paediatrician who oversaw his care and a team of doctors at the hospital who managed his various complex medical problems. The job for me and the specialist palliative care team was to help reduce his vomiting and pain which we did using comfort measures, managing his anxiety, and working alongside therapists to manage his positioning and breathing. We talked with his family over several home visits about what might happen if Jayden's health did decline. His mother who cared for him day in and day out since birth, with no carer support, knew that she wanted him to be at home with her and she would care for him until the end.... just as she had done until now. Despite all of the challenges he faced, Jayden never moaned, always gave freely of his warmth and sense of humour, and we all knew that if he could speak to us.... he would tell us what a joy filled life he had.

Over time and even with the intense holistic support being provided, his condition deteriorated, and he became increasingly unwell with chest infections. His lungs were compressed from his spine curvature, and we reached the decision with the family and his spinal surgeon that operating would carry too much risk. He became increasingly challenging to care for at home and school. As a team we had to work together, holding regular meetings with school staff/nurses/hospital teams/social workers and the children's hospice Naomi House who were providing support. We had to make sure we all understood where Jayden was in his health journey, and make sure we all used our strengths and skills to support this family effectively. Despite coming from different organisations, across different disciplines, it was only working together to understand and meet the needs of Jayden and his family, that we would be able to ensure the last stages of Jayden's life were as positive and profound as the rest.

As Jayden became more unwell, he required increasingly intense support at home. This was when the cracks in the palliative care provision around Jayden became all too visible. During the school term Jayden had support for his complex health needs at school and the family had respite whilst he was there. However, school were struggling with managing his vomiting, episodes of going blue with breathing changes and needed more clinical support from trained carers and confident nursing staff who could meet his needs. As the autumn term ended, this coincided with Jayden entering the end-of-life phase of his illness. Being the school holidays, care fell to the community and hospital teams. His health was too unstable for regular council respite providers to manage. The community nursing and therapies teams were facing increased numbers of patients with complex needs and acuity of care, alongside rota shortages and just could not provide 24/7 care at the end of Jayden's life at home.



Although the children's community nursing team were able to provide visits during the working day there was no medical support provision for the family or nursing staff out of hours. With a shortage of specialist palliative care services in the hospital over the Christmas bank holidays it meant this family were faced with managing his care needs without the 24/7 support from a highly skilled nursing and medical team that Jayden needed..... Team members did offer to go over and above but this quickly became unsustainable, and it became clear that services could not provide safe end of life care at home.

I had to sit down with Jayden's mother and tell her that sadly we could not meet her only wish for her dying child... to be cared for in the home where she had cared for him all her life. It broke my heart. We arranged prompt transfer to the regional children's hospice who had already been providing the family with support. The family quickly settled into a new environment. They were all able to stay and received emotional and spiritual support, meals and rooms provided, and Jayden was able to be cared for by a care and medical team who were confident managing his needs. The stay wasn't easy, Jayden developed seizures and his breathing worsened requiring us to escalate his medical treatment rapidly. It remained very hard for his mother, not being able to be in their family home, saddened and frustrated that her role as provider, carer, nurse, comforter was not able to be fulfilled as she would have liked. However, Jayden died peacefully a few weeks later, surrounded by his family, supported by the hospice team.

Teams across Wessex support young people like Jayden day in, day out, as well as children with a variety of conditions, from neonates born with severe congenital abnormalities, children with cardiac anomalies, those with cancer. We know that you only get one chance to get care right for these children and young adults, especially caring for them at the end of life. We want to get that one chance right and keep doing it week in week out.



1. Context

The Health and Care Act 2022 [Health and Care Act 2022 \(legislation.gov.uk\)](https://www.legislation.gov.uk) introduced a statutory requirement for Integrated Care Boards (ICBs) to commission health services that meet their population needs, including palliative care services. The core responsibility for commissioners is to commission high quality safe services that are tailored to the needs of the individual. The Health and Care Act 2022 states a legal duty on ICBs to commission palliative care services under s3(1) NHS Act 2006 (as amended):

- An integrated care board must arrange for the provision of the following to such extent as it considers necessary to meet the reasonable requirements of the people for whom it has responsibility —
- Such other services or facilities for palliative care as the board considers are appropriate as part of the health service.

Further information is contained within statutory guidance for ICBs that was published in September 2022; <https://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf>. A summary of the requirements contained within the statutory guidance is as follows:

Illustration 1

NHS England National Delivery Plan		
Priority	Action	Delivery Asks of ICS/ICB
Improving Sustainability	People are identified as likely to be in the last 12 months of life and are offered PCSP	<ul style="list-style-type: none"> • Palliative care registers across primary and secondary care in place, for timely PCSP • Identification tools implemented to increase identification of people in last year of life • Full implementation of EPaCCs
	Staff, patients and carers can access the care and advice they need, whatever time of day	<ul style="list-style-type: none"> • All patients with PEoLC needs, including those not yet listed on palliative care registers, can access the appropriate advice and signposting supported by a SPOC • Collaborative working to achieve seamless transition between care settings

	Equitable access to PEoLC for all, focussing on locally identified under-served populations.	<ul style="list-style-type: none"> • Evidence how plans and actions address priority underserved populations • Equalities and Health inequalities impact assessment and action plan focused on PEoLC and EARLY/risk stratification extractions
Improving Quality	High quality PEoLC for all, irrespective of condition or diagnosis	<ul style="list-style-type: none"> • Collaborate with system-level networks, e.g. CYP, dementia, frailty, cancer to ensure high quality personalised PEoLC for all, across all settings
	A confident workforce with the knowledge, skills and capability to deliver high quality PEoLC	<ul style="list-style-type: none"> • Roll out training for staff in terms of personalised PEoLC, including PCSP, e.g. QoF Qi training, E-eLCA and Personalised Care Institute ³
Improving Sustainability	High quality PEoLC across all system	<ul style="list-style-type: none"> • Adopt QI Methodology for PEoLC, at system level engage with local quality and improvement leads, in both acute and community settings, to ensure an outstanding CQC rating is achieved consistently across the ICS
	PEoLC is sustainably commissioned	<ul style="list-style-type: none"> • ICB Plans have PEoLC as a strategic priority <ul style="list-style-type: none"> ◦ PEoLC service specification, contracting arrangements against investment framework and data collection methodologies • Sustainability of CYP PEoLC through CYP match funding and CYP hospice grant
	The PEoLC workforce is fit for purpose, now and in the future	<ul style="list-style-type: none"> • Future workforce evidenced in all ICB generic workforce plans • Implementable specialist palliative care workforce plan, progress in implementing that plan and utilising the regional mapping tool
	Personalised and community approaches are fundamental to improving PEoLC experience	<ul style="list-style-type: none"> • Personalised and community centred approaches across ICS, place and PCNs
Ambitions Outcomes <i>Everyone person is seen as an individual Each person gets fair access to care Maximising comfort and wellbeing Care is coordinated All staff are prepared to care Each community is prepared to help</i>		



The guidance above identifies that 'Every ICB should commission PEOLC services that meet people's needs, aligning to the commitments within the [ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/100000/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf) ([england.nhs.uk](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/100000/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf)) detailed in Illustration 2.

Illustration 2

- 01 Each person is seen as an individual**
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.
- 02 Each person gets fair access to care**
I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.
- 03 Maximising comfort and wellbeing**
My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.
- 04 Care is coordinated**
I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.
- 05 All staff are prepared to care**
Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.
- 06 Each community is prepared to help**
I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.



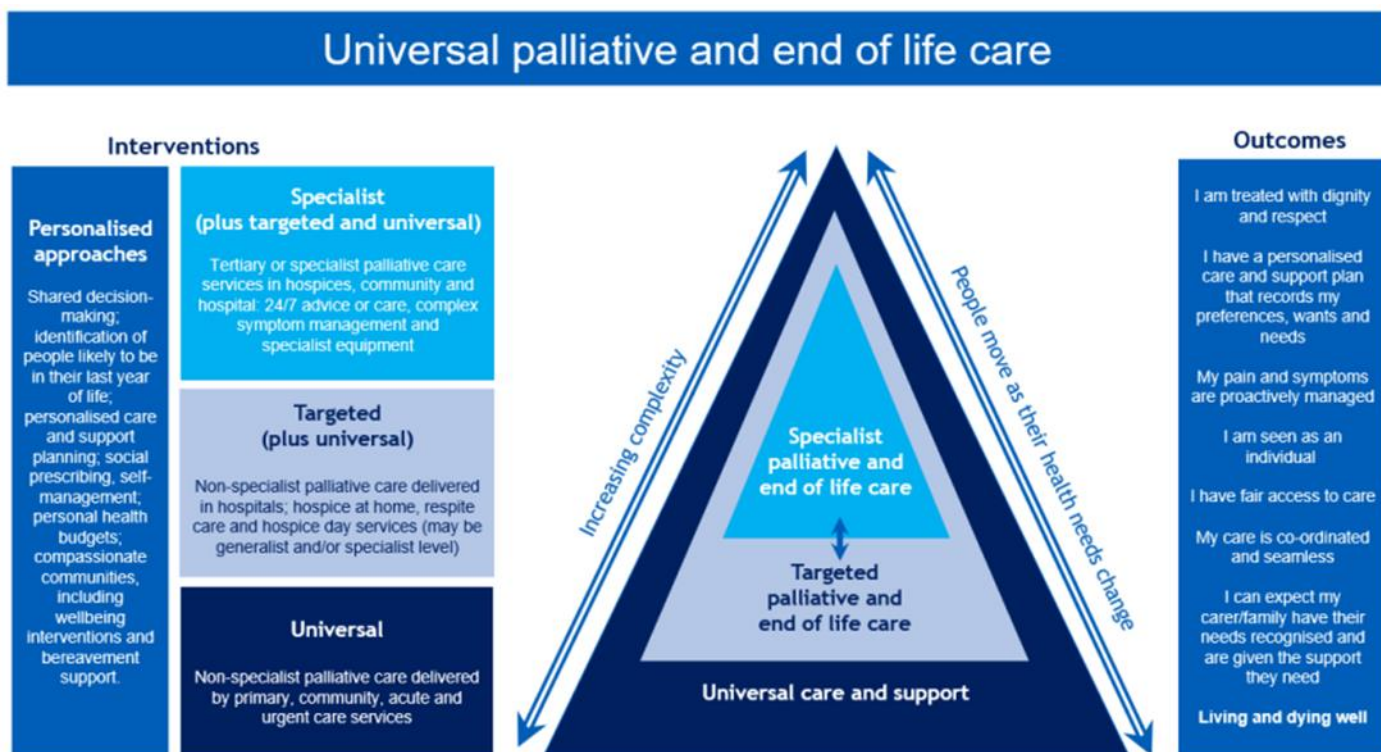
Reference to the palliative and end of life care is also included within the [NHS Long Term Plan](#) » [The NHS Long Term Plan](#).

In January 2023 NHS England published the Children and young people service specification for Specialist palliative and end of life care services <https://www.england.nhs.uk/wp-content/uploads/2023/01/B1675-specialist-palliative-and-end-of-life-care-services-cyp-service-spec.pdf> that illustrates a whole system approach noting that ‘Commissioners should ensure that appropriate services are available to children and young people from universal services, through to core services and to specialist provision. The tiers of provision are not compartmentalised but joined for a seamless patient journey. The right professional should provide care and support at the right time and in the right place, with no opportunities for support missed and specialist provision targeted where it is needed most.

The model is tiered only to help commissioners plan development; not create barriers to integrated working. Close engagement between tiers is vital to ensure the child or young person’s story does not need to be told more times than necessary; key health and wellbeing needs are identified and addressed effectively; and all professionals involved in the child or young person’s care are aware of personalised plans agreed with the child, young person, their family and/or carer.

The model is not a stepped approach. It is flexible with each service area’s involvement fluctuating through a child or young person’s journey in response to need. Each tier of provision depends on the others to ensure a holistic approach to the health, wellbeing, emotional, social, and spiritual needs of the child or young person and their families and carers. No single provider can provide for all these needs.’

Illustration 3





2. Background:

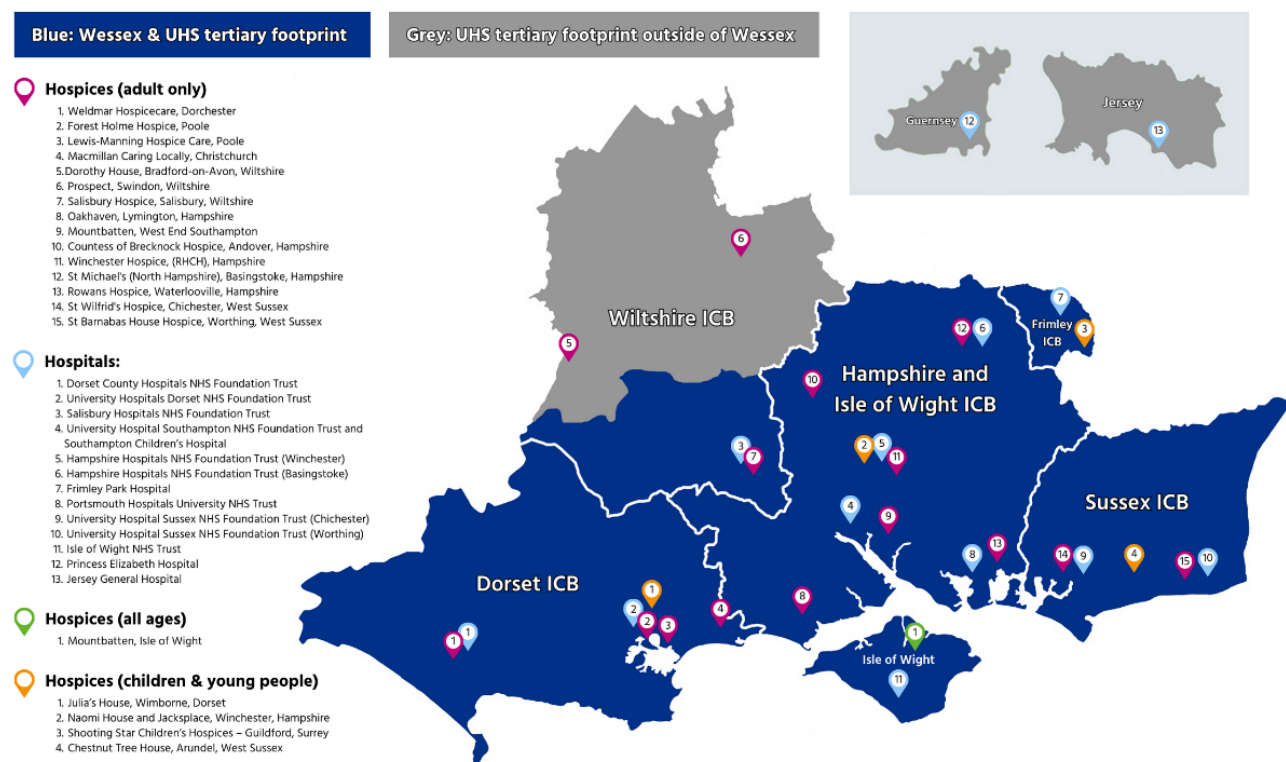
Wessex is not an absolute geography but follows patient flow across the region, where tertiary care is provided at University Hospital Southampton (UHS) and Southampton Children's Hospital. Children and young adults' hospice care is provided by Julia's House, Naomi House & Jackspace, Chestnut Tree House and Shooting Star Children's Hospice. The Wessex footprint covers the following ICBs;

- Hampshire and Isle of Wight
- Dorset
- Sussex
- Frimley
- Bath and Northeast Somerset (Wiltshire area)
- Berkshire, Oxford, and Buckinghamshire (Berkshire area)

And is illustrated in the following geographical map:

Illustration 4

Footprint for Wessex Children's and Young Adults' Palliative Care Network, University Hospital Southampton and Tertiary Southampton Children's Hospital



There is a mix of support to these 6 ICBs for example, Sussex has a steering group supporting Sussex ICB and the Pan Dorset network are supporting Dorset ICB both funded, Surrey and South London support Frimley and the South-West regional network support Wiltshire.



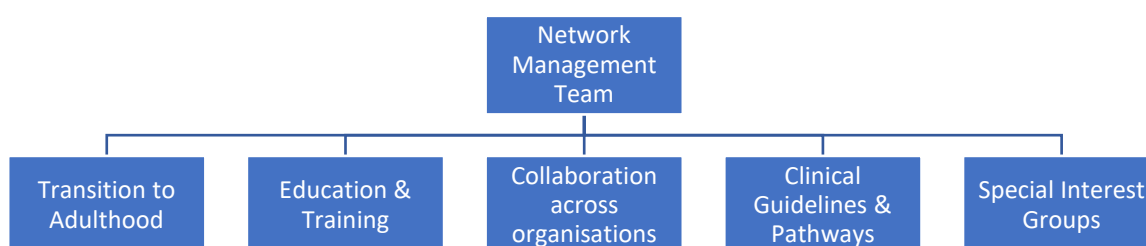
Since 2020, the Wessex Children's and Young Adults' Palliative Care Network (WCYAPCN) has consisted of a small steering group set up to form the backbone of the network approach. This group included representatives from hospice, secondary care, tertiary care, community nursing, specialist nursing, commissioning, education, and organisational leadership. The aim of the network was to develop an integrated and strategic approach to the expansion of services, expertise, education, training, and support across Wessex. The priority was to ensure children and young adults (CYA (0-25)) with life limiting conditions (LLC) receive the care they need, by the right person, in the right place, at the right time and that care is provided by confident, competent, compassionate professionals in a way that is both sustainable and equitable across the Wessex region.

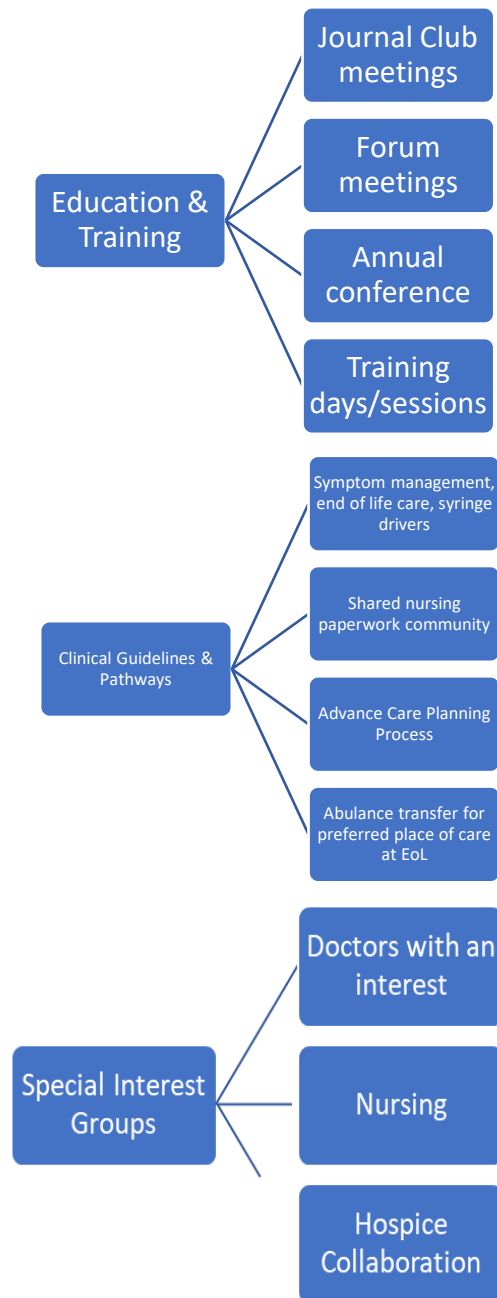
In April 2022 a manager for the network was funded via a match-funding bid with NHS England and HIOW ICB. This role was filled from April 2022 until August 2022 but then remained vacant until the end of February 2023. This role is currently funded and filled under the same basis until August 2024.

During the period from February 2023 until June 2023 the WCYAPCN came to a natural turning point where it needed to revisit the approach and ensure that they were both more visible and clearly Wessex wide for the aspects such as education, guidelines, collaboration on projects, whilst being transparent about the fact that as there are so few clinicians in CYA palliative care some of them will be involved in HIOW ICB work, much as others are involved in their respective ICB regions development.

In 2023 the strategic and service development aspects of the network were separated into individual 'integrated care board' areas. WCYAPCN are now able to focus on the professionals' network across the broader Wessex region for education, training, guidelines, patient pathways and support. This ensures that training, guidelines, and patient pathways are consistent for patients and families across this broad region and organisations can collaborate in a meaningful way. Similar approaches are being developed by our regional partners on all sides. Therefore, a decision was reached within WCYAPCN to focus on the following aspects:

Illustration 5





Collaboration work will feed into many of the other aspects, in particular:

- Joint delivery of training and education.
- Shared development of regional guidance.
- Joint task and finish projects e.g. ambulance transfer process
- Annual conference



Education and Training

Training Days to support skills of doctors and nurses, teachers, and social workers in the region, enabling them to support schools, hospitals, hospices, carers and families, as well as other networks who look after life limited children and young adults such as PICU/NICU/oncology/respiratory/cardiology as part of their ongoing programs of work.

Please see Appendix A for project definition document for education and training.

Already delivered:

- Nurse training day – Child Health department UHS, for whole region.
- Neonatal Palliative Care Training Day – Thames Valley & Wessex.
- WCYAPCN Forum meeting – Case presentation and discussion on pain and dystonia and advance care planning.
- Gathering of education and training group
- Development of standardised feedback form for education across the southeast.
- School teacher 3x 1hr session series on advance care planning.
- Teaching within other networks including Congenital Heart Disease, Adult palliative care.

Forum meetings held 4 monthly provide opportunity for regional updates, updates on projects/pathways and training and education. First session delivered Sept 2023.

Journal club meetings held 4 monthly provide opportunity to discuss latest evidence, share ideas and challenge norms/processes in palliative care across the region. First delivered Oct 2023.

Clinical guidelines

Development of guidelines to support generalist staff across the region to deliver safe, consistent, joined up care. Current guideline in development on pain and dystonia management and use of syringe drivers for end-of-life care. Priority guidelines are:

- end of life care checklist (in development)
- pain and opioid management (in development)
- syringe driver use (awaiting sign off)
- transfer for removal of life sustaining treatment,
- other clinical symptoms, use of version 5 of the CYACP.

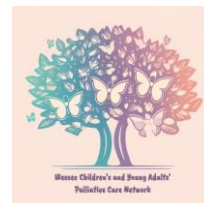
Ambulance pathways

Meetings have taken place with South Central Ambulance Service NHS Foundation Trust (SCAS), who are the predominant ambulance service provider for 999 and non-emergency patient services. SCAS have agreed to develop a standard operating process (SOP) for the transfer of patients at the end of their life to their preferred place of care/death. The purpose of this SOP is to provide consistency and equity of service across SCAS' Front Line operation area and to promote quality of care for this cohort of patients at such a critical and sensitive time for both the patients and those close to them.

Dependent on the clinical need of the patient the crew composition may vary and where any clinical interventions are required during conveyance fall outside of the Scope of Practice of the crew then an escort must be provided who is competent in operating the equipment and delivering the care required for the patient.

Julie.Gumbrell@nhs.net

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Examples might include variable infusions of medication, mechanical ventilation, pressure support ventilation, specialist suctioning and so on. Said escort may be a clinician or a member of public e.g. family member, caring for the patient and competent in the use of the equipment/technique required.

Every journey is unique, and where there is uncertainty as to the requirement and/or suitability of the transfer then senior advice will be sought from within SCAS. Once the SOP has been finalised then the WCYAPCN will share this with other ambulance services across the country for consideration in their own service areas.

Transition

Transition Working Group to ensure that children up to the age of 18 transition in a planned, informed, included and seamless way from children's palliative care services into adult palliative care service where appropriate. To ensure that the child, their family, and the staff caring for them are confident and competent in the delivery of P&EoLC care being provided.

Please see project definition document at Appendix B

Special Interest Groups

Engagement underway with medical staff and nursing staff to identify key programs of work. Groups have been established of senior nurses and doctors with an interest in palliative care across the region with priority setting underway.

In respect of schools, there is work underway at a regional level, with consideration ongoing to determine if there is a separate need to focus at ICB levels. This will be for each ICB to determine.

Integrated Care Boards (ICBs)

On the 1st July 2022 Integrated Care Boards (ICB) became statutory bodies in place of the previous clinical commissioning groups (CCGs). These ICBs work in collaboration with health and social care providers as follows:

Illustration 6

Integrated Care System (ICS)

Are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area.
Includes all of Hampshire and Isle of Wight geography

Integrated Care Board
(as was CCG) statutory NHS
commissioning organisations

Integrated Care Partnership
Statutory committee jointly formed
between the NHS Integrated Care Board
and all upper-tier local authorities that
fall with the ICS system



Developing the vision

It is vital that wherever possible aims, objectives, and work streams are aligned. There is opportunity for ICBs to consider work already undertaken by the WCYAPCN as the work already undertaken has considered the national requirements such as the NHS Long Term Plan, NHS England/Improvement Standard Contract (2013) and Service Specification (2020), as well as the Specialist palliative and end of life care services, Children and young people service specification 18 January 2023 and the Ambitions for End-of-Life Care Framework 2020-2024.

The WCYAPCN vision statement is;

To ensure children and young adults with life limiting and life-threatening conditions across HIOW and the wider Wessex geography have access to equitable, sustainable, high quality, palliative and end of life care.

together with their mission statement;

To develop an integrated approach to achieve equitable local and regional palliative and end of life care services for Children and Young Adults across HIOW and the wider Wessex geography.

Strategic Aims and Core Objectives

Following a series of engagement meetings with stakeholders across the Wessex region by the WCYAPCN the following aims and objectives were developed:

Strategic Aims

1. Develop a collaborative network co-produced with children and young adults with life-limiting and life-threatening conditions, their parents, and carers.
2. To identify the workforce supporting CYA with life limiting conditions within health, education, and social care in Wessex (clinical and non-clinical) and provide a forum of support for the children's palliative care workforce.
3. Support a strategy for the expansion of workforce in CYA palliative care services across the region facilitating an integrated approach between integrated care boards.
4. Support the provision of education and training in P&EoLC to professionals in this workforce.
5. To identify and share evidence based best practice from within both clinical and wider professional organisations and networks within the Wessex region.
6. To develop Wessex wide guidance to support integration across organisational boundaries, ensuring these are operational and applicable across clinical and non-clinical settings.
7. Advocate for equitable end of life care provision, reducing variation across Wessex, whilst working with ICSs to ensure local needs are prioritised.
8. Advocate for a sustainable, commissioned 24/7 model of end-of-life care including local medical and nursing provision and access to specialist palliative care support.
9. Align contracting, funding approaches and policy development.
10. Advocate for CYP and their families to ensure they are represented in the local and regional care planning and commissioning agenda.
11. Advise on the development of a strategic and integrated approach to local and regional palliative care services across Wessex.



Core Objectives

1. Strengthen stakeholder engagement and co-production by continuing to develop network links and identifying key representatives, including young people with life-limiting and life-threatening condition and their parents and carers.
2. Complete initial benchmarking of provision against national standards (completed 2022)
3. Complete mapping of population of CYA with LLC (including transition 18-25) and services and identification of key underserved groups.
4. Identify and advocate for improvements to inequity of access to services and to address health inequalities.
5. Develop an ongoing education program in Palliative and End of Life Care aimed at all those involved in the care of children and young adults with life-limiting and life-threatening conditions in the Wessex region.
6. Develop an annual study day to deliver key education topics requiring interaction, support networking and network development.
7. Develop key guidance as determined by the network priorities.
8. Develop formal links in education and training with other key regional networks – Cancer, NICU, PICU and Wessex Palliative Care Network Group (adults).
9. Support collaboration between hospices across the Wessex region through education, training and as a joint forum for workforce and project development.
10. Collect evidence of the need for CYA P&EoLC services across Wessex.
11. Develop a clear transition plan including population identification, needs analysis and service mapping. Develop regular meetings as a forum for professionals to include education and training, case discussion and support, formation, monitoring and completion of task and finish groups and national and regional updates.
12. Support collaboration with respect to workforce development strategies within ICB areas and expansion across the region in CYA P&EoLC.

3. Recognising the need:

Using hospital episode statistics and office of national statistics mortality data for England, it is estimated that there were 86,625 (66.4 per 10,000) children and young people (CYP) aged 0-19 years with a life limiting condition in 2017/2018. This represents an increase of nearly 40% on figures from 2001/2. This trend is likely to increase to a prevalence of between 67 per 10,000 and 84.2 per 10,000 in England by 2030. In addition to an increasing number of children requiring palliative care services, the care needs, management, and clinical decision-making for these children is becoming increasingly complex. This requires more time to achieve co-ordination amongst an increasing number of professionals involved in their care and more robust systems across various settings to enable safe care.

In 2019/2020, there were 105 CYP (<18yrs) deaths across Hampshire and Isle of Wight, with 75% of these in hospital, 4% in hospices, 14% at home, and 7% in other (audit data from specialist palliative care service). Typically, one could expect that 70% of these patients (n=72) may have required palliative care services as they would be considered 'expected' deaths. A conservative estimate is that within the Wessex region there would likely be 150 expected deaths per year of CYP who would benefit from multidisciplinary palliative and specialist palliative care services, not including those young adults whom we also serve.

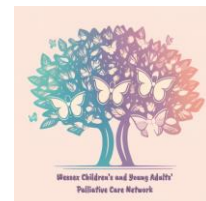
4. Demographic Considerations

Age

Given the NHSE frameworks are moving towards a 0-25 model, the WCYAPCN have agreed for a 0-25 network approach, encompassing transition and the needs of adult services adapting to the new population of CYA with severe neurological impairment surviving into adulthood with significant palliative care needs. Wherever possible and

Julie.Gumbrell@nhs.net

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relevant this will be replicated across HIOW. However, for HIOW there are still instances where the age range 0-18 will be a focus of attention and this group of individuals are referred to as children and young people (CYP).

Geography

WCYAPCN and HIOW are acutely aware of the need for a dedicated focus on the needs of CYA with life limiting conditions (LLCs). The 'Wessex' region encapsulates the emphasis placed by NHSE on primary-secondary-tertiary integration as well as taking account of hospital and hospice footprints making up patient flow across the region. In addition, collaboration of CYA P&EoLC services will require joint working between clinical and commissioning teams across several Integrated Care Systems, further emphasising the need for a practical and broad geography from the beginning.

Key Relationships

Integration with cancer, neonatal, paediatric intensive care units (PICU) and adult palliative care networks across the wider Wessex region are crucial.

5. Service Evaluation Analysing the Standard of End-of-Life Care and Service Provision for CYP in Wessex

The WCYAPCN carried out an audit against selected standards from the Ambitions for Palliative and End of Life Care and NICE guideline NG16 End of Life Care for CYP to identify broad gaps in patient care and service provision and create a benchmarking tool for future use. The following outcomes have been shared nationally at various forums.

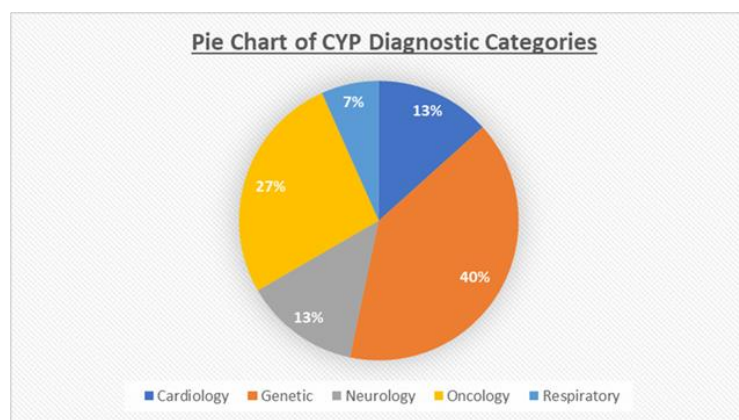
The audit was as follows:

- 20 deaths of CYP between 1st April and 5th October 2021 were collected – 5 excluded.
- Inclusion criteria: deceased, 0-18 years old at time of death, Wessex regional DGH, primary, secondary and tertiary P&EoLC support.
- Patient data collected from eDocs on UHS system and NH care database.
- Service data collected through discussions with clinical managers.
- 52 standards

Outcomes

- Mean age at death was 4.5 years old
- Largest proportion of children (n=7) died in hospital and smallest proportion in a hospice (n=2)

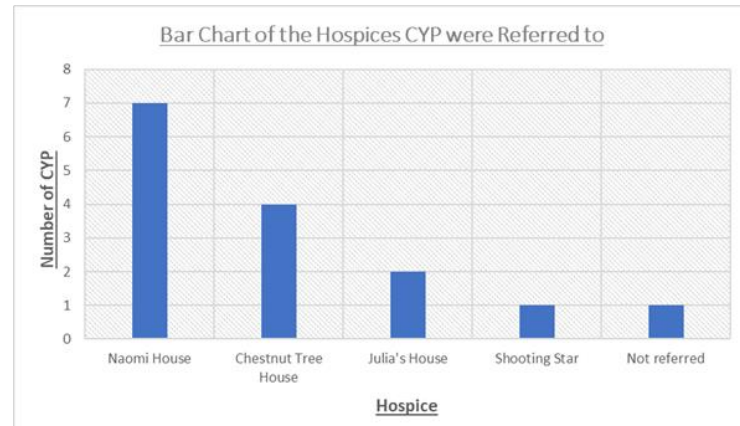
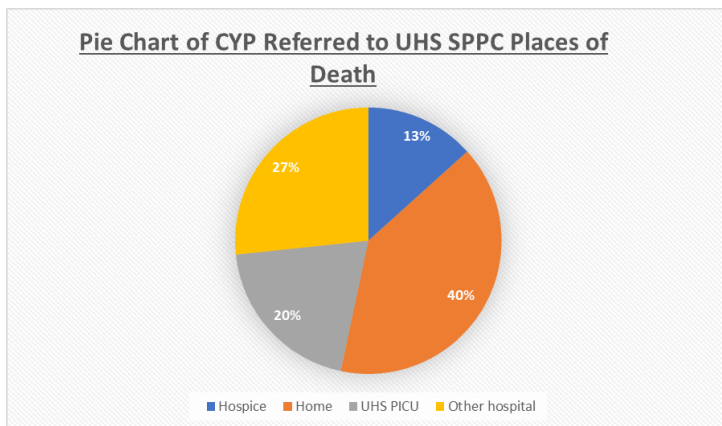
Illustration 7 - Diagnosis



As can be seen opposite, the largest proportion of CYA died from non-oncology health issues.



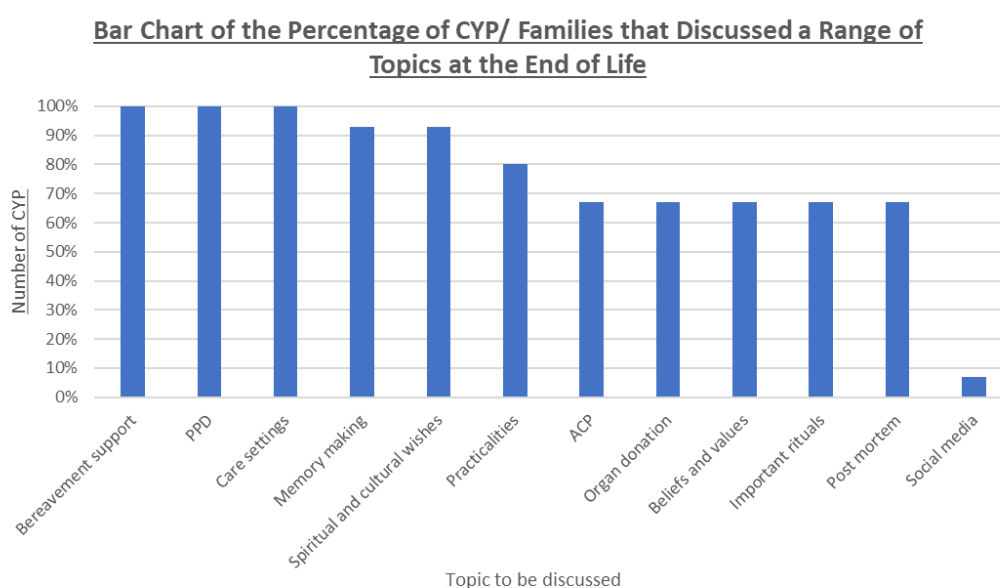
Illustration 8&9 – Referrals to Hospice and CYP referred to UHS Specialist Paediatric Palliative Care Places of Death



14 out of 15 CYP were referred to a hospice, but key barriers were identified during the audit;

- Communication – especially transition patients, unclear who is responsible for who. Barriers between services too great, lack of joint pathways.
- Preferred Place of Death (PPD) – Referrals too late so too unstable to transfer. Unable transfer weekends/holidays/out of hours.
- Resources
 - Community nursing shortages.
 - Hospices in regions around Wessex unable to provide hospice care.
 - Wessex hospices medical cover.
 - SPPC provision out of hours.
 - Local skills and training in CYP PEoLC.

Illustration 10





- It is positive to see that 100% of families discussed their place of death (PPD), however only 67% achieved PPD. This was mainly due to the children being too clinically unstable to move or lack of service provision in the community.
- 93% had a symptom management plan (SMP) and 80% had an advance care plan (ACP). However, out of the 2 children who undertook rapid transfer neither of them had a documented ACP.
- 100% had psychological support, however this wasn't by a psychologist as there is no service within the specialist paediatric palliative care team.
- Only 8% discussed social media plans after death (what happens to their Facebook or Instagram accounts etc), but this is likely to be due to the average age of those children who were part of the audit.

Illustrations 11 (UHS) & 12 (Naomi House) below show the % of Grouped NICE and Ambitions Standards relating to the service either being met (blue) or not met (orange). Neither service met any standards that fell under data management or service improvement.

Illustration 11

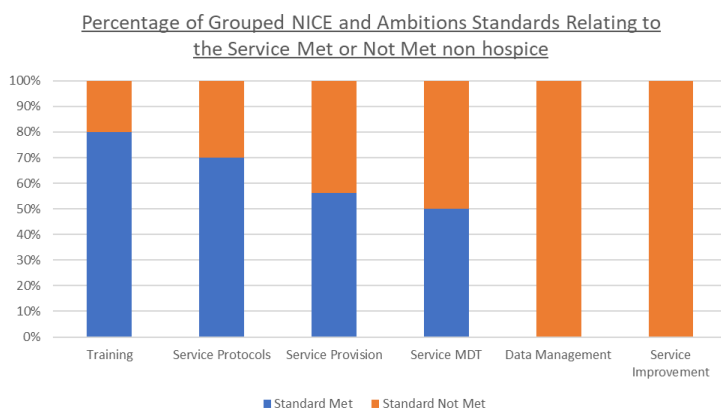
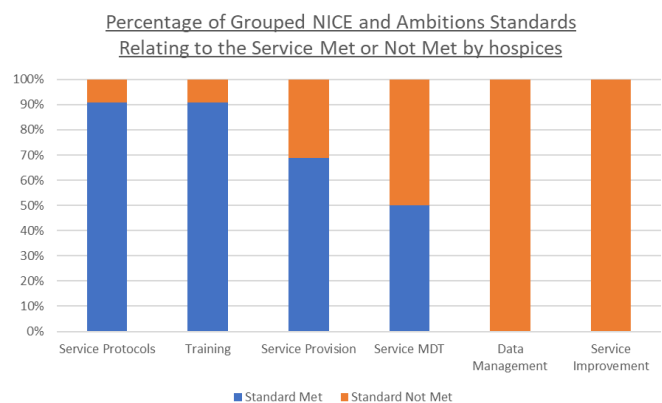


Illustration 12



Looking at the outcomes in the bar graphs detailed above areas of focus should include:

Service Protocols

Positive Outcomes Noted

- System to recognise and acknowledge physical, psychological, emotional, social, or spiritual distress at the end of life.
- Includes providing information about emotional support available and how to access it.
- Rapid transfer process to allow urgent transfer to the preferred place in some centres.

Areas for Improvement

- No consistent approach to anticipatory prescribing.
- Variable pharmacy support.

Service Provision

Positive Outcomes Noted

- Use of technologies in the advancement of care.
- Provide access to rehabilitative services.
- Enable patients and the people who care for them to self-manage aspects of their care.



Areas for Improvement

- No specific bereavement support for many non-hospice patients.
- Gaps in community nursing limiting PPD and support in the home.
- Absence of formal medical support in many community areas and some hospices.
- No 24/7 access to specialist symptom control/EoL.
- No dispensers for medication 24/7 – only in hospice.
- Not a 7-day service for SPPC assessments.

Service MDT

Positive Outcomes Noted

- A clinical lead is identified for each key provider.
- There is strong and clearly defined leadership for palliative and end of life care.

Areas for Improvement

- Representation in services of various faith groups and cultures in region.
- SPPC provision:
 - Pharmacist with expertise in SPPC.
 - Experts to provide social, emotional, psychological, and spiritual support.

Data Management

Areas for Improvement

- No system to enable data sharing with all care providers.
- No regular audit plans in place.
- No mechanism for patient to review and update end of life wishes electronically.

Service Improvement

Areas for Improvement

- To use validated tools (e.g IPOS) to measure patient outcomes against patient goals.
- Population based needs assessments.
- Regularly collect and report on data.
- To demonstrate how services have been influenced by local population-based needs assessments.
- To have a process to analyse patient outcomes to ensure equity of care.

6. Needs Assessment

To drive improvement, it is vital that we know who we need to deliver care to. At the current time there is no single source of data that identifies children and young adults (CYA, (aged 0-25 years)) with a LLC. Currently CYA may be known to many or only a single provider of care, each providing care and capturing information on stand-alone systems. However, an accurate and up to date Proactive Care Plan (previously anticipatory care plan (ACP)) will enable each CYA to contribute to a single source of information that clearly articulates how they wish to live their life to their full potential, rather than preparing how they wish to die.

A single CYA ACP has been almost universally adopted nationally. However, currently each organisation may be using their own rather than one that has been developed collaboratively across all organisations. This leads to patients and parents (or those individuals who care for a CYA) to often repeat information. Some children may not even have one.



With the lack of interoperability at the current time it is not possible for services to see a single record for each child or input into a single system.

ICBs should look at ways of determining current and future demand so that commissioning work streams identify resilient and sustainable models of care for CYA.

The ambition is for all children born with a LLC, or diagnosed at some point in childhood, to have an advance care plan (ACP). This should be considered as proactively planning for their needs and via the use of the CYP ACP (5th edition) being adopted across the Wessex region. The CYPACP contains a wealth of information to be able to support a child's needs at any time to live their best life and not just as their health deteriorates and they approach the end of their life. This will enable services and support to be identified to the CYA and their families, or those caring for them, even if they choose to not engage, or have no need to engage, at the current time as the areas where softer intelligence is gathered can be supportive at any point in a child's care.

Going forward that ambition is for collaborative work to develop a single process to ensure that at the point of diagnosis proactive care planning via an ACP is commenced with the CYA, their families, or those important to them, together with the relevant teams.

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care. <https://www.nice.org.uk/about/nice-communities/nice-and-the-public/making-decisions-about-your-care>. What is vital is that the decisions about their care and how they want to live their life are captured, accessible, updateable, and clearly articulated so that children and young adults are supported to live their best life.

7. Funding and Management;

The Wessex Children's and Young Adults' Palliative Care Network Manager role is a match funded post with NHS England. This role is currently filled on a secondment basis up until August 2024.

A separate match funding bid between NHSE and HIOW ICB was submitted for 2023/24 in response to the January 2019 the NHS Long Term Plan (LTP) statement that:

Children's palliative and end of life care is an important priority for the NHS. But local NHS funding has not kept pace with growth in clinical care costs or inflation.... Over the next five years NHS England will increase its contribution by match-funding clinical commissioning groups (CCGs) who commit to increase their investment in local children's palliative and end of life care services including children's hospices.

The bid for £121k was successful and although the arrangement is with HIOW ICB as the CYA P&EoLC is intrinsically linked with the WCYAPN the bid will support the following high-level work streams;

- 2 x Programmed activity (PAs) for clinical leadership and oversight of the CYA P&EoLC work streams across both Wessex and HIOW ICS.
- 1 x project manager.
- 1 x administrative assistant.



- Community engagement to ensure the voice of children and young adults is heard and reflected in the work that is done.
- Developing sustainable education and training.
- Developing a digital programme to enable the creating and sharing of the agreed children and young people's advance care plan (CYP ACP).

8. Conclusion

The report highlights the journey that the specialty of children's and young adults' palliative care work has been on to ensure that the focus and energy can begin to replicate the same levels of commissioned and recognised services that all age, and particularly frail elderly, P&EOLC has received for a number of years.

There is only one chance to deliver end of life care well, often referred to as a 'good death' for all ages. The experience encompasses the need to support the patient and those important to them prior, during and post death by creating positive memories and experiences, encouraging them to discuss what lies ahead and ensuring that services are there to support those left behind. The impact of a poor death can have a profound effect on those families and friends left behind, together with the staff who have supported them including school staff and fellow students, community nursing teams, hospital and hospice nurses, medics, social workers, and carers to name but a few.

Fortunately, the numbers of children and young adults requiring support from these specialties are low however, the cost of these services financially and emotionally are high. This is due to the complexity of their needs and the impact of losing a child or young adult through a life limiting condition many years ahead of what that they themselves, their families and society anticipated their future would be.

The Wessex network was created to develop an integrated and strategic approach to the expansion of services, expertise, education, training, and support across Wessex. The priority was to ensure children and young adults with life limiting conditions receive the care they need, by the right person, in the right place, at the right time. Care that is provided by confident, competent, compassionate professionals in a way that is both sustainable and equitable across the Wessex region.

During this period previous clinical commissioning groups were being restructured nationally into integrated care boards. Now that this has been completed and national guidance has been published this provides both the Wessex network and ICBs with an opportunity to focus on areas of work that have been clearly defined between the two organisations for the benefit of our children and young adults who have been diagnosed with a life limiting condition.

For the period up until 31st March 2024 the additional match funding from NHSE will ensure that work streams can be moved forward at pace. We need to develop clear metrics both quantitative and qualitative so that we can measure and report on the progress we have made. Looking to the next 6 months we need to ensure that future collaborative working between the Wessex Network and ICBs continues so that aspirations and work streams are clearly embedded within work programmes in the future to enable continual improvement in the services we deliver.



Appendix A – Education and Training project definition document



Education and
Training Project Defin

Appendix D – Transition project definition document



Transition Project
Definition Document.c

Appendix B – WCYAPCN Aims and Objectives

Aims

1. Develop a collaborative network co-produced with children and young adults with life-limiting and life-threatening conditions, their parents and carers.
2. To identify the workforce supporting Children and Young Adults (CYA) with life limiting conditions within health, education and social care in Wessex (clinical and non-clinical) and provide a forum of support.
3. Support a strategy for the expansion of workforce in CYA palliative care services across the region, working with integrated care systems to deliver this. Provide education and training in PEoLC to this workforce.
4. To identify and share best practice from within both clinical and wider professional organisations and networks within the Wessex region.
5. To develop Wessex wide guidance to support integration across organisational boundaries, ensuring these are operational and applicable across clinical and non-clinical settings.
6. Advocate for equitable end of life care provision, reducing variance across Wessex, whilst working with integrated care systems to ensure local needs are prioritised.
7. Advocate for a sustainable, commissioned 24/7 model of end-of-life care including local medical and nursing provision and access to specialist palliative care support.
8. Align contracting, funding approaches and policy development.
9. Advocate for CYA and their families to ensure they are represented in the local and regional care planning and commissioning agenda.
10. Advise on the development of a strategic and integrated approach to local and regional palliative care services across Wessex.

Objectives

1. Strengthen stakeholder engagement and co-production by continuing to develop network links and identifying key representatives, including young people with life-limiting and life-threatening conditions and their parents and carers.
2. Complete initial benchmarking of provision against national standards (see benchmarking plan). To identify the workforce supporting CYA with life limiting conditions within health, education and social care in Wessex (clinical and non-clinical) and provide a forum of support.

Julie.Gumbrell@nhs.net

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3. Complete mapping of population of CYA with LLC (including transition 18-25) and services and identification of key underserved groups.
4. Identify and support improvements to inequity of access to services and health inequalities.
5. Commission low volume high-cost services for HIOW, realising efficiencies of scale.
6. Develop an ongoing education programme in Palliative and End of Life Care aimed at all those involved in the care of Children and young adults with life-limiting and life-threatening conditions in the Wessex region.
7. Develop an annual study day to deliver key education topics requiring interaction, support networking and network development.
8. Develop key guidance as determined by the network priorities.
9. Develop formal links in education and training with other key regional networks – Cancer, NICU, PICU and Wessex Palliative Care Network Group (adults).
10. Support collaboration between hospices across the Wessex region through education, training and as a joint forum for workforce and project development.
11. Collect evidence to support the need for expansion of CYA PEoLC services across Wessex.
12. Develop a clear transition plan including population identification, needs analysis and service mapping.
13. Develop regular network meetings as a forum for professionals to include: education and training, case discussion and support, formation, monitoring and completion of working groups, national and regional updates"
14. Develop a strategic document outlining a recommended strategic and integrated approach to the formation of local and regional palliative care services across Wessex.
15. Support workforce development strategy and expansion across the region in CYA PEoLC.
16. Support the development of Service Specifications for ICSs in the Wessex Region including collating data to support this where resourced to do so.