



East Anglia's Children's Hospices

# East Anglia's Children's Hospices (EACH)

# Quality Account 2024-25

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# Our Vision, Mission and Values

# **Our Vision**

We aspire daily to lead the way in providing world-class care for children with life-threatening conditions. Every child deserves support, alongside their families, whenever and wherever they need it.

# **Our Mission**

To improve the quality of life and wellbeing of every child and family under our care, by providing individual and comprehensive services at all times.

# 

# **Our Values**

Empathy, understanding and inclusion Understanding the views and feelings of others is central to our work relationships and how we interact daily. We actively encourage unique perspectives, backgrounds, and experiences of others, fostering an environment where all voices feel valued.

Commitment to quality We consistently employ our best efforts and strive for the highest standards in a that we do, always looking for ways to improve. Make it happen We are empowered to take responsibility for getting things done.

Open, respectful and accountable We operate in an honest, respectful and collaborative way, encourage open constructive feedback and celebrate diverse viewpoints. We are mindful of the power of our words, actions and biases, and hold ourselves accountable to ensure a safe and inclusive environment for everyone.

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# Part 1. Introductory statement

On behalf of the whole team at EACH, we are delighted to present the organisation's Quality Account for 2024-25.

We are extremely proud all three of our hospices remain assessed as 'Outstanding' by the Care Quality Commission and equally proud we supported 594 life-threatened children and young people during the year, together with their mums, dads, carers, grandparents and siblings.

We delivered a total of 89,054 hours of care and wellbeing support for families, including those who are bereaved.

As always, we continued to be flexible and responsive in our approach to service delivery and continued the development of our objectives to implement the strategic plan.

Regular, open engagement with families is a vital part of our service delivery approach, and we have worked hard this year to evolve our feedback mechanisms. Initiatives include the use of QR codes around the hospices enabling families to scan and record feedback online, and the integration of family forum discussions into well-attended groups and events.

This year, we are putting forward a plan to continue developing and growing our service offer for the next three years and reach more children and families who need our support. This includes infrastructure, workforce recruitment, development and innovation, and enhancing our training both internally and externally with our partners. As we enhance our services, we strive to meet families' expectations by offering increased care, specialised support and wellbeing services that align with our improvement priorities.

We are committed to using evidence-based practices to guide our decisions and ensure the highest quality of support. This includes regularly reviewing and updating our equipment to reflect the latest advancements in the field. By maintaining the most up-to-date and effective tools, such as communication and mobility aids, we aim to be equipped to meet the evolving needs of those we support.

We have been successful in our workforce recruitment and development, including appointing into our Transition Lead, Research Nurse, Clinical Student Co-ordinator and Lead Physical Therapist posts. The care directorate employs 156 whole time equivalent staff including clinical staff, administrators and facilities teams.

Innovation has grown our Clinical Education team, with an on-the-floor approach to education, competency and development. Career development pathways have also been introduced to

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support Nurse Associate and Nurse Apprenticeship programmes. Our first Nurse Associate students started in September 2024 and Nurse Apprenticeships began in October 2024.

We believe our clinical education strategy is integral in our aim to establish EACH as a leader in specialist paediatric palliative care through education, innovation and sector influence. Further information demonstrating the breadth of our education approach is detailed in Part 2 of this report.

The second area of focus in this Quality Account is a detailed Wellbeing 'stocktake'. There has been a significant amount of change for the EACH Wellbeing Service throughout the past twelve months. This includes transition of new staff into key posts, vacancies in high-level positions, as well as the creation of, and appointment to, a Head of Service role. The priority has been to maintain stability across the three Wellbeing Teams whilst working within an interim structure. The focus has been on providing safe and responsive interventions and developing events and activities for those using our services.

We are delighted Kevin Clements was promoted after a rigorous selection process to Chief Executive from his previous role as Director of Fundraising and Communications. We also welcome the appointment of Helen Finlinson as Director of Care who is bringing extensive experience in palliative care including the innovative ZEST Service from her role at St Elizabeth Hospice in Ipswich. David Vickers supported EACH as Interim Clinical Director during this time of transition. He will continue to support us in ensuring the quality of care remains high and our teams are supported through his ongoing involvement as Medical Director.

We are grateful to all our Trustees who give their time and expertise to EACH. We welcome Anna Lipp as the new Chair of Clinical Governance Committee. This committee is responsible for overseeing and improving the quality and safety of patient care. We are also pleased to welcome new trustees with clinical backgrounds to provide expertise to the Board and the Clinical Governance Committee.

As ever, we are indebted to our generous communities, supportive organisations, employees, volunteers and commissioners who, collectively, continue to enable our mission to improve the quality of life and wellbeing of every child and family in our care, and the growing number of those who will need our support in the future.

AKLEPP

Anna Lipp EACH Trustee Chair – Clinical Governance Committee

17<sup>th</sup> April 2025

David Vickers Interim Clinical Director

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# Part 2. Priorities for improvement for 2024-25 and statements of assurance from the board

# 2.1 About EACH

East Anglia's Children's Hospices (EACH) is registered as a service provider under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, to carry out the regulated activity of the treatment of disease, disorder or injury.

EACH is a registered charity, number 1069284, and has the legal status of operating as a Company Limited by Guarantee, company number 3550187.

# Our Mission

To improve the quality of life and wellbeing of every child and family under our care, by providing individual and comprehensive services at all times.

We provide a range of physical, emotional, social and spiritual support services which are offered:

- holistically
- centred on the family
- to all eligible families in East Anglia with babies, children and young people with lifethreatening illnesses and complex health care needs
- across a range of settings, including the home, hospice and hospital
- by specialist staff
- with the engagement of the community.

A baby, child, young person, their family and those significant to them are eligible to access services from EACH if the following criteria are met:

The baby, child or young person (BCYP) has a life-threatening or life-limiting condition and may benefit from palliative care input, which is tailored to their needs. The 'Guide to Specialist Paediatric Palliative & End of Life Care in the East of England (2016) and the British Association of Perinatal Medicine Palliative Care – Recognising uncertainty: an integrated framework for palliative care in perinatal medicine (2024) provides more information.

The BCYP is less than 18 years of age.

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The BCYP or family live in Norfolk, Suffolk, Peterborough, Cambridgeshire and North and West Essex. There is an agreed pathway with Keech Hospice Care to provide care on an individual basis to families living in North and East Hertfordshire.

In exceptional circumstances, EACH may offer a service to BCYPs and families who live outside these areas, if deemed safe to deliver the care required and there is no other service available to meet the family's need.

The needs and goals of young people referred aged 16 years and over are considered on an individual basis. They are eligible for a service if they are entering the final phase of their life and there are no alternative services available to match their choice of place of care.

Families bereaved of a BCYP who died as a result of a life-threatening/life-limiting condition, not previously known to EACH before their death, are eligible for bereavement support from EACH.

Services are delivered wherever they are needed. This includes care and support in the family home, in one of three hospices: EACH Milton (Cambridgeshire), The Nook (Norfolk) and The Treehouse (Suffolk), in hospital and in the wider community. Care is delivered by our hospice-based multi-disciplinary team, which includes nurses, care assistants, therapists and our specialist symptom management nursing service, all supported by our administration and facilities teams. Staff are trained to deliver care wherever it is required.

Our wide range of services includes:

- Expert nursing care and short breaks
- Symptom management support
- Long Term Ventilation support
- Family activities and events
- Physical therapies, including occupational therapy, hydrotherapy and physiotherapy
- Wellbeing, including counselling (one-to-one and group), art and music therapies, spiritual care and specialist play
- Care at end of life
- Bereavement support
- Practical help in the family home

# EACH Wellbeing Service

Each of the three hospices has a Wellbeing Team, which consists of art and music therapists, counsellors, family support practitioners, play specialists, child and family practitioners, spiritual

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care support, and groups and events co-ordinators. The team is led by a Locality Wellbeing Lead who forms part of the Locality Leadership Team, alongside the Matron and Service Manager. The Locality Wellbeing Lead maintains a clinical caseload as well as delivering management and clinical supervision to members of the team. The Wellbeing Leads also facilitate weekly Systemic Case Consultation Meetings with the Wellbeing Team, and twice monthly Multi-disciplinary Reflective Peer Group Supervision and individual/group consultations with the wider Care Team. During the period of this report there have been two Locality Wellbeing Lead vacancies which have now been successfully recruited to and whilst managing the vacancies, an interim structure was agreed to provide leadership and management cover across the service areas. The Wellbeing Leads report to the Head of Wellbeing and Spiritual Care, which was a new post introduced in June 2024.

The service has a diverse range of delivery methods for psychological interventions tailored to each individual situation, following in-depth assessment and agreement with the child/young person/family. To ensure quality, efficacy and equity of service, the Head of Wellbeing and Spiritual Care and Wellbeing Leads meet regularly to review and develop all aspects of service delivery, while managing demand and making best use of the staffing resources that are across all three hospices. The Head of Wellbeing and Spiritual Care leads strategy discussions and provides the wellbeing lens and expertise at a senior leadership level.

#### • Wellbeing Review

Following the recommendations from the January 2024 internal wellbeing review, consideration was given to the leadership roles within the service. As a result of this, a Head of Wellbeing and Spiritual Care role was created and appointed to. Dedicated wellbeing administrative support has also been highlighted and is a priority for discussion moving forward. Further recommendations are also being considered alongside the development of the wider care strategy from 2026.

#### • Holistic Assessments

The Family Support Practitioners undertake a holistic assessment for each accepted referral, working alongside the family to determine their priorities and how the organisation can support them. An internal referral for wellbeing support can be made ensuring a seamless transition for further intervention.

# • End-of-Life and Post-Death Care

The Wellbeing Team prioritises end-of-life and post-death care. There is a need for a psychological underpinning for families and care teams, during times of heightened stress, and the wellbeing staff are required to respond, with speed and flexibility during end-of-life scenarios. This is undertaken with a high standard of skill and compassion and requires dynamic case management.





# • Groups and Events

EACH delivers a wide-ranging selection of hospice and community-based activities as well as online groups and events. These include siblings' days, family fun days, music-themed events and an annual winter wonderland. Planning and delivery are overseen by the Groups and Events Coordinators assisted by members of the wellbeing and wider care teams. The groups and events are needs-led and developed via a Logic Model with defined goals in relation to outcomes and impact.

Bereavement support groups are offered to families, including siblings and grandparents. Some activities are offered to all family members and others are specifically for non-bereaved families, e.g. a Christmas Panto and Dream Night at Colchester Zoo. A number of events are focused on bereaved families, e.g. Memory Day, Remembering with Love and sessions that recognise Baby Loss Awareness Week.

In the last twelve months, there have been a total of 197 events delivered across the tri-site with a footfall/attendance of 3,162 children/adults.

# • Teaching and Training

In addition to family interventions, the Wellbeing Team contributes to teaching and training for EACH staff and externally to network partners. They are key in the delivery of specific elements of the Palliative End of Life Care Training (PEOLC) programme and are responsive to requests from stakeholders, particularly around themes of grief and loss.

# • Volunteers

The Wellbeing Service is supported by a team of volunteers who engage in the preparation and delivery of groups and events, enabling families to utilise our hospice facilities and assisting with the general day-to-day tasks in the hospice buildings. Volunteer drivers also play a crucial role in supporting families to access the service.

# • Audits and Evaluations

The Wellbeing Service, audits and evaluates all interventions and sessions it provides. Through reviews and consultations with service users, the Wellbeing Service is able to offer an appropriate level of intervention that is not limited to a finite number of sessions, this approach reflects the needs-led model. To ensure the psychological and psychotherapeutic intervention is of the highest level, each Wellbeing staff member receives robust clinical and management supervision. Further training and learning are encouraged and aligned to the various professional bodies that support staff.

# • Spiritual Care

The Spiritual Care aspect of the service has been provided by the Spiritual Care practitioners however those posts have been vacant whilst the service has undergone a period of change.

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During this time the spiritual care needs of children, families and the staff teams have been well supported by a small but consistent team of Spiritual Care and Chaplain volunteers. Following the appointment to the new Head of Wellbeing and Spiritual Care post, there has been consideration about the Spiritual Care element of the service. Proposals have been made, and these will be discussed with the new Director of Care.

#### • External Agencies

The team continues to work closely with external agencies, including adult mental health, CAMHS (Child and Adolescent Mental Health Services), schools, perinatal health, GPs and NHS psychology and wellbeing services, and the RAaFT (Regional Advice and Facilitation Team) service. There is regular attendance at external meetings, and this has strengthened links with regional and specialist hospitals, mental health teams and wellbeing colleagues. This also supports a joined-up approach to the sharing of information and reinforces Safeguarding procedures.

# • Wellbeing Student Placements

The service continues to receive requests to offer student placements and the organisations reputation, and the experience of the Wellbeing Team supports this. During this period, the service has supported various enquiries including a placement to a Genetic Counselling student as well as, provided tours and shadowing opportunities to counsellors, music and art therapy students and chaplains. Enquirers are also invited to the regular Professional Evenings to understand further the work of the hospices. The aim is to develop capacity to offer more placement opportunities.

#### • Summary

Recruitment to the vacant Locality Wellbeing Lead posts has now been achieved and with the engagement of the existing staff teams and personnel, there will be further analysis of the findings of the Wellbeing Review with a focus on the priorities that have emerged during this period. The Wellbeing Service delivery will be part of the overall Care Strategy from 2026.

Please refer to Appendix 2 for Wellbeing Service data.

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# Clinical Education

# • Essential Role-Specific Training

Medication training is included in the initial induction programme and the extended medication training is running three times a year. This allows care assistants and senior care assistants to administer medication. Long-Term Ventilation (LTV) training continues for nurses, care assistants and senior care assistants.

# • Competencies

Our Clinical Educators continue to assess the competencies of all staff, ensuring they meet the standards of EACH to deliver safe care. The Clinical Education Lead is currently reviewing competencies, linking them to career pathways and the development of our staff.

# • Positive Behaviour

We now have three fully trained staff members to deliver positive behaviour training. All care staff have received training in the last 12 months. Refresher training is provided biannually and to all new starters. The trainers are supporting individual cases as needed at each site and are now part of the physical therapies quality and safety group to support discussions incidents that require positive behavioural oversight.

# • Incident Training

We continue to deliver bespoke training related to recurring internal incidents. We have developed six education days which include a theory session in the morning and practical workstations in the afternoon. All content is related to reported incidents or changes in practice. Future audits will assess the frequency of repeat incidents to determine the efficacy of the training.

# • Internal Training

We run our care development programme three times a year to meet the needs of the care certificate (a requirement for all care assistants). The Care Certificate is being reviewed in 2025 by Skills for Care and we will update our care development program once the updated version is released.

We continue to provide one-to-one bespoke training to those who require or request additional support.

In the last 12 months, we have commenced delivery of stage three of our PEOLC Education & Training programme. This is looking at specific areas, such as communication, oncology and neuro-disability.

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We have reviewed and developed our resuscitation training, recognising that the provision we had was not meeting our specific needs. We have three staff members who have completed training to be able to train our staff and all Clinical Educators have attended anaphylaxis training, which is now incorporated in the training. This piece of work was shared as a poster presentation at the 2025 Together for Short Lives conference.

• Nurse Associate Training, Nursing Apprenticeship and Nurse Preceptorship

We have three Senior Care Assistants undertaking the Nurse Associate training and one on the Nursing Apprenticeship programme. We are hopeful that by 2026 we will have our first 'home-grown' children's nurse. We plan to maintain nurse apprenticeship enrolment. Two nurses from the Nook are due to complete their preceptorship programme in July 2025 and we aim to recruit a preceptee each year. A summary of this work was presented as an abstract, oral presentation at the 2025 Together for Short Lives conference.

#### • Clinical Student Co-ordinator

To support the increase in students, the Trainee Nursing Associates, Nursing Apprentices and our Preceptees EACH has integrated a Clinical Student Co-ordinator into the Clinical Education team. This role is proving effective in planning, supporting and co-ordinating all training placements.

#### • Clinical Education Students

We continue to welcome paediatric nursing students across all three hospices and are now welcoming first-year students in addition to those in their 2<sup>nd</sup> and 3<sup>rd</sup> years of training. There is high demand for student placement due to excellent feedback from students. After discussions with the University of Suffolk, we now also welcome paramedic students with positive feedback from the initial cohort.

#### • Transition

Over the last 12 months, we've delivered five joint drop-in sessions for families and young people exploring transition, working collaboratively with Tapping House, Pricilla Bacon Hospice and St Elizabeth's Hospice. The sessions have been well received, with lots of activities for the young people and information available for families.

We have continued our partnership with Zest and we aim to enhance and evolve our transition offer with the introduction of the EACH Transition Lead post due to start in May 2025.

#### • External professional training provided by EACH

We continue with our PEOLC training in collaboration with Norfolk and Waveney ICB. An abstract of this work was presented as an oral presentation at the 2025 Together for Short Lives Conference.

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Our aim is to develop and build on our external training offers. As well as a potential income generation opportunity, delivering training to other professionals would improve the network of EACH and sharing knowledge to enhance a collaborative approach to paediatric palliative care.

#### • Clinical Education Strategy

We will be looking at role-specific growth pathways and career progression of all staff. We will outsource specialist training in specific areas such as non-medical prescribing and Advanced Clinical Practice (ACP).

We continue to explore the use of Simulation (SIMs) training following successful inclusion during our PEOLC training programme. We are considering working with other centres to develop a simulation working group. This would enable us to spread the cost of equipment acquisition.

# 2.2 Priorities for improvement for 2025-26

Our priorities are informed by the existing four-year strategic plan (Stepping Forward 2022-2026), the results of Investors in People development work and our ongoing care objectives.

The Board approved the four-year plan in January 2022 following a period of engagement with families, staff and key partners by the Management Executive Team.

The Stepping Forward strategy ensures direction of the necessary infrastructure and investment choices are made to provide the workforce, training, equipment, technology and environment to deliver the best possible care. It sets out how we will grow the organisation in capacity and capability over this period, delivering a balanced and sustainable budgetary position.

The priorities for care are managed by the EACH Care Strategic Leadership Team (SLT-Care), with progress being monitored by the Clinical Governance Committee and Management Executive and reported to the Board quarterly.

In line with the Stepping Forward strategy, our key priorities for improvement in 2025-26 are:

Table 1 – Priorities for improvement	Desired outcome
Priority 1: Voice of service user To develop a family feedback mechanism ensuring the voice of the child/young person and family is heard	<ul> <li>Feedback opportunities available enabling a consistent and regular reporting route for evidencing how family and service user</li> </ul>

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and has direct influences over service delivery and development.	feedback informs service delivery with measurable outcomes.
Priority 2: Invest in people Recruit and retain a skilled workforce. Development of an EACH career pathway for care roles, ensuring streamlined access to role-specific development opportunities.	<ul> <li>Implementation of education strategy regarding growing our own staff, e.g. Nurse Apprenticeship, Nurse Associate and Nurse Preceptorship Programmes.</li> <li>A strategic plan for volunteer services within care.</li> </ul>
Priority 3: Wellbeing Development of a strategic plan for wellbeing.	<ul> <li>Implementation of the Wellbeing Strategic Plan.</li> </ul>
Priority 4: Sustainable resource Develop capacity and demand modelling to influence future staffing establishment and wider care resources.	<ul> <li>Robust staffing model which is responsive to the fluctuating demand of personalised approach to palliative care.</li> <li>LTV educational programme for regional professionals to access.</li> <li>Fully integrated transition role with network links to all adult service stakeholders.</li> <li>Designated research nurse and development opportunities to participate in research.</li> <li>Sustainable care environments and buildings fit for the future.</li> <li>Sustainable statutory income.</li> </ul>

We make these commitments to our staff, partners, supporters and customers.

- We will operate in a way consistent with the EACH Values.
- We will communicate clearly and transparently.
- We will respond quickly and effectively when called upon.
- We will ensure careful stewardship of our finances, relentlessly focusing on frontline service delivery.

A copy of our Stepping Forward four-year strategy can be found at the following link: <u>www.each.org.uk/about-us/stepping-forward/</u>







We are currently in the process of developing a further three-to-five-year forward plan for care, building upon 'Stepping Forward' and to support development and innovation beyond 2026.

# 2.3 Statements of assurance from the board

The following are statements that all providers must include in their Quality Account. Many of these statements are not directly applicable to specialist palliative care providers such as EACH, and therefore explanations of what these statements mean are also given. The 2024-25 Quality Account will be endorsed by the Board at the meeting in July 2025.

# 2.3.1 Review of services

The EACH Strategic Leadership Team for Care has reviewed all the data available to them on the quality of care when compiling this report.

During 2024-25, EACH provided the following services to BCYPs and families living in Norfolk, Suffolk, Cambridgeshire, including Peterborough, and North East, Mid & West Essex:

- End-of-life care
- Symptom management and LTV
- Short breaks
- Universal level emotional health and wellbeing support for all family members and those important to them, before and into bereavement
- Mental health interventions, including counselling, family therapy, and music and art therapy
- Specialist play
- Physiotherapy
- Occupational therapy
- Practical help in the family home through the Help at Home volunteers' service
- Spiritual care
- Family information service
- Hydrotherapy.

A 24/7 end of life care and symptom management service for the baby, child or young person, including face-to-face care and access to 24/7 support, has been available throughout the year wherever they are being cared for.

We continue to use virtual technology to deliver some of the clinical and mental health and wellbeing interventions to children/young people and their families, as well as some of the activities and groups and events such as Musical Keys and Playdays. These virtual opportunities

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complement a full calendar of face-to-face events, including band practice, coffee mornings, curry nights, Christmas shows, summer garden parties and the winter wonderland.

#### Managed Clinical Network

EACH hosts the East of England Children's Palliative Care Managed Clinical Network (MCN). In the East of England Region this consists of:

- One Children's Palliative Care Specialist Team
- Five Children's Hospice Services
- One Tertiary Centre
- One Children's Hospital
- Three Level 3 Neonatal Intensive Care Units (NICUs)
- Fifteen District General Hospitals
- Seven Community Nursing Services.

The MCN provides support for the delivery of 24/7 children's palliative care across the East of England through the provision of specialist telephone advice by Consultant Clinicians to the first tier on-call service provided by the EACH SMNS and Keech Hospice Clinical Nurse Specialists.

The MCN Mission is:

- For every life-limited baby, child or young person and their family to access the care they need in the right place at the right time, both before and after the death of the child.
- To enable progress and development in palliative care through education and collaboration; sharing skills and knowledge to support professionals to act as advocates and provide high quality care.
- To provide specialist clinical advice and support for professionals across the East of England 24/7.

MCN achievements in 2024 included:

- The teams within the MCN have contributed to a programme of palliative and end of life care teaching, including bespoke programmes in Norfolk & Waveney, Essex, for Little Havens, and as part of the ECHO (Extension for Community Healthcare Outcomes) transition Network.
- Point Prevalence data capture: to support the development of palliative care services a point prevalence survey involving partnership with acute, community services and children's hospices was undertaken for the third consecutive year in March 2024. The survey provides information about the number of children with palliative care needs at a given time. This has become established as an annual process to produce valuable and reliable data that will help to inform our strategic aims. Round four took place in March 2025, awaiting results to inform further strategic planning.

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- The MCN has made significant progress in establishing a network of Wellbeing practitioners. Work has been undertaken to understand the wellbeing services that are offered regionally and created opportunities to learn from each other. A Wellbeing Conference is planned for 2025.
- The Paediatric Palliative Care Study Day was delivered by RAaFT (Regional Advice and Facilitation Team), supported by Consultants and Hospice Teams in September 2024, attended by 30 delegates with excellent feedback.

There are currently 246 members of the MCN who are registered to directly receive updates and information.

A total of 85 people attended an MCN Nursing Practice Day provided by EACH Clinical Nurse Specialists.

The Journal Club continues to run on a monthly basis. There have been seven sessions, each led by a different team from across the region. Articles discussed covered topics including palliation, end-of-life care and ventilation withdrawal in neuromuscular disorders; making polypharmacy safer for children with medical complexity; and stress among parents of children with severe neurological impairment in the paediatric intensive care unit.

#### Funding

All services delivered by EACH are funded through a combination of donations, fundraising activity, retail income and statutory funding from Norfolk County Council, NHS England, and NHS Integrated Care Boards across Norfolk & Waveney, Suffolk & Northeast Essex, Cambridgeshire & Peterborough, Mid & South Essex and Hertfordshire and West Essex.

These arrangements mean all services delivered by EACH are only partly funded by the statutory sector NHS/local authority to the tune of about 15% of our total income, leaving the balance to be found through voluntary income generation.

We have a diverse range of voluntary income streams covering donations, fundraising activities, charitable trusts, gifts in Wills, and from our shop and online sales.

# 2.3.2 Participation in national audits

There were no national clinical audits that EACH were eligible to participate in in 2024-25.

EACH provided information to the confidential David Fuller enquiry in December 2024.



# 2.3.3 Statement: participation in local clinical audits

EACH has an annual programme of local clinical audits. Oversight and scrutiny of the programme is provided by the Clinical Governance Committee of the Board.

#### Audits undertaken

The following audits were carried out by EACH in 2024-25.

- 1. Clinical Safety Alerts
- 2. Controlled Drugs
- 3. Medicine Management
- 4. Infection Prevention and Control: Hand Hygiene
- 5. Infection Prevention and Control: Environmental
- 6. Actions from Safeguarding Supervision
- 7. Resuscitation Episodes of Resuscitation and Status and Documentation
- 8. Moving and Handling Risk Assessments
- 9. Consent Documentation
- 10. Paediatric Early Warning System (PEWS)
- 11. Care Records Care Plans
- 12. Transporting Service Users
- 13.Bed Rails and Safety
- 14.SystmOne records accessed for non-current service-users

Audit	Key Recommendations	Progress/Change to
	Practice	
Clinical Safety	o Consideration to be given as to whether	o Alerts are now shared
Alerts	hard copy of the alerts should continue to	electronically only.
	be held in a folder on the Care floor.	
	o Care Managers to review spreadsheet	o The spreadsheet has
	where alerts are recorded and	been streamlined.
	disseminated.	
Controlled Drugs	o Clarification of what contemporaneous	o Included in Clinical
	documentation means and what good	Education Days.
	looks like.	
	o To consider if the audit frequency needs to	o Decision to continue
	be amended in order to facilitate a larger with current frequ	
	pool of eligible records to be reviewed.	
Medicine	o Remind all staff that signing the back of	o Reminder shared via
Management	the Medication Administration Record is a	Medicines Matters.
	mandatory part of the admission as it	Education day focused

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Audit	Key Recommendations	Progress/Change to Practice		
	provides evidence that the admitting Authorised Person having confirmed all medicines with the parent.	on management of medicines, including verification and reconciliation.		
Infection Prevention and Control: Hand Hygiene	o Continue with hand hygiene audit 3 monthly.	o No change to audit plan required.		
Infection Prevention and Control:	<ul> <li>Introduced new cleaning regime at The Treehouse to ensure work surfaces are cleaned in the kitchen after use.</li> </ul>	o Cleaning regime amended.		
Environmental	<ul> <li>Replace damaged examination/treatment couches at The Treehouse.</li> <li>Eliminate risk of contamination of opened foodstuff at The Nook.</li> <li>Remind staff to complete monthly stock inspection to ensure that all foodstuff past its 'use by' or 'best before' date has been discarded.</li> </ul>	<ul> <li>o Treatment couches replaced.</li> <li>o New storage containers purchased.</li> <li>o Reminder shared with staff.</li> </ul>		
	<ul> <li>Keep records at Milton for all cot mattress inspections and actions taken.</li> </ul>	o Records initiated.		
Actions from Safeguarding Supervision	<ul> <li>To insert an extra box in EACH safeguarding supervision tab to identify when and how actions are completed.</li> <li>Remind staff during supervision to go back and document actions prior to the next session. Supervisor to check for completed actions.</li> </ul>	<ul> <li>Safeguarding tab within SystmOne amended.</li> <li>Progress / completion of actions checked during supervision by supervisors.</li> </ul>		
Resuscitation – Episodes of Resuscitation, Status and	<ul> <li>Remind SMNS that on completion of a BCYP ACP/RESPECT document in the community the resuscitation template in SystmOne must be completed.</li> </ul>	o Shared with SMNS team.		
Documentation	<ul> <li>Member of Locality Leadership Team to ensure that Resus status is checked for each admission during Daily Care Planning for 1 month.</li> <li>Resus template to be updated to include</li> </ul>	o 1 month consolidation of checks completed.		
	additional wording in bold underneath "discussed with parent/carer" tick box to	o Resus template amended and teams		

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Audit	Key Recommendations	Progress/Change to Practice
	remind this must be ticked on each admission/session of care.	updated during Education Days.
Moving and Handling - Risk Assessments	<ul> <li>Progress changes to risk assessment on SystmOne.</li> </ul>	o New risk assessment has gone live on SystmOne.
	• Prompts in pre-admission planning and daily care planning to ensure moving and handling risk assessment is in date and appropriate or identify if a review and / or reassessment is required.	<ul> <li>Progress continues with embedding the necessity of checking Moving &amp; Handling requirements in advance of each stay.</li> </ul>
Consent - Documentation	<ul> <li>An up-to-date S1 report will be shared with the care coordination teams asking them to confirm and update sharing preferences to increase recording compliance.</li> </ul>	<ul> <li>Report shared with care teams to update sharing preferences.</li> </ul>
Paediatric Early Warning System (PEWS)	<ul> <li>Roll out the new PEWs charts and provide resus and clinical deterioration training.</li> </ul>	<ul> <li>New PEWS chart in circulation and amended training delivered.</li> <li>PEWS training included in yearly mandatory resuscitation training.</li> </ul>
Care Records – Care Plans	<ul> <li>Training on the importance of documentation and legal aspects of non- compliance with accurate documents will be held at the next Education days.</li> </ul>	o Training delivered across all sites.
	<ul> <li>Agreed changes to the infection control template will be cascaded as soon as possible.</li> </ul>	o Template updates shared with staff at Education Days.
Transporting Service Users	<ul> <li>Safe practice was supported however staff members observed would benefit from additional support and practice</li> </ul>	o One-to-one advice and training provided.
Bed Rails & Safety	<ul> <li>Liaison with care managers re: outcome of audit and also re: monitoring completion of Bed Rail Risk Assessments in pre-admissions and Daily Care Planning, ensuring documented communication with parents/carers re: outcome following reviews.</li> </ul>	<ul> <li>Progress continues with educating staff re: the importance of BRRAs requirements in advance of each stay. Discussions incorporated into daily care planning meetings.</li> </ul>

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Audit	Key Recommendations	Progress/Change to	
		Practice	
SystmOne	o Consideration of whether SystmOne	o Agreed for DPO to	
Records accessed	Privacy Officer role sits best with Data	complete monthly check	
for non-current	Protection Officer (DPO).	once capacity allows.	
service users			

Clinical managers meet weekly as the Care Operational Leadership Team, all clinical audits are presented to the group. EACH has five Quality & Safety groups (Medicines Management, Infection Prevention & Control, Clinical Practice, Care Records and Physical Therapies). These groups monitor action plans which arise from recommendations made through clinical audits. Progress is reported quarterly to our Quality & Safety Strategic Leadership Team which is chaired by the Head of Nursing and Therapies. The full audit programme is approved and overseen by the Audit, Risk and Compliance Committee and clinical audits are also monitored by the Clinical Governance Committee which comprises Trustees and Senior Leadership Team.

The audit feedback can lead to learning and changes to practice and is shared through a wide range of media and activities, including designated newsletters, EACH-wide care meetings, via subject matter champions, locality-based training days and events delivered by the clinical education team, and through line management cascade.

# Trustee Quality Visits

Our Board of Trustees conducts hospice quality visits at each site. The visits are conducted by two trustees on a rotational basis completing a written report using a template adapted from the NHS 15-step tool. The trustees observe care delivery in the hospice, talking to CYPs and families, visitors, employees and volunteers. Initial feedback from each visit is provided to the locality leadership team and recommendations from the subsequent report feed into the Clinical Governance Committee.

Location	Key Recommendations	Progress/Change to Practice
Milton	<ul> <li>Procurement of new training equipment / manikins for each of the three hospice sites.</li> <li>Understand the work required and timeline for completion of the leak rectification works and upgrade to the family accommodation area.</li> </ul>	<ul> <li>New equipment purchased for all sites.</li> <li>Leak repair works completed, and the refurbishment of family accommodation has been completed.</li> </ul>
The Nook	<ul> <li>Review arrangements for training days to enable the hospice to remain open for care.</li> </ul>	o Processes in place to initiate staff out of hours

# Key recommendations have included:





Location	Key Recommendations Progress/Change to Practice	
	<ul> <li>Revisit incident reporting process ensuring definition of reportable incidents is clear and process of feedback to reporting staff is consistent.</li> </ul>	if need to open hospice arises. o Operational Leadership Team (OLT) agreed to retain low threshold for incident submission with no removal or deletion of non-incidents.
The Treehouse	<ul> <li>Utilise current and projected service demand data to inform proposals for expansion and / or reconfiguration of the building and grounds.</li> </ul>	<ul> <li>Projected population</li> <li>data has informed</li> <li>proposed building plans.</li> </ul>
	o Review admission / discharge process to reduce time spent completing documentation with children and family.	<ul> <li>Feedback from staff has been collated indicating opportunities for development of admission process. Working party to be initiated to progress.</li> </ul>

# ICB Quality visits

We welcome visits from our ICB partners to review and evaluate EACH processes. EACH values a collaborative relationship and wishes to strengthen these across the East Anglia region. Quarterly meetings occur between key staff to discuss hospice activity and performance data, funding and future developments.

# 2.3.4 Participation in clinical research

Over the last 12 months. EACH has participated in the following research:

- The CPOS (Children's Palliative Care Outcome Scale) research project closed to referrals at the end of July 2024. EACH referred 19 families in this final phase of the study. Of these, 11 parents/carers and five children or young people participated in the study. Additionally, three health or social care professionals took part. EACH is awaiting a more detailed summary of the study results and the implementation plan for using the CPOS tool.
- We acted as a participation identification centre with the ENHANCE research project (endof-life care for infants, children and young people: a mixed methods evaluation of current practice in the UK) led by the University of York. We invited 53 families who met eligibility

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to take part and three families were recruited. The project closed at the end of December 2024, and we're now awaiting results.

# 2.3.5 Use of the Commissioning for Quality Improvement and Innovation (CQUIN) payment framework

There were no CQUIN payment frameworks applied to EACH this year.

# 2.3.6 What others say about us

#### Care Quality Commission

EACH is registered with the Care Quality Commission (CQC) and the CQC rated each of the three hospices as Outstanding in 2020. There were no CQC inspections during this reporting period. The registered managers maintain regular proactive dialogue with the CQC as required.

#### External Professionals, Organisations and Students – examples of feedback

"Thank you so much for your support with BCYP and family, you guys are phenomenal!" *External Professional* 

"Thanks ever so much for your kind email and the wonderful words for us both. I am so pleased to read that you and the team have felt supported throughout BCYP journey at the hospice. I had never worked with your team before, and despite the very sad and difficult circumstances, it has been a real pleasure to meet you and work together, while knowing that BCYP was in the best possible hands in their last days. Heartfelt thanks to you and the team for the meaningful input and support throughout." *External Professional* 

"Thank you for your kind words, I totally echo X's message and feel that we have learnt and developed as a team through being able to work with you and the wider hospice team." *External Professional* 

"Thank you so much for all your support in the care of X. Your expertise, kindness and empathy were invaluable." *External Organisation* 

"I wanted to express my appreciation to you all for your help with supporting BCYP, his mum, and our team, as well as checking in since then. Sitting with BCYP and his mum at the time, was a deeply sad but peaceful experience. I know I'm not alone in admiring BCYP mum's love, strength, and courage. I feel genuinely lucky to have so many experienced and caring people to call on and have had check in. Thank you." *External Professional* 

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"Thank you for being the kindest, most welcoming supportive placement I've ever had. I've loved my time here and I've learned so much from every single one of you. You have all been so generous with your time and your skills you make this such a special place." *Student* 

"Just wanted to say a massive thank you for allowing me to join this wonderful world of EACH. My time there was magic, and I felt like I developed superpowers before I left. Making those fabulous children smile, made me think that I deserve a place on this planet." *Student* 

# 2.3.7 Data quality

Good data quality and information management is essential to delivering high quality care. The Information Governance Policy and procedures provide the framework to ensure it is an integral part of EACH's governance arrangements. Work was completed to ensure compliance with the Data Protection Act 2018, the National Data Opt-Out Programme and the Data Security and Protection Toolkit.

# NHS Number and General Medical Practice Code Validity

During 2024-25, EACH did not submit records to the Secondary Users Service for inclusion in the hospital episode statistics which are included in the latest published data. This is because EACH is not eligible to participate in this scheme.

# Data Security and Protection Toolkit Attainment Levels

EACH attained the standards required in the NHS Data Security and Protection Toolkit for 2024-25.

# 2.3.8 Clinical coding error rate

EACH was not subject to the Payment by Results Clinical Coding Audit during 2024-25 by the Audit Commission.

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# Part 3. Review of activity and quality performance

Over the last 12 months, EACH cared for 594 children and young people.

The snapshot number of families with lead children/young people using services at 31<sup>st</sup> March 2025 was 453. In addition, there were 95 bereaved families, including 147 individual family members receiving targeted level interventions from an EACH therapist.

Of the 185 referrals from April 2024 to March 2025, 36 did not meet EACH eligibility criteria, this equates to 19%. In each case, feedback was provided to the referrer and signposting to other organisations was completed where appropriate. Next year, EACH will aim to identify any trends in source of referral for those not meeting eligibility, to determine if any targeted education regarding our referral process is required.

There was a total of 48 deaths during the year.

	Milton	The Nook	The Treehouse	TOTAL	Change from 2023-24
New referrals for the year	75	64	46	185	+22%
Deaths during the year	23	15	10	48	+2%
Lead children for the year	215	212	167	594	+11.5%

#### Hospice site breakdown of referrals, deaths and caseload

Place of death	Home	Hospice	Hospital	Other	Total
2024-25	13	9	26	0	48
2023-24	13	10	23	1*	47
2022-23	12	15	27	0	54
2021-22	18	8	24	0	50
2020-21 (Covid)	14	7	14	0	35
2019-20	10	11	32	1	54

\* Child died during journey from hospice to home.

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# 3.1 Review of priorities for improvement 2024-25

The priorities identified in the last Quality Account, 2024-25, are recorded below followed by a response which reports progress on these.

Table 2 Priorities for improvement	Desired outcome	
Priority 1:		
Voice of service user To develop a family feedback mechanism ensuring the voice of the child/young person and family is heard and has direct influences over service delivery and development.	<ul> <li>Feedback opportunities available enabling a consistent and regular reporting route for evidencing how family and service user feedback informs service delivery with measurable outcomes.</li> </ul>	
RESPONSE:		
We've acknowledged that the limited atter meetings is not always able to provide true experiences of all EACH families. Therefor successfully piloted reaching into pre-exis is high. Members of the leadership teams h interface with family members, providing u 26 we will roll out this approach across al initiatives to develop a co-produced appro participation.	e representation of the views and re, to increase active participation we ting groups and events where attendance have also attended specific events to updates or to seek feedback. During 2025- I three sites and will continue to explore	
In December 2024, we introduced feedback posters in the hospice buildings with a QR code so families can simply scan and send us confidential online comments about their experiences. Postcards featuring the QR code are distributed at groups and events. All responses are reviewed by the Operational Leadership Team with action points allocated to local hospice representatives.		
Priority 2: Invest in people Recruit and retain a skilled workforce. Development of an EACH career pathway for care roles, ensuring streamlined access to role-specific development opportunities.	<ul> <li>An education strategy regarding growing our own staff, e.g. Nurse Apprenticeship, Nurse Associate and Nurse Preceptorship Programmes.</li> <li>A strategic plan for volunteer services within care.</li> </ul>	

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#### **RESPONSE**:

We have three Senior Care Assistants undertaking the Nurse Associate training and one on the Nursing Apprenticeship programme. We are hopeful that by 2026 we will have our first 'home-grown' children's nurse. We plan to maintain Nurse Apprenticeship enrolment. Two Nook nurses are due to complete their Preceptorship programme in July 2025 and we aim to recruit a Preceptee each year.

A 2024 review of the EACH-wide 'Help at Home' service demonstrated that volunteers continue to provide approximately 100 hours of support per month to families. Primarily, support is offered in the family home, common interventions being gardening, cleaning and decorating. Further development will be included as we progress the overall volunteer strategy in 2025-26.

Over the last 12 months, The Treehouse has successfully piloted the integration of seven 'Helping Hands' volunteers, who support the care team with a diverse range of tasks, including preparing for groups and events, meeting and greeting visitors, and supporting families during their hospice stays. Initial recommendations suggest consideration of the model being rolled out at our other two sites.

of Wellbeing and Spiritual Care post. <ul> <li>Implementation of the Wellbeing Strategic</li> <li>Plan.</li> </ul>
ppointed to a new Head of Service post for ccessfully recruited to Locality Wellbeing

Wellbeing and Spiritual Care. We have successfully recruited to Locality Wellbeing Lead vacancies at The Nook and at Milton. Recommendations from the Wellbeing Review (January 2024) will continue to be considered as part of the overall Care Strategy from 2026 and a wellbeing operational plan will be devised.

Priority 4:	<ul> <li>Robust staffing model which is responsive to</li> </ul>
Sustainable resource	the fluctuating demand of personalised
Develop capacity and demand modelling	approach to palliative care.
to influence future staffing establishment	<ul> <li>LTV educational programme for regional</li> </ul>
and wider care resources.	professionals to access.
	<ul> <li>Fully integrated transition role with network</li> </ul>
	links to all adult service stakeholders.
	• Designated research nurse and development
	opportunities to participate in research.
	• Sustainable care environments and buildings
	fit for the future.

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Sustainable statutory income.

#### RESPONSE:

Whilst the lead child caseload continues to grow, the service works flexibly to meet demand. There are currently no waiting lists, however, in order to ensure end-of-life care needs are met, families do occasionally have short breaks cancelled to enable EACH to focus resources on end-of-life care or urgent/crisis care. All requests to deliver or support the provision of end-of-life care were met during 2024-25.

Approximately 75% of the BCYP who received short break care in the last year were classified as stable, the remaining 25% reported to be deteriorating in their phase of illness. Our future staff planning model is considering the phase of illness information. It may be appropriate to employ a higher percentage of skilled Care Assistants who will be able to safely care for those BCYP classified as clinically stable, allowing nursing resource to focus on end-of-life care, or those BCYP unstable or deteriorating.

The EACH LTV team has continued to provide clinical and teaching/educational support to patients with LTV needs (n=64), their families, carers and professionals around them. The team is responsible for training and competency sign-off of staff who are then independently able to care for the BCYP. EACH has provided investment into establishment of the LTV service with an additional Band 6 post.

In addition to the increase in nurse and care assistant posts, EACH has successfully integrated five new clinical posts to support the development of the care team. These include a Clinical Student Support Co-ordinator, a Specialist Clinical Educator, a Research Nurse, a Transition Lead and a Physical Therapies Lead.

EACH is embarking on a major capital project to expand and improve The Treehouse, ensuring we can offer more care, of a higher quality, to all local children and families who need it. Plans have been submitted for planning approval and include a new care activity area, a new wellbeing and therapies suite and a larger hydrotherapy facility.

At Milton, we have widened the driveway to accommodate emergency vehicles, completed a full upgrade of our hot and cold water systems, refurbished and refitted the staff changing area, remodelled and refurbished the parent's accommodation, completed fitment of new windows to the hospice building and have added new security doors to parts of the building including the reception area.



At The Nook, we have made some subtle changes to some of the bedrooms and therapy rooms with the introduction of colour and some soft furnishings in response to feedback from families. Families are also benefitting from the inclusion of new electric vehicle charging points.

EACH's Business Development Manager continues to work with statutory services, including our ICB partners, to develop a pricing strategy that achieves a fair price for services delivered.

# 3.2 Additional quality indicators we have chosen to measure

In the absence of a national minimum dataset and nationally agreed indicators of quality for children's palliative care, EACH monitors service user experience, clinical effectiveness and patient safety by reporting:

- complaints and concerns
- commendations
- incidents and accidents
- staff knowledge, skills and practice development, including scholarly activity, involvement in clinical practice development activities and compliance with professional education and training requirements
- HR indicators (sickness absence, vacancies and staff stability for care department staff).

# 3.2a Complaints and concerns

A complaint or concern by a service user is considered by EACH to be any expression of dissatisfaction whether it is made verbally or in writing. EACH believes a concern or complaint is an opportunity to improve our care, so treat both with equal importance and rigour. All concerns and complaints are investigated, and complainants receive responses, with the aim of resolving their concern or complaint to their satisfaction.

All concerns, complaints or incidents are viewed as an opportunity for learning, development and service improvement and learning, are shared with staff, including changes to practice.

The person raising the concern/complaint is advised of the investigation process, findings and resulting changes to care practice.

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#### Number of CYP/family member-related concerns/complaints:

Service	2024-25
Milton	2
The Nook	21
Symptom Management	1
The Treehouse	9
Total	33

There has been an increase of complaints from 2023-24 (n=25). The Operational Leadership Team acknowledges the fact that The Nook has received the majority of complaints. It is known that families accessing continuing care services from The Nook are appropriately advised by the commissioner to share their concerns and reflections in a timely fashion. These conversations are supported during regular reviews between the families, EACH and the ICB.

Following a successful 12-month pilot, a second care manager post, covering 12-hour shifts, has been instigated to increase additional management and leadership support to the care floor alongside an increase in support from the Clinical Education Team. The day-to-day presence of the Care Manager may explain an increase in recorded complaints as they are on hand to discuss and explore real time feedback from families, maintaining a low threshold for reporting concerns via the incident reporting system.

Summary of themes of CYP/family member-related concerns and complaints in 2024-25 The complaints have been themed as follows:

Theme	2024-25
Communication	4
Amount of care and support	3
Standards of care	17
Staffing Levels	5
Other	4
Total	33

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Theme	Milton	The Nook	Symptom Management	The Treehouse	2024-25
Communication	0	З	0	1	4
Amount of care and support	1	1	0	1	3
Standards of care	0	10	1	6	17
Staffing levels	1	4	0	0	5
Other	0	З	0	1	4
Total	2	21	1	9	33

Those marked as other included the following:

- Concern raised by EACH staff regarding behaviour of family member.
- Concern raised over behaviour of an external professional.
- Concern raised over staff member's professional conduct.

Examples of changes to practice from the complaints include:

- Resuscitation status added to the pre-admission checks.
- More in-depth resuscitation status discussions during Daily Care Planning.
- Bespoke resuscitation training to be delivered by EACH rather than external provider.

# 3.2b Commendations

EACH received over 127 recorded commendations throughout the year, including from families about various elements of the service. The following are a sample of some of the commendations received. Locations of care have been removed, and details anonymised to protect the privacy of the families.

#### Help at Home Service

"I just wanted to say an absolutely huge thank you to you all for the wonderful job you have done in our garden. It's absolutely brilliant and I must admit I had forgotten just how big our patch is! Thank you all so very much, I know X will be able to move around much easier and get to appreciate all of his beautiful plants." *Family member* 

"This year has truly flown by. Our gardens have never looked so good, our kitchen never stayed so clean for so long. The piles to move to the tip have never moved so fast. There are truly no words to express how much, knowing you will be here on a Friday, not to judge but to help and to listen. Thank you. You have helped us to keep going. Truly, thank you." *Family member* 

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#### Wellbeing groups and activities

"Can we also say a massive thank you for all your hard work organising the recent sibling day. It must have taken an enormous amount of time and effort to plan. X had an amazing day." *Family member* 

"This is lovely to be able to come to an event where we are all in a similar position. I have not felt like we have been able to come to the zoo before as it's been a challenge for us as a parents! This is our first time and meeting new families and talking to others has been great. We have also had the opportunity to meet with friends who we don't get to see very often." *Family member* 

"Just wanted to say a really big thank you for organising the coffee morning today. It was so nice to meet other mums and chat to you all also. What a fabulous spread you put on and to top it off we got a bunch of Daffodils. It's these sort of things that are so important and beneficial for my mental health. It makes the hard times with X that little bit easier." - *Family member* 

#### Short Break Care

"The facilities at the hospice are second to none, I was blown away by it all and the space and the warm feeling there. The staff are incredible so attentive and nothing is too much trouble for them. I love the fact that the whole family is catered for and considered, especially the sibling days. Cannot praise EACH enough." *Family member* 

"The hospice has been a place of sanctuary for me and my little boy since his diagnosis. The love and support received by all the staff here are truly amazing." *Family member* 

# Wellbeing Support

"I would just like to express my gratitude to you for putting me back together for want of a better word. When we started after the loss of our grandson I couldn't see a way forward, I felt like a broken vase in a thousand pieces. During our time together you have rebuilt me piece by piece till I was ready to put flowers in the vase again. You also have given me the confidence to look into my future and move on not hiding behind the buggies and children anymore. For this I will be forever grateful." *Family member* 

We currently have a total of <u>90 different family stories and 16 service-based films on our</u> <u>website</u>. All contain very powerful and personal commendations about the services children, young people and families have received.

# 3.2c Incidents and accidents

EACH encourages a positive and proactive approach to incident reporting and management. Staff are encouraged to report all incidents within the context of a learning culture. Incidents are

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categorised by type and severity using a red (catastrophic), amber (major), yellow (moderate) and green (minor) scoring system.

Notifiable incidents are those that have resulted in major harm or death of a service user.

Incidents which are scored as amber or red are reported to both the Management Executive and Clinical Governance Committee of the Board.

Service User Clinical Incidents are categorised and reported as follows: Care plans, Clinical intervention, Communication, Consent, Confidentiality, Documentation (care records), Emergency Protocol, Infection Control, Manual Handling, Medication, Medication Controlled Drugs, Medication Homely Remedy, Pressure Sore, Resuscitation and Self Harm.

Clinical incidents are scrutinised by the relevant clinical practice, governance and health & safety groups. For example, medicines management incidents by the Medicines Management Group, infection control and prevention incidents by the Infection Control Group and patient-related information incidents by the Information Governance Management Group.

All clinical incidents and accidents are reviewed weekly by the Care Operational Leadership Team; learning is identified, and it is agreed how best to share the learning across all teams. This includes sharing learning via the daily stand-up meetings held in each locality, Care Matters newsletters, clinical meetings and through training sessions.

The trends, number, outcomes, changes to practice and learning from incidents are monitored by the Senior Leadership Team for Care and the Clinical Governance Committee of the Board every quarter.

# Service User Incidents - 1 April 2024 – 31 March 2025

In 2024-25, there were a total of 278 green and yellow rated incidents completed (including 82 relating to medicines), this equates to less than two incidents per hospice site per week.

There was one (1) resuscitation incident identified learning included the following:

- Resuscitation status confirmed at admission and discussed in handover and as part of the daily care planning meeting.
- Changes to SystmOne pre-sets to include resuscitation status on pre-admission information.
- Changes have been implemented to mandatory resuscitation training to include interpretation of ACP / ReSPECT documentation.

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There was one (1) notifiable controlled drugs incident, identified learning included the following:

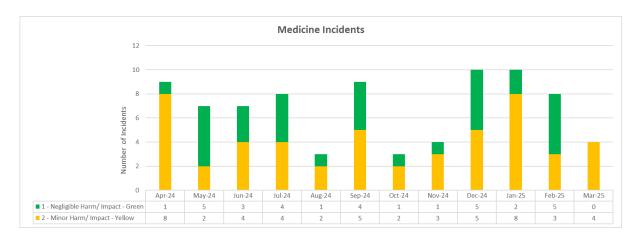
• Additional training and support provided to individual staff with regards to preparation and administration of neonatal drug calculations and administration.

There were zero (0) notifiable clinical incidents and zero (0) orange or red-rated incidents during 2024-25.



30% of these incidents (n=82) related to medicines management.

The frequency of medicines incidents reflects the nature and complexity of clinical interventions and treatment of children and young people we care for. On all occasions, appropriate and timely action was taken in terms of ensuring child/young person safety, seeking advice from a prescriber and observing for any adverse consequences.



There were 6 recorded safeguarding incidents, identified learning includes the following:

- Internal processes of Social Care referrals confirmed by Service Managers.
- A reminder was given to all staff to ensure that their professional conduct is in line with EACH's Professional Boundaries Policy.

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# 3.2d Staff knowledge, skills and practice development

The evidence of learning and development activities carried out by staff demonstrates EACH's commitment to this aspect of quality assurance. A summary of learning and practice development activities is provided in the sections below.

# 3.2d (i) Annual Mandatory Training

Annual mandatory training was provided to care staff in the following areas. EACH has a target compliance standard of 90%. The levels of compliance for the year 2024-25 are as follows:

Торіс	Compliance		
Data Security Awareness	97%		
Fire Safety (Advanced)	99%		
Food Hygiene Catering (e-learning)	98%		
Infection Prevention & Control	97%		
Medical Gas Safety	97%		
Moving & Handling (Clinical)	97%		
Resuscitation & Anaphylaxis	96%		
Safeguarding Adults – Level 2 (e-learning)	97%		
Safeguarding Children (Clinical)	95%		

The compliance figures do not include staff who are on long-term absence or within six weeks of their induction period. Training reminders have been sent to all non-compliant staff and their managers.

# 3.2d (ii) EACH Quality and Safety Framework

Quality and Safety is monitored and recommendations for improvement are informed by the work of key clinical risk groups which meet quarterly and include representatives from all three hospices.

Groups are as follows:

Title
Clinical Practice Group
Care Records Group
Infection Control Group
Medicines Management Group
Safeguarding CYP & Adults Group (corporate)
Physical Therapies Group

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The key functions of all groups within the EACH Quality and Safety Framework are to:

- Review operational risk
- Review safeguarding incidents
- Review, audit and evaluate practice standards
- Make recommendations for the development of practice standards
- Champion and provide oversight of the implementation of practice standards
- Ensure practice is current and based on evidence or best practice standards
- Share learning.

Medicines Management, Infection Control and Clinical Practice Groups hold workshops twice a year to incorporate development time for the group and in-depth discussions, such as review of trends in reported incidents.

# 3.2d (iii) External Practice Development Groups

Care staff participated in the following external groups:

The East of England Children's Palliative Care Managed Clinical Network (MCN) – Norfolk, Suffolk, Cambridgeshire and Peterborough, Essex, Hertfordshire, Bedfordshire, Luton and Milton Keynes. This is chaired by the EACH Medical Director. The steering group is attended by the Head of Nursing and Therapies, and the EACH Matrons.

East of England Children's Palliative Care Forum and county-based palliative care networks. These are responsible for developing and implementing the priorities of the Managed Clinical Network. The Regional Forum is attended by the Medical Director and Head of Nursing and Therapies. The county-based networks are attended by the Matrons, Service Managers and Clinical Education Lead.

East of England Palliative & End of Life Care Strategic Clinical Network. The EACH Medical Director is CYP PEOLC Lead and attends this in their capacity as chair of the MCN.

External groups attended by members of the LTV team:

- LTV National Forum
- Complex Chest Regional Meetings
- Trachestomy Working Group

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- Transition drop-in sessions in Norfolk (Commissioned)
- LTV Champions Meeting (run by LTV ODN)
- UK Kids LTV Google Group
- Members of the team attended the F&P and Breas Training Events, which involved networking with others in the LTV network
- Completion of BLS Trainer Qualification (to specifically support BCYPs with Tracheostomies) by one team member.

External groups attended by members of the Wellbeing team:

• Anna Freud Learning Network

### 3.2d (iv) Scholarly Activity

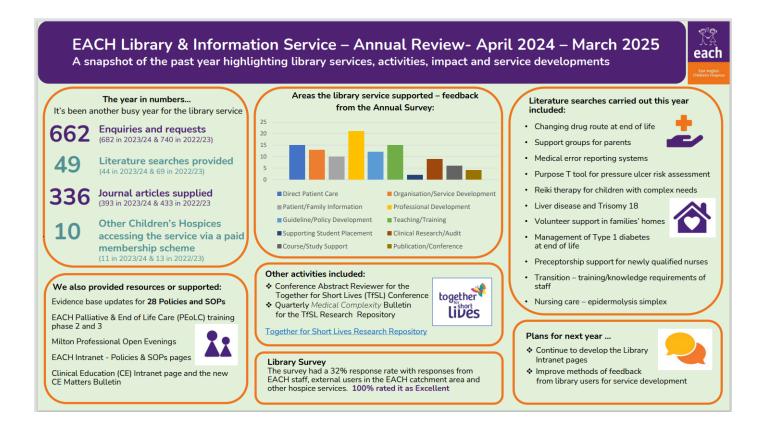
- Supporting a Multidisciplinary Approach to Promote Safe Sleep at a Children's Hospice. C. Harper. Poster presented at the Rome Global Conference, October 2024.
- Who are the Children? Point Prevalence Survey to understand who needs Children's Palliative Care. L Maynard, D Vickers, C Cannon, E Cattaneo. Poster presented at the Rome Global Conference, October 2024.
- Do regional multidisciplinary children's palliative care meetings support health care system development? L Maynard, C Cannon, J Woolley, D Vickers. Poster presented at the Rome Global Conference, October 2024.

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### 3.2d (v) Library & Information Service









### 3.2d (vi) External Study and Conferences

EACH supported applications from care staff to undertake accredited modules/courses, study days, extended study learning and conferences during the reporting period. Examples include:

- Aromatherapy for Children & Babies
- Basic Life Support Instructor
- Anaphylaxis Trainer
- Advanced Communication condensed
- Autism & Attention Deficit / Hyperactivity Disorder training
- Music Therapy Charity Research conference
- Sands training for Therapists & Counsellors
- Supervision training
- Jessie's Fund making music training
- UK Paediatric Network conference
- Becoming a designated prescribing practitioner
- Paediatric Palliative Care study day
- Foundation course in Play therapy
- Hospice UK conference
- Advanced Clinical Practitioner Masters
- Advanced Assessment Module
- Non-Medical Prescribing Module
- Education in Palliative and End of Life Care (EPEC) conference
- Association for Paediatric Palliative Medicine (APPM) conference
- Association for Paediatric Palliative Medicine (APPM) Nurses networking & education day
- Managing complex symptoms
- Trainee Nurse Associate program
- Nursing Apprenticeship program
- International Congress on Paediatric Palliative care conference
- Clinical Skills Occupational Therapists & Physiotherapists
- National Back Exchange (NBE) conference
- Wheelchair Accessible Vehicle training
- Transport training
- Grief Awareness training
- Cruise bereavement support
- British Association of Art Therapists working with loss
- British Association of Art therapy Eye Movement Desensitisation and Reprocessing (EMDR) meets art therapy for children
- BSc in interactive counselling
- Working in childhood bereavement.

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#### 3.2d (vii) Non-Nursing Student Placements

Since 2019, EACH has provided placements as part of the Cambridge General Practice Vocational Training Scheme. These placements are part of Integrated Training Posts in which the doctor spends six months working half time in a GP practice and the other half in a speciality.

EACH has accommodated two placements for trainee GPs working in children's palliative care. These have been based at Milton and the doctors work with the care team and symptom management nursing service, under the supervision of the Matron at Milton and the EACH Medical Director. The posts have been positively evaluated by the trainees and provide valuable learning about children's palliative care for GPs in training. This programme was paused in Summer 2024 due to new members joining the team within Milton SMNS and requiring induction. It restarted in February 2025 with one GP trainee.

### 3.2d (viii) Commissioned Training

A total of 85 professionals benefitted from the following training and education events provided by the Managed Clinical Network, hosted by EACH:

- Management of Intravenous Therapy for Nurses
- Management of Subcutaneous Medication Therapy for Nurse.

External commissioned training days delivered by the EACH Long-Term Ventilation (LTV) team to the following:

- Sunflowers Care Ltd, Cambridge
- Clare School, Norwich
- Dussindale Primary School, Norwich
- Sue Ryder Thorpe Hall, Peterborough
- Bespoke training to families.

162 professionals benefitted from the following training provided by our Specialist Clinical Educator:

- Norfolk & Waveney Neonatal Palliative Care Study Day 61 attendees
- Norfolk & Waveney Basic Principles of Paediatric Palliative Care 51 attendees
- Norfolk & Waveney Managing Symptoms at End of Life 15 attendees
- Queen Elizabeth Hospital Neonatal Webinar 29 attendees
- Palliative Care Registrars Paediatric Services and Transition Study Day 6 attendees.

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### 3.2d (ix) Human Resources Indicators

Sickness absence

During the report period, the average sickness absence rate for care staff was 3.97% which is below comparable benchmarks in the NHS. The average sickness absence rate for the whole of EACH for the period 1<sup>st</sup> April 25 – 31<sup>st</sup> Mar 25 was 3.28%. Care staff absence was slightly higher than the EACH benchmark as a result of an increase in sickness over the winter months of November, December and January.

The latest NHS data for November 2024 (published March 2025) put the rate for Community Provider Trusts at 6.10% and 5.70% for Community Provider Trusts in the East of England. This is the closest type of provider to benchmark against.

Source: NHS Sickness Absence Rates, November 2024 - NHS England Digital

# 3.3 How children and families are involved in EACH and what they say about the service they received

EACH believes that children and young people and family members who use our services have the right to be involved in decisions that directly affect their care and support, and are engaged in shaping and influencing EACH care services. The skills and wealth of experience that those who use our services can bring to the organisation are recognised and positively valued. Acting on service user feedback is important to EACH and the principle of 'you said, we did' is built into our service user engagement strategy.

We seek feedback from and involve the children, young people and families in several ways, including 'Family Forums' and having two trustees who were users of EACH services. Families are encouraged to give feedback via a range of means, including the Family Forums, QR code feedback posters, the Family Zone section on our website, surveys, requests in the family e-newsletter, and via Facebook and Twitter. Much of the rich feedback is gathered via ad hoc conversations with families at groups and events and during planned episodes of care.

Examples of feedback received from families are noted earlier in section 3.2b.

We are working with our Marketing and Communications team to further progress improvement priority one, to assess other avenues for gaining service user feedback, and giving consideration to utilise an external patient advocate.

A new format of Family Forums has been embedded at The Treehouse during 2024-25 and is detailed in section 3.3b below.

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All eligible families engage in a holistic assessment following their initial referral to EACH, to identify their personal goals and to consider their different areas of need. Families identify what is most important to them and their priorities for care and support that would make the most difference to them. Our Family Support Practitioners meet with families at least annually or when there has been a significant change, to carry out a review of the assessment, goals and priorities.

## 3.3b Family Forums

Family Forums provide the opportunity for families to share their feedback and views, and historically have been hosted by the Service Managers at each locality, held quarterly on a day and time that best suits the families who attend. Attendance has primarily been face to face at The Treehouse and The Nook, however, the option of attending via MS Teams has been offered. Families at Milton have attended via this method.

The forums provide the opportunity to hear from families about what is working well, what they have concerns about, and to be updated on what is happening at EACH and in their own locality service. They also provide the opportunity for feedback on proposed developments.

Attendance from families at the forums has been low over the past few years despite attempts to generate additional uptake. As described in the introductory statement, representatives from the Locality Leadership Teams have attended the start of pre-existing planned groups and events to speak to family members directly face to face. This more relaxed approach has now been ingrained at The Treehouse, with the other sites now replicating this approach to gain access to a wider audience.

Examples of information exchanged at the Family Forums include:

- Updates on proposed building works
- Staffing updates within the care directorate
- Feedback on the EACH website, organisational communication and general family information
- Feedback and suggestions around the delivery of groups and events
- The roll-out of feedback posters with QR codes around the hospices.

## 3.4 Involving EACH staff

EACH operates a variety of ways to communicate with, engage and gather feedback from our employees to drive meaningful transformation. Feedback is sought from staff via daily care planning meetings, weekly locality multi-professional meetings, quarterly locality team meetings

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and tri-site meetings. Some staff are also members of care and corporate quality and safety groups, and project development groups.

There is a weekly organisational update communication to staff from the Chief Executive and care staff also receive regular updates from the care management team via Care Matters, Medicines Matters and Infection Control Matters newsletters. Each of the three hospices produce a locality weekly newsletter for staff. A page has been added to the staff intranet which focuses on safeguarding and updates are added following each Corporate Safeguarding Quality & Safety Group meeting.

#### Investors in People

EACH is currently Investors in People (IIP) accredited and is being reassessed in July 2025, including an all-employee engagement survey to review ongoing areas for development.

### The EACH Staff Intranet and Viva Engage Platform

We have a well-established staff intranet available to all EACH employees and trustees. Sharing key operational news, information, documents and processes, including policies and standard operating procedures, monthly reporting demonstrates high user-activity across all departments. Other content includes individual hospice weekly staff newsletters and links to useful websites and resources, such as pension information, the EACH Strategic Plan, the full range of staff benefits and our Employee Handbook. We also use Microsoft's employee social media/engagement platform, Viva Engage, for posting key information and items of interest. All staff can share their own content to the platform, comment on posts and work together in specific discussion groups.

#### Line Managers

Line managers are responsible for ensuring staff are kept up to date with policy changes and decisions that affect them and are the first point of contact for staff for information regarding any issues at work. They hold regular team meetings to ensure staff are updated with developments on subjects that affect their team. All three hospice localities continue to deliver quarterly team locality days.

Line managers hold regular 1:1 management supervision sessions and catch-up meetings with employees to discuss performance and wellbeing, and formally record performance discussions annually via our appraisal process.

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### 3.5 Statements from Lead Commissioners and Healthwatch

EACH provides services across Norfolk, Suffolk, Cambridgeshire and Essex. This Quality Account has been sent to Integrated Care Boards and Healthwatch in the above counties to provide the opportunity for comment and a statement.

The list of those sent a copy is tabled in Appendix 1 with their responses shown in Appendix 3.

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# Appendix 1: Commissioners and Healthwatch contact details

ICB area	Integrated Care Board (ICB)	ICB Contact	Healthwatch contact
Norfolk & Waveney	Norfolk & Waveney ICB	pmercer@nhs.net Rebecca.godfrey1@nhs.net	Alex Stewart <u>Alex.stewart@healthwatchnorfolk.co.uk</u> Chief Executive Tel: 0808 168 9669
Suffolk & North East Essex (SNEE)	SNEE ICB	anthea.christodoulides@snee.nhs.uk Jaime Hawkins Transformation Lead jaime.hawkins@snee.nhs.uk clinical.quality@snee.nhs.uk	Andy Yacoub Chief Executive <u>Info@healthwatchsuffolk.co.uk</u> Tel: 01449 703949
Cambridgeshire & Peterborough	Cambridgeshire & Peterborough ICB	<u>cpicb.qualitydirectorate@nhs.</u> <u>net</u>	Jess Slater Chief Executive <u>jess.slater@healthwatchcambspboro.co.uk</u> Tel: 0330 355 1285
Mid Essex	Mid Essex and South Essex ICB	Susanna Vaughan susanna.vaughan@nhs.net mseicb-me.quality@nhs.net	Sharon Westfield-de-Cortez <u>sharon.westfield-de-</u> <u>cortez@healthwatchessex.org.uk</u> . Tel: 0300 500 1895
West Essex	Herts and West Essex ICB	<u>Rosalind.French@nhs.net</u> Smita Rai <u>smita.rai1@nhs.net</u>	

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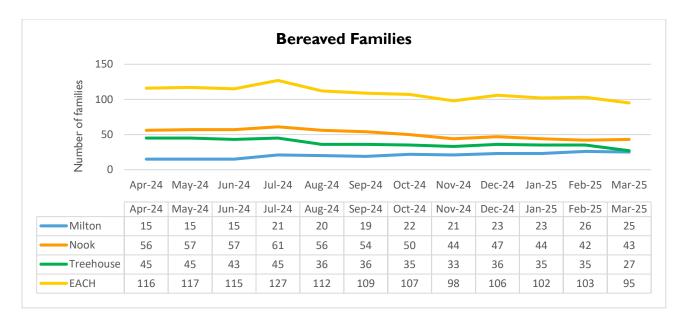


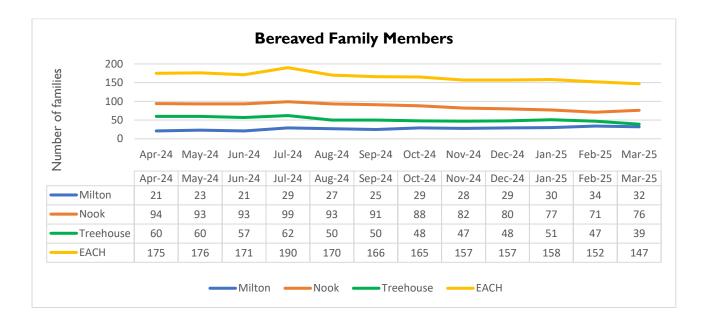




### Appendix 2: Wellbeing service data

Number of bereaved families and family members on caseload for Q1 to Q4 (taken from the Q4 performance report):

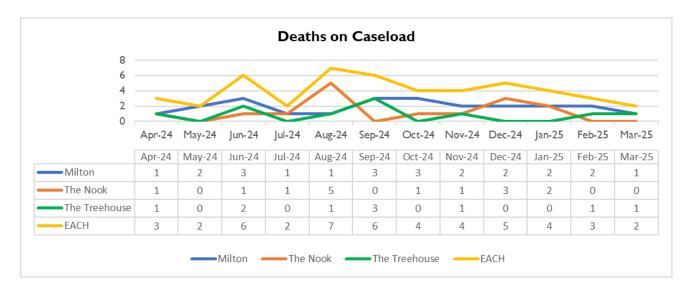




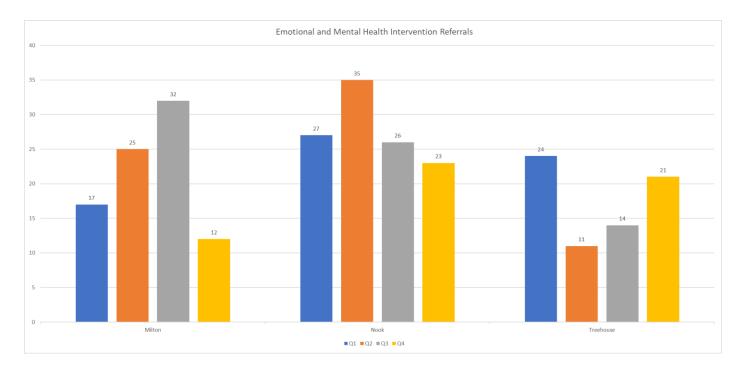
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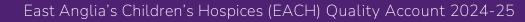


### Deaths on caseload for Q1 to Q4 (taken from the Q4 performance report):

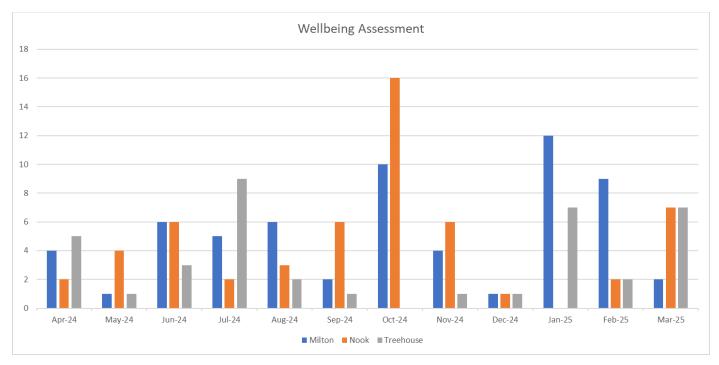


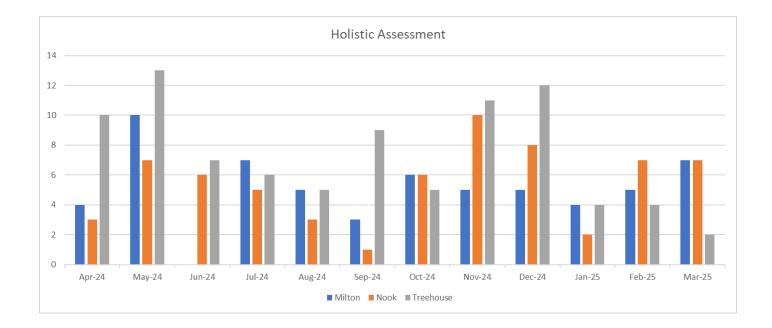
### Emotional and Mental Health Interventions for Q1 to Q4











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## Appendix 3 Commissioners and Healthwatch Responses



### Response to EACH Quality Account 2024-2025 from Healthwatch Essex

Healthwatch Essex is an independent organisation that works to provide a voice for the people of Essex in helping to shape and improve local health and social care. We believe that health and social care organisations should use people's lived experience to improve services. Understanding what it is like for the patient, the service user and the carer to access services should be at the heart of transforming the NHS and social care as it meets the challenges ahead of it.

We recognise that Quality Accounts are an important way for EACH to report on their performance by measuring patient safety, the effectiveness of treatments that patients receive and patient experience of care. They present a useful opportunity for Healthwatch to provide a critical, but constructive, perspective on the quality of services, and we will comment where we believe we have evidence – grounded in people's voice and lived experience – that is relevant to the quality of services delivered by EACH. In this case, we have received no additional feedback, and so offer only the following comments on the EACH Quality Account.

- It is reassuring to see EACH achieve 'Outstanding' from the Care Quality Commission and inspiring to learn about the number of children and young people supported through 89,054 hours of care and wellbeing support, although this figure was higher in last years quality account of 92,142, it is still an incredible achievement which supported 594 life-threatened children and young people during the year, together with their mums, dads, carers, grandparents and siblings. Such amazing and impactful work.
- It is great to see EACH improving their engagement with families through innovative improvements such as QR codes within the hospice to make it easier to capture valuable feedback. The implementation of the family forum discussions into groups and events is great to see, and shows the determination of EACH to listen to the community's voice to enhance service delivery and support.
- We are pleased to see the commitment from EACH to engage with their community through events and it is inspiring to see 197 events delivered reaching around 3,162 children and adults. Again, this shows great work and effort has been delivered by EACH to engage with the community and hear their voice.
- It is extremely positive to see the list of progress and change of practice from EACH's audits, showing a true commitment to improve service delivery.

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- We are pleased again this year to see the EACH board of trustees completing hospice quality visits with recommendations and feedback given apparent. Again, showing a clear determination to ensure fantastic service delivery.
- Although the increase in complaints is concerning it is great to know that EACH have robust processes in place to understand these concerns, and there is a clear desire to engage with families to understand their thoughts which is encouraging to see.

Listening to the voice and lived experience of patients, service users, staff, and the wider community, is a vital component of providing good quality care and Healthwatch Essex supports the encouraging work of EACH.

Scott Tatum Engagement Manager 29.05.2025

EACH Response:

Thank you for taking the time to read our report and providing informative feedback.

We are striving to increase our co-production approach with families we support, and the communities we would like to reach more. We are keen to learn, improve and grow our service to ensure it can meet the needs of all families who need our support. We look forward to working with you to maximise our engagement and collaborative approach.

Helen Finlinson Director of Care East Anglia's Children's Hospices (EACH)

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Review of 2024/25 Quality Account EACH

Healthwatch Norfolk (HWN) welcomes the opportunity to review the draft East Anglia's Children's Hospices (EACH) Quality Account for 2024/2025 and to comment on the quality of the services commissioned locally to meet the needs of residents in the Norfolk area.

Review question		Comments
1. Readability		
Is there an executive	Yes	
summary/CEO statement?		
Is the document well laid out,	Yes	Clear description of the services
easy to read?		provided.
Is there a glossary?	No	
Is the document available in	Not	Electronic version only provided for
different formats? e.g. electronic,	clear	review.
hard copy, Braille, other		
languages		
Are priorities for the past year	Yes	
clearly identified?		
Have the priorities been achieved?	Yes	
Are the priorities for the	Yes	Part of the 4-year strategic plan
forthcoming year clearly		
identified?		
2. Are the following areas		
included?		
Patient safety?	Yes	
Clinical quality and effectiveness?	Yes	Robust framework in place
Patient experience including the	Yes	Captured in a variety of ways
family & friends test?	No	
	FFT	
Incident reporting & never events?	Yes	Strong evidence of learning from
		incidents
Complaints?	Yes	Complaints reviewed by site and
		addressed in training plan
Workforce?	Yes	Currently Investors in People (IIP)
		accredited and being reassessed in
		July 2025, including an all-

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		employee engagement survey to review ongoing areas for development. Sickness rate is low. No information on staff turnover. No information on wellbeing support for staff. Education and training is excellent.
Audits including participation in national audits?	Yes	No national audits. Appropriate internal audits conducted and actions undertaken.
Data quality?	Yes	Strong data capture, easy to interpret, well reported
Feedback from CQC?	Yes.	All three sites are rated "Outstanding".
New services?	No	New developments include roles added to team, capital investment in premises.
CQUIN?	No	Not eligible
PLACE results?	N/A	3 sites, data reported separately as well as aggregated
18-week target (where applicable)?	N/A	
IG Toolkit compliance?	Yes	

Strengths

• Excellent model of care

Clearly a very patient focused, holistic and flexible service, tailored to the specific needs of BCYP and their families and carers.

• Service user engagement

The family forums, which provide the opportunity for feedback and raising concerns have been strengthened in the last 12 months with a new approach to reach a wider audience. Representatives from the Locality Leadership Teams now attend the start of pre-existing planned groups and events to speak to family members directly face to face. Feedback is also gathered digitally on website, QR code on poster, surveys, Facebook and Twitter.







• Staff education, training and communication

There is an established ethos encouraging and supporting staff education, involvement in research and career development. The provision of a staff intranet to share and discuss issues together is noted as a positive feature.

• Collaboration with partners and external agencies

Evidence of strong partnership working, generating and maintaining an excellent network, sharing best practice and jointly developing innovative ways of working to improve patient care.

### Gaps

It was not clear whether staff have access to wellbeing support to cope with the emotional pressures of caring for BCYP with life limiting illness. Staff have regular 1:1 supervision meetings with line managers in which wellbeing is discussed but there was no clear information about pastoral support offered to them.

Spiritual care seems to have been rather lacking in the last 12 months.

Concerns

None.

Healthwatch Norfolk would welcome the opportunity to work with EACH to ensure that the views of their patients, their families and their carers are considered and to make recommendations for change, where appropriate.

Alex Stewart Chief Executive Officer June 2025

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EACH Response:

Thank you for your encouraging feedback.

With regards to staff support, EACH provides access to de-briefs after every death of a baby, child, or young person. We also provide regular access to group and 1:1 supervision sessions tailored to the needs of the different roles in the team. Pastoral care is also provided by our spiritual care volunteers. Within our development plans is the re-establishment of a spiritual care role this year.

We would welcome the opportunity to work with you to engage with communities and families as we seek to extend our reach.

Helen Finlinson Director of Care East Anglia's Children's Hospices (EACH)

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#### Cambridgeshire & Peterborough Integrated Care Board

# Stakeholder Feedback – East Anglia Children's Hospice (EACH) Quality Account 2024/25

Cambridgeshire and Peterborough Integrated Care Board (ICB) has reviewed the Quality Account produced by East Anglia Children's Hospice for 2024/25.

The quality account has been produced in relation to all three hospices that the East Anglia Children's Hospice run. They cover a large geographical area offering multiple services within the overall offer and take the lead role in regional network for children with life limiting illness.

The provider supported 594 life-threatened children and young people during the year. EACH are a very impressive organisation, providing an outstandingly high level of care for so often highly complex children and their families. All three hospices have 'Outstanding' ratings by the Care Quality Commission; they are to be warmly commended for their excellent work.

The organisation has produced a clear report with concise information. This supporting statement is in relation to the care and services that the hospice provides for Children in Cambridgeshire & Peterborough.

Milton Hospice in Cambridge received 75 new referrals during 2024/25 and there were sadly 23 deaths. The account reports on the total number of deaths in EACH hospice is given with a break down by site and by month.

During 2024/25 there were occasional cancellation of short breaks supporting families during end-of-life care. These were due to staffing issues which EACH are mitigating by re-assessing staffing model to provide better coverage. This should be an area of focus for 2025/26.

The appointment of a transition lead to support children moving into adult services is a positive move and the ICB are looking forward to seeing the impact of this role and seeing positive outcomes for children.

Compliance with safeguarding adults and children's training are both over 95% compliant. It is positive to see safeguarding supervision has been audited and that the voice of the child is a key priority area.

The account has minimal overview of infection, prevention and control but confirms participation in hand hygiene and environmental audits. However, this is an area of focus for the hospices which could be detailed further next year.

Each received a total of 33 complaints throughout the year, with only 2 related to Cambridgeshire & Peterborough. There was a disproportionate number of concerns and complaints received by The Nook which the organisation acknowledges. It would be good if the themes and trends of these complaints could be reviewed to assess whether there is learning and improvements that can be shared across all hospices.

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ACH Healthcare clinical education is very diverse with a focus to support staff competency and positive behaviours all to ensure quality care, patient safety and family support. The professional development offered within the hospice for all grades of staff is congratulated.

Each prioritise the voice of service users and their families and recognise that it is essential for continuous improvement and the delivery of high-quality, person-centred care.

EACH contributed to two research projects in 2024-25, which is good, recruiting 16 patients or family members and health care professionals to the Children's Palliative Care Outcome Scale (CPOS) research project and acting as a participant identification centre (PIC) with the ENHANCE research project into end-of-life care for infants, children and young people, inviting 53 families to join the study. The organisation appointed a designated research nurse in the last year, earlier than anticipated and the ICB look forward to seeing the outcomes of this new role.

The ICB would like to thank all staff working for East Anglia Children's Hospice for their dedication, professionalism, hard work and commitment to patient care throughout the year and looks forward to continuing to work with them as part of the Cambridgeshire & Peterborough Integrated Care System.

Overall Cambridgeshire and Peterborough ICB agree the EACH Quality Account is a true representation of quality during 2024/25.

CANCESON

Carol Anderson Chief Nursing Officer Cambridgeshire & Peterborough ICB

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EACH Response:

Thank you for your informed response to our Quality Account 2024-2025. We are pleased to report that Milton have had a successful recruitment effort of nursing staff which we hope will provide greater staffing resilience and reduced cancellations going forward.

We note your request for increased focus on Infection Prevention and Control. We will consider how we can present this more fully in future to reflect our commitment in this area.

We acknowledge the omission of key learning from complaints from this year's Quality Account; however we do provide this information in our quarterly integrated performance / quality and safety reports. We will look to incorporate a section in next year's Quality Account. Key learning from complaints from the last year has initiated a review of our staffing ratios and a working party which will look specifically at enhancing our electronic care planning processes.

We look to reporting on the impact of our two new roles - Transition Nurse and Research Nurse and thank you for your ongoing support.

Helen Finlinson Director of Care East Anglia's Children's Hospices (EACH)

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### East Anglia's Children's Hospices (EACH) Care Quality Account 2024/25 Hertfordshire and West Essex ICB Feedback

Thank you for sharing the Quality Account for 2024–25, which has been reviewed by various members of the Hertfordshire and West Essex Integrated Care Board (HWE ICB). Feedback has been collated to support the preparation of the final draft.

The Quality Account is well-structured and clearly presents the organisation's strategic priorities and service delivery goals. The account demonstrates a strong commitment to hearing the voices of children and families, and to collaborative improvement. It provides assurance on progress made across a range of quality improvement priorities for 2024/25.

We would like to commend East Anglia's Children's Hospices (EACH) on a number of notable achievements:

- The integration of QR code posters and event-based engagement demonstrates a forwardthinking approach to gathering valuable insights from families.
- Workforce development initiatives, including the Nurse Apprenticeship and Associate pathways, reflect a strong commitment to long-term staff investment and professional growth.
- The establishment of the Wellbeing and Spiritual Care service, alongside the appointment of a Head of Service, is a significant development.
- The wide range of audits conducted, and the organisation's responsiveness to their findings, demonstrate a mature and effective clinical governance framework.
- EACH's coordination of the Managed Clinical Network (MCN) and point prevalence survey for the East of England region provides critical insights that drive service improvement.
- Engagement with pre-existing groups has yielded positive results, demonstrating an effective and responsive strategy.
- High compliance rates with annual mandatory training reflect EACH's dedication to quality and continuous staff development.
- The progress in capital expansion is highly encouraging, and continued updates on developments would be welcomed.
- The organisation's support for staff accessing a diverse range of external training opportunities is reflective of EACH's commitment to continuous professional development.

Looking ahead to 2025/26, the ICB supports EACH's quality priorities and welcomes the planned focus on strengthening the voice of the service user, developing a structured career pathway for care roles, creating a strategic plan for wellbeing, and advancing capacity and demand modelling to inform future staffing establishment and the allocation of wider care resources.

The following recommendations may provide added value by highlighting specific areas in greater detail:

 EACH is encouraged to provide more detail on how equitable access to services is ensured across diverse communities, including initiatives related to cultural competence and language support.

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Care System



- There is interest in understanding the outcomes for the 19% of referrals that did not meet the criteria, specifically where these individuals were signposted and any follow-up from ongoing work to track referral trends.
- It would be valuable to hear more about the impact of recent initiatives such as the introduction of a second care manager and the Clinical Education Team on reducing the number of complaints received at The Nook. Sharing any early outcomes or plans for further improvement would help highlight EACH's continued commitment to enhancing service quality and patient experience.
- We also note the commitment to increasing the voice of service users. Case studies from Hertfordshire, particularly those involving transitions to adult services, would be valuable additions, if available
- Greater clarity on infection prevention and control (IPC) audits, including their range, frequency, and alignment with the National Standards of Healthcare Cleanliness 2025, would be beneficial. Additionally, details on audit results, water safety measures, and any IPC incidents or outbreaks, along with lessons learned, would enhance understanding. Information on progress against the annual IPC programme and any IPC-related risks in the organisation's risk register would also be valuable.









Hertfordshire and West Essex Integrated Care System



### NHS Hertfordshire and West Essex Integrated Care Board (HWE ICB) response to the Quality Account of East Anglia's Children's Hospices for 2024/2025.

NHS Hertfordshire and West Essex Integrated Care Board (HWE ICB) welcomes the opportunity to provide this statement on the East Anglia's Children's Hospices (EACH) Quality Account for 2024/25. The ICB would like to thank EACH for preparing this Quality Account, developing future quality priorities, and recognising the importance of maintaining quality amid ongoing operational challenges. We recognise the dedication, commitment and resilience of staff, and we would like to thank them for this.

HWE ICB is responsible for the commissioning of health services from EACH. During the year the ICB has been working closely with EACH in gaining assurance on the quality of care provided to ensure it is safe, effective, and delivers a positive patient experience. In line with the NHS (Quality Accounts) Regulations 2011 and the Amended Regulations 2017, the information contained within the Quality Account has been reviewed and checked against data sources, where this is available, and confirm this to be accurate and fairly interpreted to the best of our knowledge.

When reviewing the progress against the 2024/25 priorities, the ICB notes clear and consistent progress and commends EACH's strong commitment to listening to children and families, as well as fostering collaborative improvement. The integration of QR code posters alongside event-based engagement exemplifies a forward-thinking approach to capturing valuable family insights. The establishment of the Wellbeing and Spiritual Care service marks a significant and positive development.

The wide array of audits conducted, coupled with the organisation's responsive actions to their findings, reflects a mature and effective clinical governance framework.

The ICB commends EACH for its continued focus on service users amid the recent organisational changes. The leadership appointments have strengthened governance pathways, assuring enhanced quality and safety of care. Workforce development initiatives, such as the Registered Nurse Degree Apprenticeship and Healthcare Support Worker to Nursing Associate pathways, evidence a strong investment in staff growth. Additionally, the organisation's support for staff participation in diverse external training opportunities underscores EACH's commitment to continuous professional development.

The ICB acknowledges EACH for their dedication in implementing the Patient Safety Incident Response Framework (PSIRF), strengthening how the NHS learns from patient safety incidents to enhance care and outcomes. We will continue our joint working with EACH and system partners as part of continued progression with PSIRF and the National Patient Safety Strategy and recognise that evidencing key principles such as compassionate engagement, proportionality, and system-wide approaches will be vital to ensure its ongoing success.

Looking forward to 2025/26, the ICB supports EACH quality priorities and we look forward to a continued collaborative working relationship, including through building on existing successes and collectively taking forward needed improvements to deliver high-quality services for this year and thereafter.

apos

David Wallace Deputy Director of Nursing & Quality Hertfordshire and West Essex ICB

Dr Jane Halpin, Chief Executive

Rt. Hon. Paul Burstow, Chair



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East Anglia's Children's Hospices (EACH) Quality Account 2024-25



EACH Response:

Thank you for taking the time to respond to the report, we very much welcome your feedback and we will look to include the recommendations as we continue to evolve our reporting methods and processes moving forwards.

Helen Finlinson Director of Care East Anglia's Children's Hospices (EACH)

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Feedback received from NHS Norfolk and Waveney Integrated Care Board (ICB)

- P28 the 2<sup>nd</sup> paragraph should say 'remaining' 25% not 'remainder'.
- P30 paragraph 2 not sure if 'disproportional' is a word and difficult to make sense of the sentence. Should possibly say that they are 'appropriately advised' rather than 'encouraged' on it too.
- Concerned regarding the number of complaints received i.e. 17 complaints (10 at the Nook) regarding standards of care. We appreciate that the presence of a day-to-day Care Manager may explain an increase in recorded complaints, but it would be helpful if a bit more information could be shared, and outcomes of the complaints.
- Excellent figures for mandatory training well done!
- A demonstrably superior report to last year's report.

#### EACH Response:

Thank you for taking the time to respond to the report, we very much welcome your constructive feedback. It's reassuring to hear that you are pleased with the additional content and evolution of our Quality Account. Changes were made based on feedback received last year.

We have included the suggested amendments on pages 28 and 30.

We acknowledge that the Quality Account only includes a brief summary of the complaints received. Additional information regarding outcomes from the complaints are now included in our quarterly integrated performance / quality and safety reports. We can ensure that these are shared with you in advance of our regular meetings.

Helen Finlinson Director of Care East Anglia's Children's Hospices (EACH)

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