



East Anglia's
Children's Hospices

East Anglia's Children's Hospices (EACH)

Quality Account

2023-24

INVESTORS IN PEOPLE®
We invest in people Standard



Milton • The Nook • The Treehouse

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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 2023-24.

We are extremely proud all three of our hospices remain assessed as 'Outstanding' by the Care Quality Commission and equally proud we supported 532 life-threatened children and young people during the year, together with their mums, dads, carers, grandparents and siblings.

We delivered a total of 92,142 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, including an annual programme of Family Forums.

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.

We continue to ensure we have the most up to date and effective equipment, including communication and mobility aids, and where we're enhancing services, ensuring we meet families' expectation by providing more care and specialist and wellbeing support that achieves our improvement priorities.

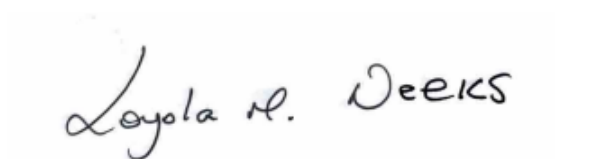
We have been extremely successful in our workforce recruitment and development, including piloting a second care manager model at The Nook and successfully recruiting three new senior physiotherapists to lead physical therapy and hydrotherapy services.

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 support nurse associate and nurse apprenticeship programmes. Our first nurse associate students start in September 2024 and nurse apprenticeships begin in October. To support these new pathways of training we will be introducing a new student support practitioner role to focus on students in training, and to develop a preceptorship programme to support newly qualified staff.

A reintroduction of our transition lead role will lead to a review and strategic development of transition services. We aim to enhance our offer at Milton and The Nook to the same level as the well-established partnership in place at the Treehouse.

Our leadership team has been strengthened with the appointment of a new Head of Nursing and Therapies and a new Head of Performance and Delivery. A new Head of Wellbeing and Spiritual Care is planned to start imminently. All this has created strong career development opportunities within our existing workforce.

As ever, we are indebted to our generous communities, supportive organisations, staff, 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.



Loyola Weeks
EACH Trustee
Chair – Clinical Governance Committee



Pól Toner RN
EACH Director of Care

11th June 2024

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 life-threatening 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 (supportive and end of life care) - A Framework for Clinical Practice in Perinatal Medicine (2010) provides more information.

The BCYP is less than 18 years of age.

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.

EACH Wellbeing Service

The EACH Wellbeing Service is based at all three sites and consists of art and music therapists, counsellors, family support practitioners, play specialists, child and family practitioners, spiritual care lead/practitioners and groups and events co-ordinators. Each of the teams are led by a Locality Wellbeing Lead who form part of the Locality Leadership Team. They maintain a caseload and deliver management and clinical supervision. The Leads also facilitate weekly Systemic Case Consultation Meetings with the Wellbeing Team and twice monthly Multidisciplinary Reflective Peer Group Supervision and individual/group consultations with the Care Team.

The service utilises a diverse range of delivery methods for psychological interventions tailored to each situation following in-depth assessment and agreement with the family/person. To ensure quality, efficacy and equity of service, the Wellbeing Leads meet regularly to discuss how to develop and take forward psychological interventions, while managing fluctuating demand and making best use of the staffing resources we have across all three sites. The Wellbeing Leads contribute to strategy discussions and provide data to inform service development and delivery.

- End of Life and Post-Death Care

The Wellbeing team prioritises end of life and post-death care. Due to the nature of rapid end-of-life situations and the need for a psychological underpinning for families and care teams during times of heightened stress, the wellbeing staff are required to respond rapidly and flexibly. This is undertaken with a high standard of skill and compassion and brings unpredictability to caseload 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 wider care team. 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 events are offered to all family members and some specifically for non-bereaved families, e.g. a Christmas Panto and Dream Night at Colchester Zoo. Some events are specifically for bereaved families, e.g. Memory Day and Remembering with Love and Baby Loss Awareness Week.

In the last twelve months, there have been a total of 219 events delivered across the tri-site with a footfall/attendance of 3,362 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.

- Volunteers

The Wellbeing Service is supported by a growing team of volunteers who engage in the preparation and delivery of groups and events, supporting families to utilise our hospice facilities on a self-care basis 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 robustly audits and evaluates all interventions and sessions it provides. The outcomes overwhelmingly show it is able to offer an appropriate level of intervention for an appropriate amount of time. 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 seen some development over the year and a document has been produced that outlines the current service with recommendations for future consideration.

- **External Agencies**

The team continues to work closely with external agencies where appropriate, including adult mental health, CAMHS, schools, perinatal health, GPs and NHS psychology and wellbeing services, and the RAaFT service. There is regular attendance at external meetings, and this has strengthened links with regional and specialist hospitals, mental health teams and wellbeing colleagues.

- **Wellbeing Student Placements**

The team continues to receive requests to offer student placements and their experience and reputation supports this. During this period, the service has supported students, including a Genetic Counsellor, Counsellors and Chaplains while offering a very rich experience to students. The goal is to develop further capacity to offer more placements.

- **Wellbeing Review**

The Director of Care, on behalf of the Care Directorate, the Executive Programme Board and the Wellbeing staff, commissioned a review of the current Wellbeing Service. Staff supported the programme board proposal for the review process, which ran from September 2023 to December 2023.

Recommendations were made and the Operational Leadership Team are working with a designated steering group to analyse the findings, review the recommendations and consider priorities.

As a direct result of this review, the board has approved the development of a new role, Head of Wellbeing and Spiritual Care; this has now been recruited to and will start imminently. This postholder will lead the development of a wellbeing strategy to enhance the work our team currently does.

[Please refer to Appendix 2 for Wellbeing Service data.](#)

Clinical Education

- **Essential Role Specific Training**

Long-Term Ventilation (LTV) training continues for nurses, care assistants and senior care assistants. 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.

- **Competencies**

Our clinical educators continue to assess the competencies of all staff, ensuring they meet the standards of EACH to deliver safe care. There has been an introduction of shift leader competencies to ensure staff are fully trained in the additional requirements.

- **Positive Behaviour**

Two members of staff are now fully trained to deliver positive behaviour support training to care staff. This training is due to commence in Summer 2024, with 'champions' being identified to support in practice and form a quality group to recognise and discuss incidents, and to then implement learning from these.

- **Incident Training**

When trends in incidents are identified by the Operational Leadership Team, the clinical educators will deliver bespoke training to the care team. This year, the clinical education team delivered face-to-face training for the recording of incidents. As a direct result, we have seen an improvement in the quality of the incident forms submitted.

- **Care Development**

We have a care development programme to meet the needs of the care certificate. This runs three times a year and is taught through a range of theory and practical sessions across all sites. We are also currently exploring putting our nurses on this programme.

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

We have almost completed phase two of our Palliative & End of Life Care Education & Training Programme, and have had animated sessions receiving excellent feedback.

- **Nurse Associate Training**

We advertised internally for expressions of interest for the nurse associate programme, and offered two places at the University of East Anglia for the September 2024 intake and three for February 2025. We plan to maintain nurse associate enrolment.

- **Nursing Apprenticeship**

We have appointed a senior care assistant from The Nook to commence the nursing apprenticeship programme with Anglia Ruskin University in October 2024. We are hopeful that by 2026 we will have our first 'home-grown' children's nurse. We plan to maintain nurse apprenticeship enrolment.

- **Preceptorship**

We have had significant interest from our nursing students and from our professionals' open evenings, with enquiries about EACH offering a preceptorship programme to newly qualified nurses. Development is now underway and we aim to take on preceptees in September 2024. The preceptees could potentially backfill the senior carers who are going to study their nurse associate and nursing apprenticeship programme.

- **Rotational Programme**

EACH is working closely with Norfolk and Norwich University Hospital and Norfolk Community Health & Care NHS Trust to pilot a nurse rotation programme. Following successful completion of the preceptorship programme, EACH nurses would then spend six months on an acute children's ward and six months working with the community team before returning to EACH. We would in turn host a nurse from the children's ward and the community. This would provide newly qualified nurses with a well-rounded skill set with relevant experiential learning.

- **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 2nd and 3rd 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. Feedback from the initial cohort has been very positive.

The introduction of the student support practitioner will help to develop support for external student placements as well as EACH staff taking on the student role in nursing associate and nursing apprenticeship programmes.

- **Transition**

EACH has been successful in a bid to develop transition services within Norfolk and Waveney. Following the success of our transition study day held in 2023, a small working group was formed to look at The Zest model used by St Elizabeth's Hospice. EACH looks to develop joint drop-in sessions for transition families and young people working collaboratively with Norfolk Hospice, Pricilla Bacon Lodge and St Elizabeth's Hospice Zest. Sessions are planned to start in July 2024.

- External professional training provided by EACH

Norfolk and Waveney Integrated Care Board

We successfully recruited a Palliative and End of Life Clinical Educator and delivered phase one of the education programme, which evaluated well. We were successful in our bid to continue to deliver phase one and commence phase two. This has also included four bespoke training days covering neonatal palliative care.

West Essex

We have a successful bid for funding in West Essex to deliver phase one of our Palliative & End of Life Education & Training Programme. EACH is working closely with the Chief Nurse from The Princess Alexandra Hospital to initiate the working group.

Cambridge and Peterborough

We have been successful in securing funding again to deliver the Palliative & End of Life Education and Training Programme within Cambridge and Peterborough. This is in the early stages, coordinating key stakeholders and developing a working group to take this forward.

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

As our clinical education strategy develops, we will be looking at the career pathway and progression of staff to provide further developmental within clinical education to progress personal career opportunities. To enable us to develop and invest further in our own staff, we will need to source outside specialist training in specific areas such as non-medical prescribing and Advanced Clinical Practice (ACP), and ensure budget planning for external training is forecasted to meet the required need.

We continue to explore the use of Simulation (SIMs) training following successful inclusion during our Palliative and End of Life Training and Education 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 2024-25

Our priorities are informed by the existing four-year strategic plan (Stepping Forward), 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 Executive Team.

As a result, we have a four-year strategy which will ensure 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 by 2025-26. This strategy does not call on our existing reserves which remain intact to insure against unforeseen events or circumstances.

Over the life of the strategy, our ambition is to expand our service by increasing our capacity and broadening our offer. Over the last ten years, we have developed 'Outstanding' services and facilities across East Anglia. The strategic challenge is to optimise these assets while investing in the people and skills necessary to realise their full potential.

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 four-year strategy, our key priorities for improvement in 2024-25 are:

Table 1 – Priorities for improvement	Desired outcome
<p>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.</p>	<ul style="list-style-type: none"> • Feedback opportunities available enabling a consistent and regular reporting route for evidencing how family and service user feedback informs service delivery with measurable outcomes.
<p>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.</p>	<ul style="list-style-type: none"> • An education strategy regarding growing our own staff, e.g. Nurse Apprenticeship, Nurse Associate and Nurse Preceptorship Programmes. • A strategic plan for volunteer services within care.
<p>Priority 3: Wellbeing Development of a strategic plan for wellbeing.</p>	<ul style="list-style-type: none"> • Successful recruitment into the EACH Head of Wellbeing and Spiritual Care post. • Implementation of the Wellbeing Strategic Plan.
<p>Priority 4: Sustainable resource Develop capacity and demand modelling to influence future staffing establishment and wider care resources.</p>	<ul style="list-style-type: none"> • Robust staffing model which is responsive to the fluctuating demand of personalised approach to palliative care. • LTV educational programme for regional professionals to access. • Fully integrated transition role with network 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. • Sustainable statutory income.

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

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:
www.each.org.uk/about-us/stepping-forward/

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 2023-24 Quality Account will be endorsed by the Board at the meeting in June 2024.

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 2023-24, 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 telephone 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. Some face-to-face events have also been held, including band practice, coffee mornings, curry nights, Christmas shows, summer garden parties and the winter wonderland walk.

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 line on-call service provided by the EACH SMNS.

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.

Achievements in 2023 included:

- The teams within the MCN have contributed to the development and implementation of standardised approaches and documentation, including the symptom management plan template and discharge checklist template.
- 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 in March 2023. The survey provides information about the number of children with palliative care needs at a given time. This was the second year

of data collection and captured information on a significantly greater amount of BCYP than the first (pilot) year (2022). This has become established as an annual process to produce valuable and reliable data.

- The MCN delivered the Children's Palliative Care Conference in May 2023. The event was attended by 85 delegates from across the region who provided excellent feedback on the presentations given by national and international speakers and contributions from parents of children with life-limiting conditions.

There are currently 264 members of the MCN who are registered to directly receive updates and information.

A total of 67 people attended an MCN Nursing Practice Day provided by EACH Clinical Nurse Specialists.

Journal Club continues to run on a monthly basis. There have been nine sessions, each led by a different team from across the region. Articles discussed covered topics including nursing in critical care, the Medical Examiner system, and artificial hydration at the end of life.

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

During 2023-24, no national clinical audits and no national confidential enquiries included NHS services provided by EACH.

The national clinical audits and national confidential enquiries that EACH was eligible to participate in during 2023-24 are as follows: NONE.

As a result of this, EACH participated in zero (0%) national clinical audits and zero (0%) confidential enquiries of the national clinical audits or national confidential enquiries.

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 2023-24.

1. Clinical Alerts
2. Infection Prevention and Control: Hand Hygiene
3. Infection Prevention and Control: Environmental
4. Safeguarding – Parental Responsibility – Documentation
5. Resuscitation – Episodes of Resuscitation and Status and Documentation
6. Moving and Handling – Risk Assessments
7. Consent – Documentation
8. PEWS
9. Care Records – Care Plans
10. Transporting 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 overseen by the Audit, Risk & Compliance Committee which is made up of our Clinical Governance Trustees and Senior Managers.

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 two times per year. 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 patients, visitors, staff 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.

ICB Quality visits

We welcome visits from our ICB partners to review and evaluate EACH processes. Recommendations from these visits have informed our care objectives. EACH values a collaborative relationship and wishes to strengthen these across the East Anglia region.

2.3.4 Participation in clinical research

The number of patients receiving NHS services provided or subcontracted by EACH in 2023-24, who were directly recruited during that period to participate in research approved by a Research Ethics Committee (the EACH Clinical Governance Committee), was 19 for CPOS and five patients' data was reviewed for CoPPAR Midazolam study.

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

- Children's Palliative Care Outcome Scale (CPOS) Study. Kings College, London and Cicely Saunders Institute of Palliative Care.
- A Prospective Observational Study by York University as part of the CoPPAR network on Midazolam prescribing in paediatric care.

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 has rated each of the three hospices as Outstanding. There were no CQC inspections during this reporting period. The registered managers maintain regular proactive dialogue with the CQC as required.

External Professionals and Organisations – examples of feedback

"Right from our first phone call your team have been so responsive and committed to helping this family get closer to home. I'm blown away that you are also supporting another family in the community today!

Thank you so, so much." *Consultant in Children's Palliative Medicine.*

"I just wanted to thank the SMT for the support they gave to me and the ward staff over the weekend." *Paediatric Oncology Nurse Specialist.*

“Thanks so much for your support over the last few weeks. It has been invaluable and on behalf of the team I just wanted to say how grateful we all were for your support.” *Clinical Director.*

“You have all been amazing and I am so grateful to have worked with such a wonderful team.” *General Practitioner.*

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 2023-24, 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 & Protection Toolkit Attainment Levels

EACH attained the standards required in the NHS Data Security and Protection Toolkit for 2023-24.

2.3.8 Clinical coding error rate

EACH was not subject to the Payment by Results Clinical Coding Audit during 2023-24 by the Audit Commission.

Part 3. Review of quality performance

Over the last 12 months, EACH cared for 532 children and young people.

The snapshot number of families with lead children/young people using services at 31st March 2024 was 418. In addition, there were 200 bereaved families, including 302 individual family members receiving targeted level interventions from an EACH therapist.

The total number of referrals in 2023-24 was 152.

There was a total of 47 deaths during the year.

Hospice site breakdown of referrals, deaths and caseload

	Milton	The Nook	The Treehouse	TOTAL
Total new referrals for the year	44	63	45	152
Total deaths for the year	19	15	13	47
Total lead children for the year	189	179	164	532
Total number of family members who had active referrals for wellbeing support or mental health interventions	157	261	164	582

Whilst demand continues to be high, the service works flexibly to meet the 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.

3.1 Review of priorities for improvement 2023-24

The priorities identified in the last Quality Account, 2022-23, are recorded below followed by a response which reports progress on these.

Table 2 Priorities for improvement	Desired outcome
<p>Priority 1: Ensure BCYP and family outcomes and experiences are gathered from the seven areas of the care model (including end of life care).</p> <p>Ensure learning from outcomes is integrated into planned service developments.</p>	<p>Evidence that feedback has been collected from service users and is used to influence service delivery.</p>
<p>RESPONSE:</p> <ul style="list-style-type: none"> Data set collected from families from outcomes and impact surveys from April 23 - March 24. Wellbeing groups and events – 95% of services users stated they achieved what they hoped to by attending the groups. With the majority reporting 'enjoyment' as the greatest gain from attending. Family reported outcomes for nursing care – we can see an increase in surveys being completed, however not all surveys were then completed on discharge to capture full 	

Table 2 Priorities for improvement	Desired outcome
impact measure. The vast majority of families stating that they had achieved what they hoped to gain from their BCYP's short break care.	
<p>Priority 2: Contribute to the review of decision-making processes relevant to individual roles, including meetings and their Terms of Reference, and action recommendations as required.</p>	<ul style="list-style-type: none"> • All meetings have terms of reference. • Staff give positive feedback about decision-making processes. • Decision-making framework is agreed.
<p>RESPONSE: Full review of all meetings undertaken to ensure most effective use of time. Amalgamation of some meetings has been possible, and the Operational Leadership Team is working to devolve responsibility to local teams to expedite decision-making processes.</p>	
<p>Priority 3: Ensure contribution to PEOLC Phase 2 training programme through participation and/or teaching; and evaluate how the sessions have influenced practice.</p>	<p>Evidence discussion that participation and/or teaching, and feedback has been collected and impact on practice reflected on with line manager.</p>
<p>RESPONSE: We have nearly completed phase two of our Palliative & End of Life Education & Training Programme. Course content for phase three is still to be determined and will take into account feedback received from staff during phases one and two. Development of clinical education strategy ongoing, including the review of the infrastructure of the clinical education team.</p>	

3.2 Additional quality indicators we have chosen to measure

In the absence of a national minimum data set and nationally agreed indicators of quality for children's palliative care, EACH monitors:

- complaints and concerns (service user experience, clinical effectiveness)
- commendations (service user experience, clinical effectiveness)
- incidents and accidents (patient safety, service user experience, clinical effectiveness)
- staff knowledge, skills and practice development including scholarly activity, involvement in clinical practice development activities and compliance with professional education and training requirements (patient safety, clinical effectiveness)
- 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.

Please see table below.

Number of CYP/family member-related concerns/complaints

Service	2023-24
Milton	5
The Nook	17
Symptom Management	0
The Treehouse	3
Total	25

The Operational Leadership Team acknowledges the fact The Nook has received the majority of complaints this year. It is known that families accessing continuing care services from The Nook are appropriately encouraged to share their concerns and reflections in a timely fashion. These conversations are supported during regular reviews between the families, EACH and the ICB.

The Nook Locality Leadership Team is implementing continuous improvement interventions including a 12-month pilot of having two care managers to increase additional management and leadership support to the care floor, alongside an increase in support from the Clinical Education Team.

Summary of themes of CYP/family member-related concerns and complaints in 2023-24
The complaints have been themed as follows:

Theme	2023-24
Communication	7
Service user information	0
Amount of care and support	2
Standards of care	14
Transition process	0
Other	2
Total	25

Theme	Milton	The Nook	The Treehouse	2023-24
Communication	1	5	1	7
Service user information	0	0	0	0
Amount of care and support	1	1	0	2
Standards of care	3	9	2	14
Transition process	0	0	0	0
Other	0	2	0	2
Total	5	17	3	25

Examples of changes to practice from the complaints include:

- Behavioural care plans have been further developed to ensure structured and effective communication. There has been development and inclusion of internal positive behaviour training to the core mandatory programme for care staff.
- Prior to publication of stories and articles regarding family stories, the Marketing and Communications team has a robust comms process with Locality Leadership Teams to ascertain if there are any underlying issues that may mean it is inappropriate to publish.
- All future care episodes involving third party providers of care will be led and overseen/supervised by EACH nursing staff (even where this may appear to result in disproportionate staffing levels).

All concerns and complaints were resolved locally with oversight from the EACH Care Operational Leadership Team. Twenty complaints and concerns were resolved and upheld and five were resolved and not upheld.

3.2b Commendations

EACH received over 111 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.

"I just wanted to say thanks so much for sorting out the sleep study at EACH last weekend, it made the process so much less anxiety driven than if it had been on HDU at Addenbrookes. We all really appreciate the effort you went to do this on our behalf and X has hardly mentioned it, so it obviously didn't impact X stay at all." *Family Member.*

Help at Home Service

"X is our number one priority, and all our time is dedicated to them. As parents we both juggle our work commitments with caring for X, but it means other things, like gardening, get forgotten about. We simply don't have time and it would look like a jungle out there, were it not for our volunteer, XX. Something like weeding and pruning, for instance, is the last thing on our minds but, thanks to her, our garden looks brilliant. She helps so much and is a brilliant, lovely, compassionate and empathetic lady. I don't think there are many people like her in life." *Family Member.*

"X's a great listener. She's never intrusive and we've got a lot of shared interests. She's full of ideas for our garden and makes such a massive difference. She's a lovely person to have in our lives and we both feel strongly about her and what she brings to our family. I can't stress enough how thankful we are." *Family Member.*

Wellbeing groups and activities

"Thank you so much for posting our photo. We have received it in the post today. It's a lovely keepsake of memories of Dream Night at Colchester Zoo and we cannot thank you and X enough for opening this opportunity for us. We captured some incredible memories because of what you and your team do for vulnerable families. Thank you to everyone at EACH and all the organisers and staff who contributed to the evening!" *Family Member.*

"Just a message to say thank you for the sessions we had, I really appreciate the time and effort. I am the calmest I have ever been for 32 years and finally feel like I understand me." *Family Member.*

"I just wanted to thank you and everybody else involved for the lovely day that we have had today at the beach. Over the last few weeks, we have been able to be part of the open gardens and today the beach day, X has enjoyed all events so much and it has enabled her to get more familiar and gaining confidence loads with everybody. X has loved it too as he always does when

he visits The Treehouse and how lovely was it to see him in the sea for me its lovely to see them both having so much fun and great getting to know other parents and their children. So, thank you for everything and please could you thank everybody else you all do an amazing job.” *Family Member.*

“We had a truly wonderful time at the EACH Christmas event. We all attended, and we all enjoyed it. X loved meeting Santa (which made me cry as X had had such a horrid morning) and loved all the crafts and dancing to the carol singers. X loved the food. So, it ticked all the boxes. It really made our day. Thank you so much.” *Family Member.*

“I hope you all had a fantastic Christmas with your family. We did have a lovely Christmas and we were perfectly set up for it with your fantastic “winter warmers”. I have completed the feedback for WW. We all had an absolutely fantastic time and were gutted we couldn’t attend last year. The lights, lively music, full sensory experience with Father Christmas and plenty of delicious food made for a fantastic evening. It was brilliant! You definitely surpassed yourselves. Please could you also pass on our thanks to the team who helped put together the event as I’m sure it involved a huge amount of planning efforts. Thank you very much as well for organising the Clip n Climb evening just before Christmas. All the C&C staff and EACH team were so welcoming, and we all had a fantastic time. Thanks very much for letting us bring ... and my mum so that it was a more family inclusive evening. We really do appreciate these wonderful events that you organise for EACH families as it just gives some normality and some much needed escapism!” *Family Member.*

Short Break Care

“Just wanted to write you a note to say a massive thank you for taking such good care of us today. I can honestly say that as a family we thoroughly enjoyed every moment of the day, and we couldn’t be more grateful to you all for arranging this for us.” *Family Member.*

Memory Day

“I wanted to email to thank the entire team at EACH for putting on the most wonderful Memory Day. The activities were so thoughtful and engaging... both for us as parents and for our 2 little girls. Walking into the service in the marquee was quite a moment- it was stunning. The flowers, the candles, the music, the readings.... so atmospheric and so beautiful. The food was incredible... such thoughtful links to the butterfly theme, and it's really nice to feel the care and nurture that comes with a lovely plate of afternoon tea and a cuppa. I cannot begin to explain how much it means to us that people who never met our X, went to such an effort to celebrate him, and of course the other children taken too soon. The Treehouse is such a special place for us. It's where we started to heal, it's where we bared such raw and painful emotions, it's where people truly understand our pain, and it is also where we can feel those emotions again without judgement, or worrying about how our sadness might affect someone, or having to wear the mask we have to put on in so many other places in life. We are so very grateful to have such a special place to bring our girls, to help them understand such a massive part of our family's' story, and to

remember the brother they never got to meet. Thank you from the bottom of our hearts for such a special day.” *Bereaved Family Member.*

“Myself, X and our families have attended the Memory days and other special events on and off for the last 9 years since losing our dear XX. We will always be indebted to the care, love and support shown to us by everyone at EACH. However, time has moved forward and with two young boys keeping us very busy these days, we have decided the time now feels right to take a step forward on our own and allow the precious time and resources provided by yourselves to help another family in desperate need for your support and guidance. Please pass our sincere heartfelt thanks and love to all of the staff who have helped us as a family over the years, you will never truly understand just how much you have helped us over the years in the deep darkness of despair and grief, What you do on a daily basis is admirable.” *Family Member.*

We currently have a total of [74 different family stories and 10 service-based films on our website](#). 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 categorised by type and severity using a red (catastrophic), amber (major), yellow (moderate) and green (minor) scoring system.

Notifiable incidents are those which 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.

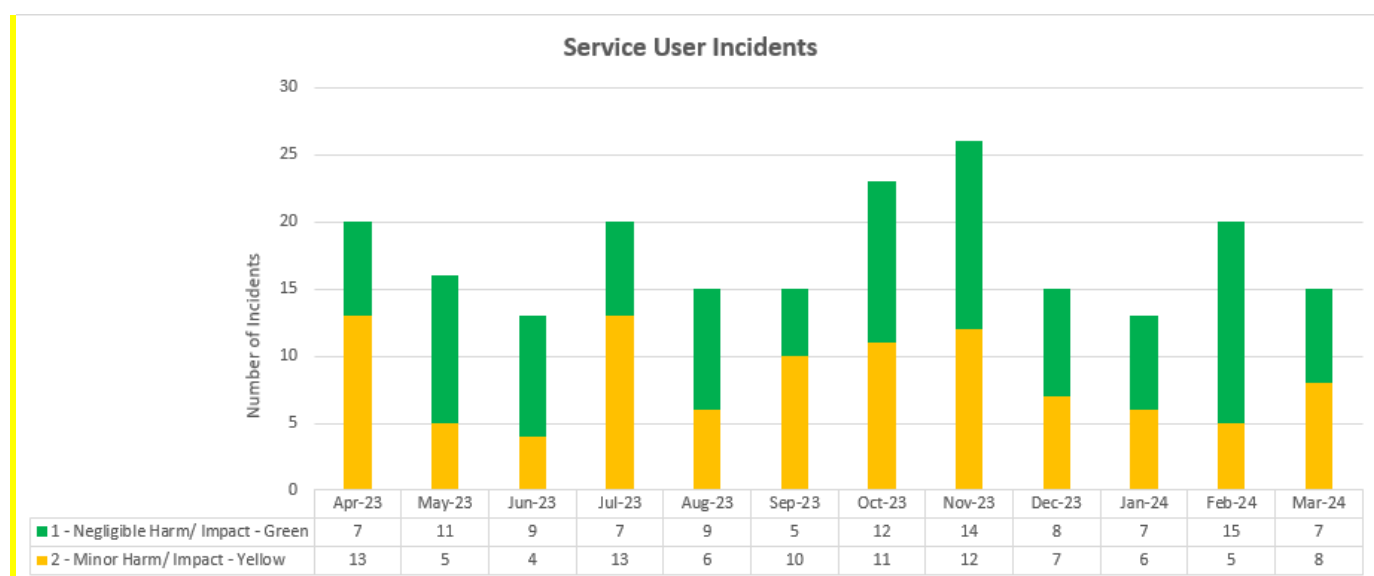
The trends, number, outcomes, changes to practice and learning from incidents are monitored by the Senior Leadership Team for Care and the Clinical Governance Committee of the Board every quarter.

Service User Incidents - 1 April 2023 – 31 March 2024

In 2023-24, there were a total of 211 green and yellow rated incidents completed (including 64 relating to medicines).

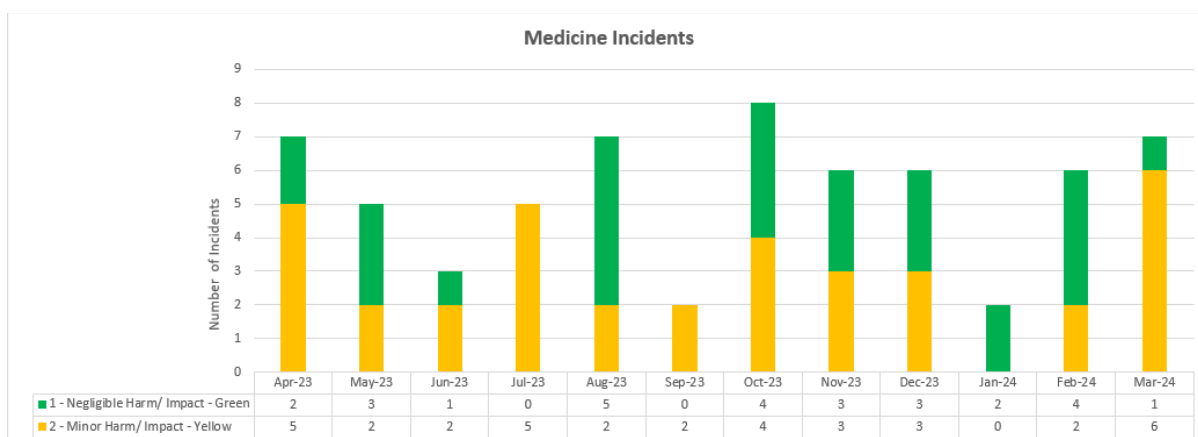
There were zero (0) resuscitation or notifiable controlled drugs incidents and zero (0) notifiable clinical incidents and zero (0) red-rated incidents during 2023-24.

There was one amber coded (moderate harm) incident, which related to a staff injury. A care assistant received a back and shoulder injury which caused them to have two weeks off work. Injury reported to RIDDOR and Health & Safety Executive.



30% of these incidents (n=64) 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 three safeguarding incidents reported over the last 12 months.

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 2023-24 are as follows:

Topic	Compliance to 31 st March 2024	Compliance allowing for staff who have booked to attend training after 1 st April 2024
Data Security Awareness	100%	100%
Fire Safety (Advanced)	98%	100%
Food Hygiene Catering (e-learning)	97%	97%
Infection Prevention & Control	89%	98%
Medical Gas Safety	99%	100%
Moving & Handling (Clinical)	96%	99%
Resuscitation & Anaphylaxis	88%	100%
Safeguarding Adults – Level 2 (e-learning)	100%	100%
Safeguarding Children (Clinical)	86%	99%

The management team continues to review mandatory training compliance as a KPI to identify as early as possible if there are issues with completion of training.

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.

These are led by a Service Manager or senior clinician. 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

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.

It was agreed that as a pilot, the Medicines Management, Infection Control and Clinical Practice Groups would hold workshops twice a year to incorporate development time for the group and in-depth discussions, such as review of trends in reported incidents. The Medicines Management and Clinical Practice groups held workshops during Quarter 4.

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.

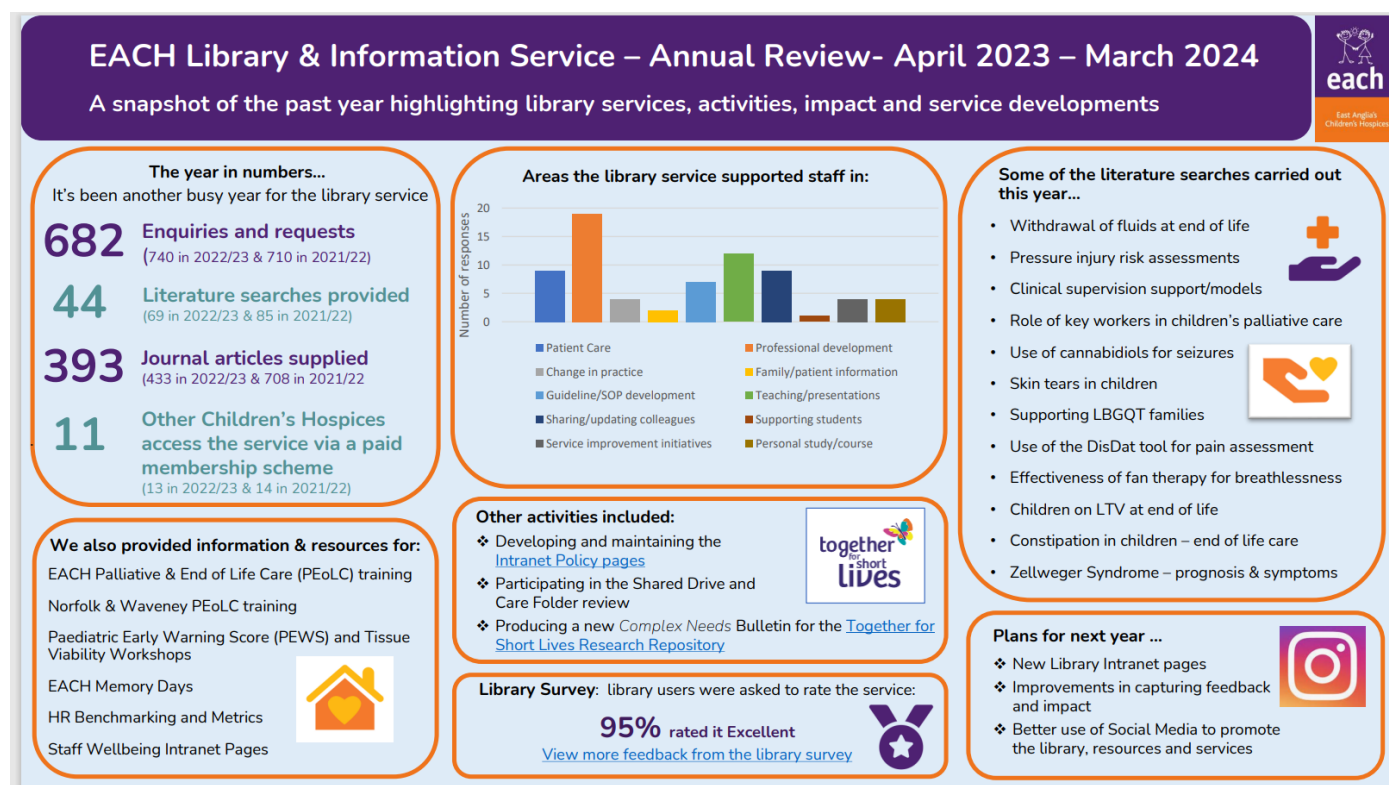
East of England Palliative & End of Life Care Strategic Clinical Network. The EACH Medical Director is CYP PEOLC Lead and attends this in their capacity as chair of the MCN.

The Director of Care also takes part in the ICB-based and regional end-of-life boards as well as liaison with the other hospice directors of care regionally, and the four other tri-site children's hospices nationally.

3.2d (iv) Scholarly Activity

Care teams are currently preparing work for international and national conferences for 2024-25.

3.2d (v) Library & Information Service



3.2d (vi) External Study and Conferences

EACH supported 26 applications from care staff to undertake study days, extended study learning and conferences during the reporting period, both in person and virtual. Examples included:

- National Library Conference and Aseptic Non-Touch Technique Conference
- Bereavement Training Winston's Wish
- East of England Play in Palliative Care Workshop
- Education in Palliative Care and End of Life
- Symptoms in Paediatric Palliative Care
- Children's Assessment Knowledge & Examination Skills
- Coaching, Counselling & Training Certificate in Therapeutic Coaching
- Family Support Practitioner Training
- Exploring Varieties of Grief
- PGC Certificate Clinical Education
- Advanced Care Practitioner (MSC).

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 is currently being paused from Summer 2024 due to new members joining the team within Milton SMNS and requiring induction. We will look to restart this in 2025.

We provided a placement to a physiotherapy student from Anglian Ruskin University (ARU) for six weeks at The Treehouse and provided an online workshop, 'The role of the Occupational Therapist at EACH' for Occupational Therapy students at ARU.

Student requests are reviewed by the Physical Therapies team monthly, and consideration is being given as to how placements can be offered across sites moving forwards. There has also been communication with Suffolk University around offering a joint teaching session around hydrotherapy at The Treehouse.

3.2d (viii) Commissioned Training

A total of 67 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.

3.2d (ix) Human Resources Indicators

Sickness absence

During the report period, the average sickness absence rate for care staff was 4.42% which is below comparable benchmarks in the NHS. The average sickness absence rate for the whole of EACH for the period 1st April 23 – 31st Mar 24 was 3.68%. Care staff absence was slightly higher than the EACH benchmark as a result of a covid peak in November/December 2023.

The latest NHS data (published April 2024) put the rate for Community Provider Trusts at 5.65% and 5.41% for Community Provider Trusts in the East of England. This is the closest type of provider to benchmark against.

Source: [NHS Sickness Absence Rates, December 2023 - 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, 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 section on the website, surveys, requests in the family newsletter, and via Facebook and Twitter.

We are working with our Marketing and Communications team to 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 trialled at The Treehouse during 2023-24 and is detailed in section 3.3b below.

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

All families engage in an holistic assessment following their referral to EACH, to identify their personal goals for involvement 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.

One of our Family Support Practitioners carries out a review of the assessment, goals and priorities within a timeframe agreed with the family. In between times, an EACH family co-ordinator, who is a member of the team, keeps in touch to check the family is happy with the type and level of support they are receiving. It is also providing opportunity to learn if needs and goals have changed.

Children, young people and families can be involved in research projects we participate in.

3.3b Family Forums

Family Forums provide the opportunity for families to share their feedback and views, and are hosted by the Service Managers at each locality.

They are held every two to three months on a day and time that best suits the families who attend. Attendance is primarily face to face at The Treehouse and The Nook, however, the option of attending via Teams is also available. Families at Milton have been attending 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. It's also a very useful opportunity to hear about the experiences and issues for families wider than EACH, to feedback into the wider health and social care sector.

Attendance from families at the forums has been low, so to access a higher number of participants the locality leadership teams have attended the start of some pre-existing planned groups and events to speak to family members directly. In effect, taking the family forums to a larger audience. Recent attendance at parent/carer events evenings provided some excellent feedback.

Some of the things the forums have discussed this year have included:

- Updates on the building work at Milton, the proposed building work at The Treehouse, and the new playground at The Nook.
- Staffing updates within the care sector.
- A representative from Marketing and Communications attends the forums to gain feedback on the EACH website, organisational comms and general family information.
- Contributing their feedback and suggestions around the delivery of groups and events.
- Hydrotherapy plans across all three localities.
- Families were asked for initial feedback for our new 'I wish you knew...' awareness project, which helped us shape the campaign.
- Milton families were updated on the proposed name change and gave their thoughts on the shortlist.
- The idea of tagging forums onto existing events was met positively by regular attendees and the first 'tagged-on' forum at The Treehouse in March saw three new people attend.
- Following an ICB visit and report, families at The Treehouse were asked for their thoughts on feedback cards, online feedback forms, an online form on a screen positioned privately in hospice reception areas and posters with QR codes around the hospice.
- We are currently working with the hospice leadership and marketing and communications teams on ideas for additional family feedback using a variety of online and digital solutions.

3.4 Involving EACH staff

EACH operates a variety of ways to communicate with, engage and gather feedback from our employees. Feedback is sought from staff via daily care planning meetings, weekly locality multi-professional meetings, quarterly locality team meetings and regular 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, Infection Control Matters and Safeguarding Matters newsletters. Each of the three hospices produce a locality weekly newsletter for staff. EACH-wide communications meetings are also held annually with the opportunity to meet with the Management Executive (MEX) members, covering key topics and the opportunity to ask questions.

Investors in People

EACH achieved Investors in People (IIP) Silver accreditation in October 2021. The IIP assessment process will be reviewed during 2024-25 by the Management Executive Team.

The EACH staff intranet and Viva Engage platform

In 2023-24, we successfully developed and delivered a brand-new staff intranet available to all EACH employees. This covers all departments within the organisation and shares key operational news, information, documents and processes, including policies and standard operating procedures. Other content includes individual hospice weekly staff newsletters and links to useful websites and resources, such as pension information, the EACH Strategic Plan and the Employee Handbook.

We also use Microsoft's employee social media/engagement platform, Viva Engage (formerly Yammer), 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 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 and catch-up meetings with employees to discuss performance and wellbeing, and formally record performance discussions annually via our appraisal process.

3.5 Statements from Lead Commissioners and Healthwatch

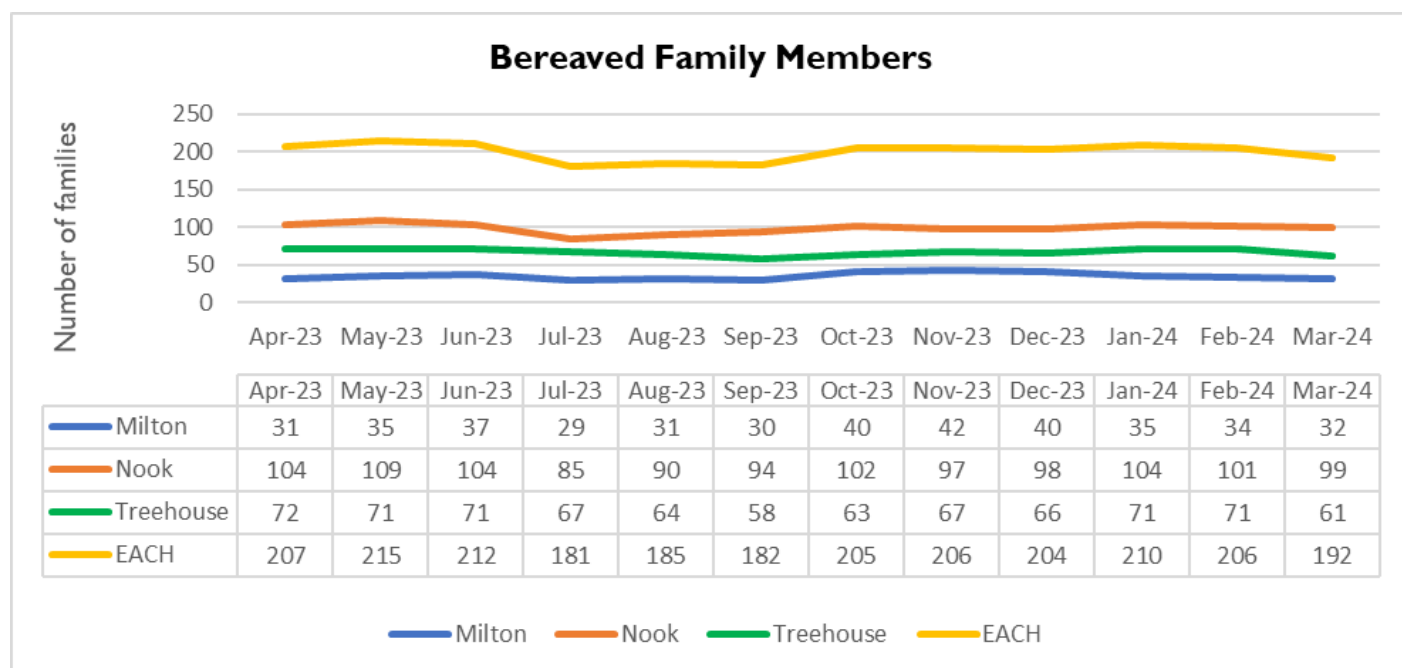
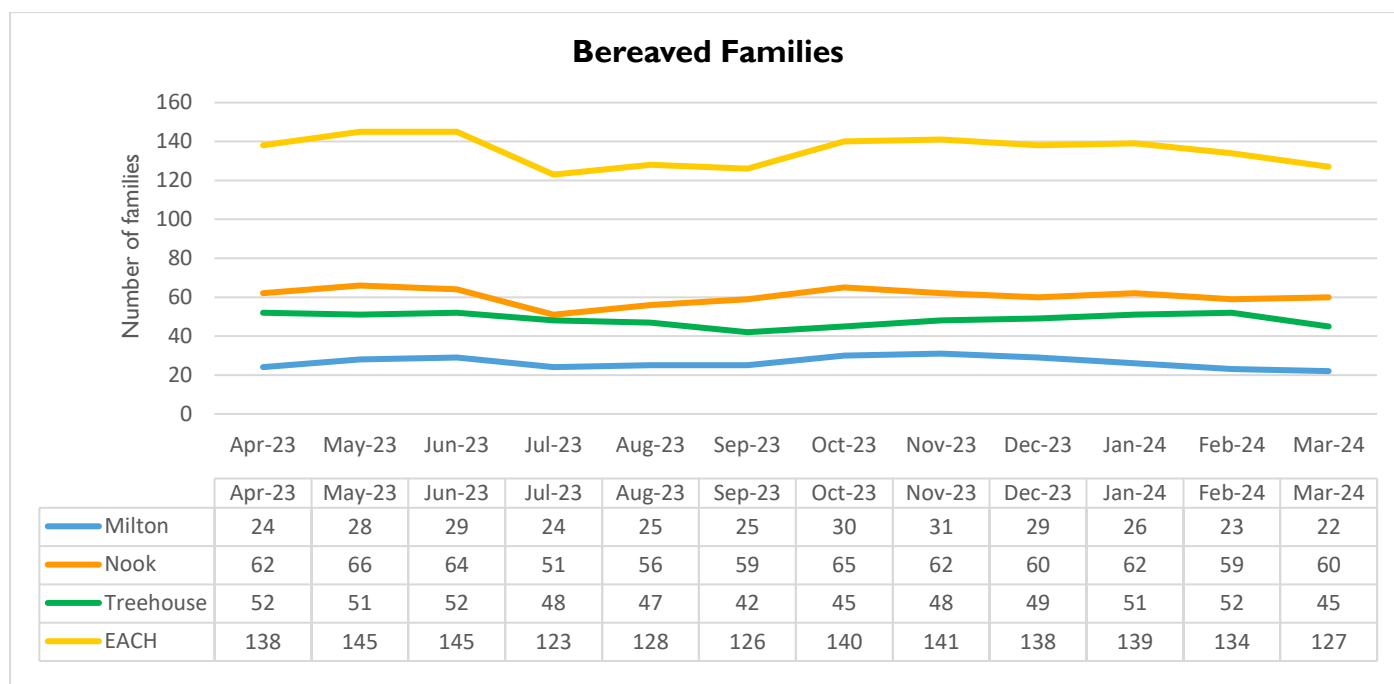
EACH provides services across Norfolk, Suffolk, Cambridgeshire and Essex. This Quality Account has been sent to Integrated Care Boards and Healthwatch in the above counties to provide the opportunity for comment and a statement. The list of those who were sent a copy of the Account is tabled in Appendix 1. Responses received are included in Appendix 3 along with the EACH responses.

Appendix 1: Commissioners and Healthwatch contact details

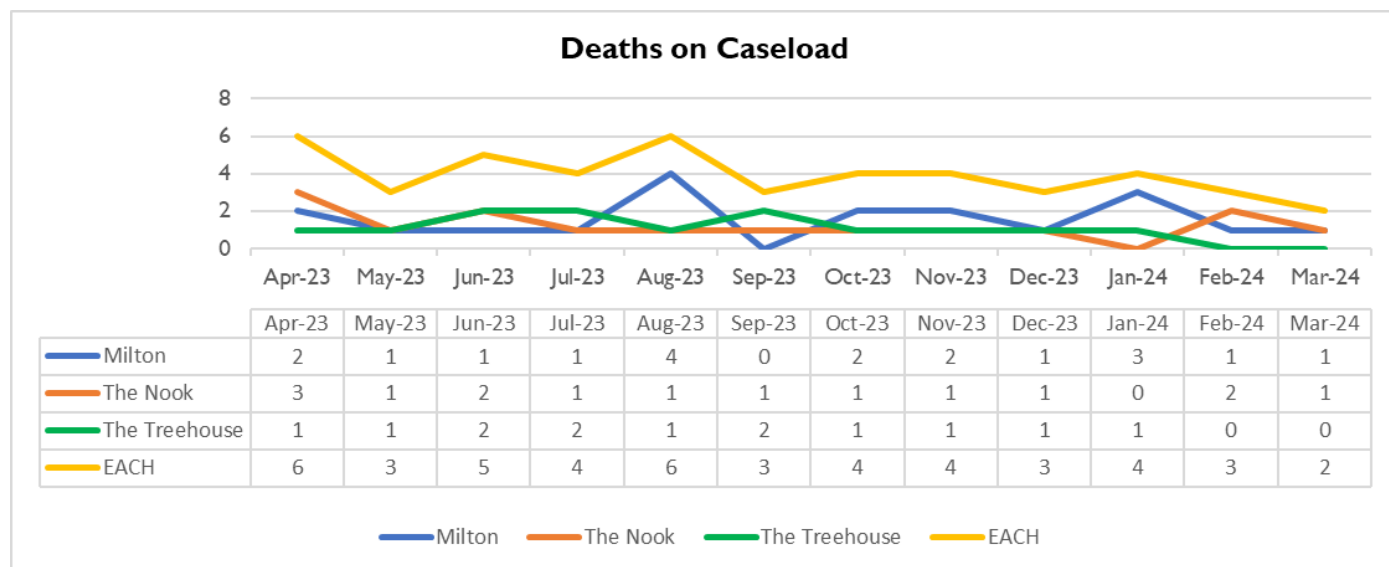
ICB area	Integrated Care Board (ICB)	ICB Contact	Healthwatch contact
Norfolk & Waveney	Norfolk & Waveney ICB	Clare.angell@nhs.net Rebecca.godfrey1@nhs.net	Alex.stewart@healthwatchnorfolk.co.uk Chief Executive Tel: 0808 168 9669
Suffolk & North East Essex (SNEE)	SNEE ICB	anthea.christodoulides@snee.nhs.uk Jaime Hawkins Transformation Lead jaime.hawkins@snee.nhs.uk	Andy Yacoub Chief Executive Info@healthwatchesuffolk.co.uk Tel: 01449 703949
Cambridgeshire & Peterborough	Cambridgeshire & Peterborough ICB	Delyth.richardson@nhs.net Karlene.allen2@nhs.net cpicb.qualitydirector@nhs.net	Jess Slater Chief Executive jess.slater@healthwatchcambspboro.co.uk Tel: 0330 355 1285
Mid Essex	Mid Essex and South Essex ICB	Susanna Vaughan susanna.vaughan@nhs.net) mseicb-me.quality@nhs.net	Samantha Glover Chief Executive enquiries@healthwatchessex.org.uk Kate Mahoney kate.Mahoney@healthwatchessex.org.uk
West Essex	Herts and West Essex ICB	Rosalind.French@nhs.net	Tel: 0300 500 1895

Appendix 2: Wellbeing service data

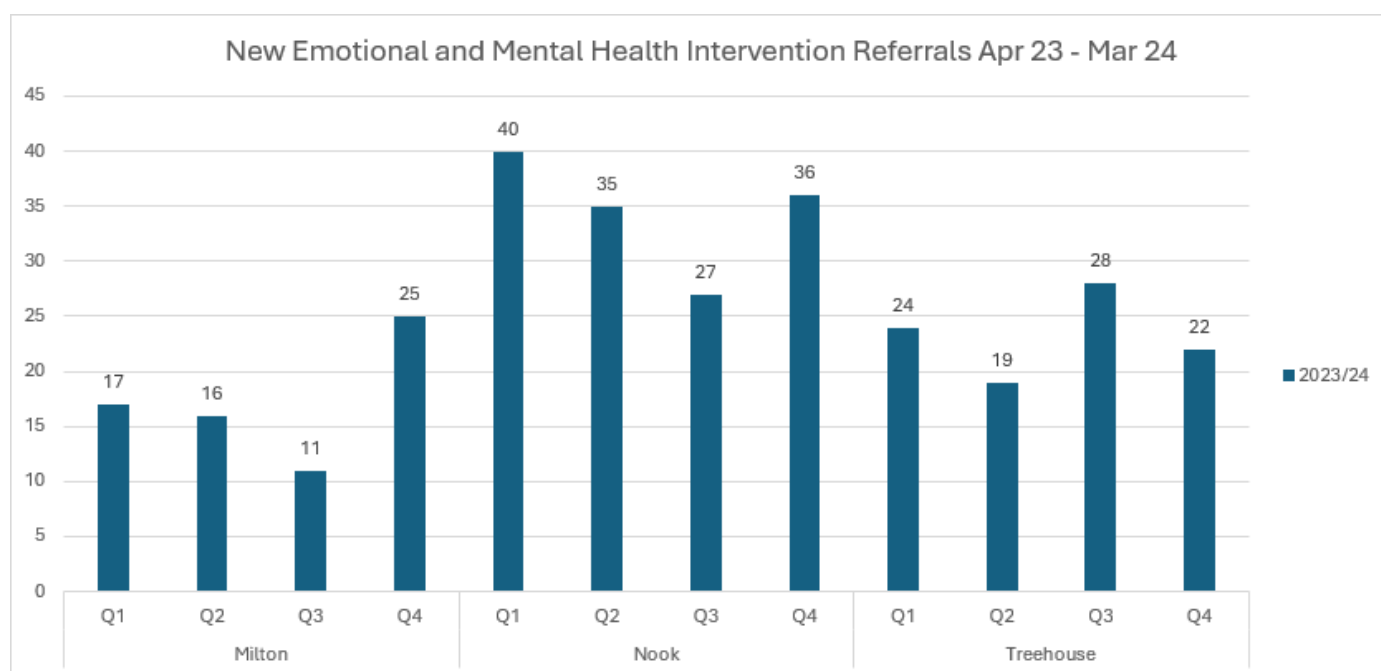
Number of bereaved families and family members on caseload for Q1 to Q4 (taken from the Q4 performance report):



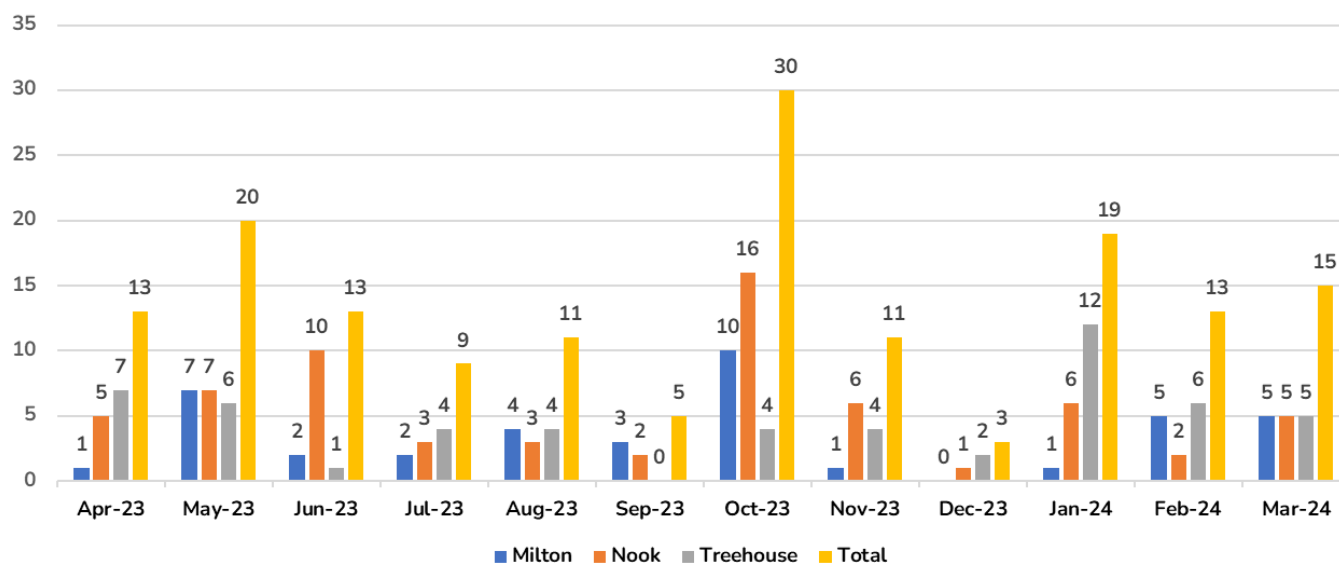
Deaths on caseload for Q1 to Q4 (taken from the Q4 performance report):



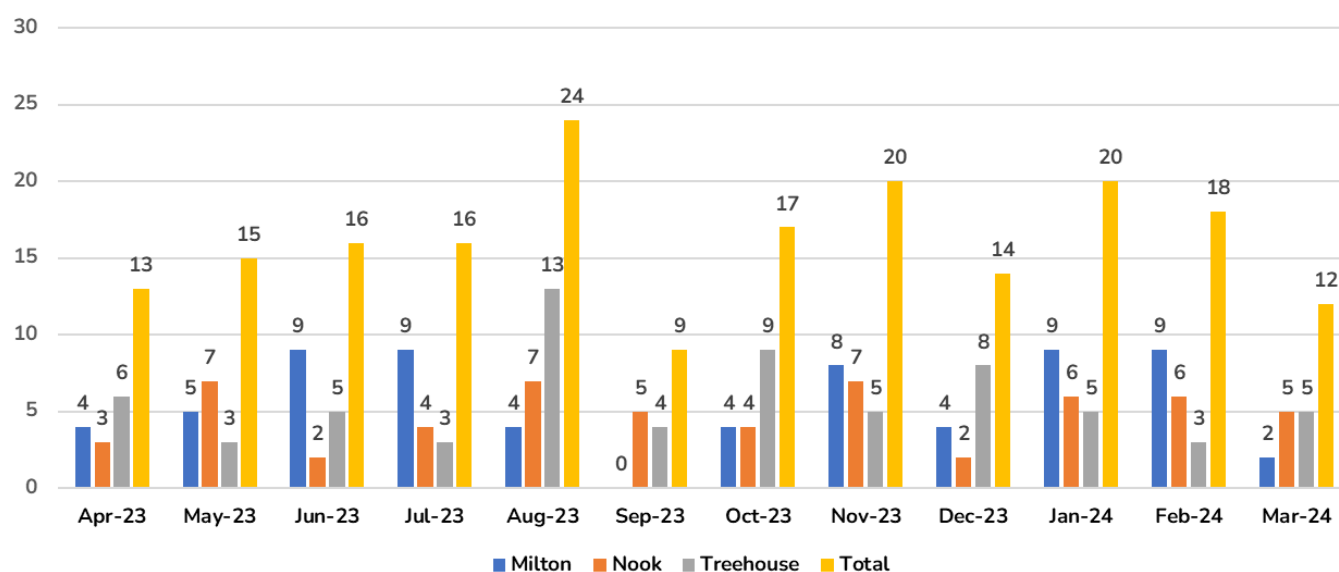
New Emotional and Mental Health Interventions for Q1 to Q4



Wellbeing Assessments Apr 23 - Mar 24



Holistic Assessments Apr 23 - Mar 24



Appendix 3 Commissioners and Healthwatch Responses

The following responses were received.



Healthwatch Cambridgeshire and Peterborough

East Anglia Children's Hospices Quality Account Statement 2023/24

Patient Involvement

Healthwatch fully supports East Anglia's Children's Hospices (EACH) in their commitment to prioritising the voice of service users. EACH's dedication to developing a comprehensive family feedback mechanism ensures that the perspectives of children, young people, and their families are not only heard but actively shape service delivery and development. This approach aligns perfectly with Healthwatch's mission to champion the views of patients and service users.

EACH's approach to patient involvement is reflecting a deep understanding of the value that service users bring to the organisation. By embedding the principle of 'you said, we did' into their service user engagement strategy, EACH ensures that feedback leads to tangible changes. This principle is evident in their diverse feedback mechanisms, including Family Forums, surveys, and direct communication channels such as newsletters and social media. These methods provide families with multiple avenues to share their experiences and suggestions, making the feedback process both accessible and comprehensive.

The inclusion of former service users as trustees is a significant step, ensuring that those who have firsthand experience with EACH services have a direct influence on organisational decisions. This level of involvement at the governance level demonstrates EACH's commitment to valuing the insights and expertise of its service users.

Healthwatch is particularly impressed by EACH's approach to Family Forums. Held every two to three months, these forums provide a platform for families to discuss what is working well, voice their concerns, and offer feedback on proposed developments. The flexibility of attending these forums either face-to-face or via Teams ensures

broad accessibility. The proactive strategy of integrating these forums into existing events has successfully increased participation, allowing for a wider range of voices to be heard.

EACH's holistic assessment process, conducted upon referral, further exemplifies their commitment to personalised care. By identifying individual goals and needs, and regularly reviewing these with a Family Support Practitioner, EACH ensures that care is tailored to what matters most to each family. Continuous communication through family coordinators helps maintain this personalised approach, adapting to any changes in needs and priorities.

EACH Response:

Many thanks for the considered and complimentary statement on our quality account, we always strive to ensure the children and family's needs remain at the centre and focus of all that we do.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)



Response to EACH Quality Account 2023-2024 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 92,142 hours of care and wellbeing support.
- We are pleased to see the commitment from EACH to engage with the community through a wide-ranging offering of activities at the 219 events delivered throughout the year. It is also great to see EACH engage within Family Forums and with staff to help shape their service.
- It is extremely positive that EACH received over 111 recorded commendations throughout the year, and although 25 complaints were received the examples of changes to practice due to the complaints is refreshing to see. It would be great to see the number of complaints reduce next year.
- It is positive to see that within the improvement priorities for 2024/25 there is a commitment to create a career pathway for care roles and a strategic plan for volunteer services within care.
- We are pleased to see the EACH board of trustees completing hospice quality visits with recommendations and feedback given to the locality leadership teams. It is also pleasing to see that ICB Quality visits occurred during 2023/24 to evaluate processes which help to inform care objectives.

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

17.06.2024

EACH Response:

Many thanks for the considered and complimentary statement on our quality account, we always strive to ensure the children and family's needs remain at the centre and focus of all that we do.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

Response to EACH (East Anglia's Children's Hospices)

Quality Account 2023-2024

Background

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, the carer, and other members of the public to access services should be at the heart of transforming the NHS and social care as it faces current challenges.

We recognise that Quality Accounts are an important way for local NHS services and other health care and social care providers to report on their performance by measuring patient safety, the effectiveness of treatments that patients receive, and patients' experiences of care. They present a useful opportunity for Healthwatch Essex 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 (East Anglia Children's Hospices). In this case, we have received no additional feedback about services provided by the hospices, and so offer only the following comments on the EACH (East Anglia Children's Hospices) Quality Account.

What is encouraging to see?

- We are reassured to see that all three EACH hospices remain assessed as 'Outstanding' by the Care Quality Commission.
- It is encouraging the EACH promote multidisciplinary reflection and supervision amongst different teams, with Wellbeing Leads regularly hosting Multidisciplinary Reflective Peer Group Supervision. Our own research highlights the value of cross-disciplinary communication when providing complex care.
- The expansive range of services provided by EACH is again encouraging, particularly the range of available therapies, including specialist play, physiotherapy, and hydrotherapy.
- We commend the holistic support that EACH provide families, as evidenced by their comprehensive events programme (219 events in the past year). The programme incorporates siblings' events, tailored events for non-bereaved families, and bereavement support.

- The introduction of a Head of Wellbeing and Spiritual Care is promising. We are keen to see how the individual in this role enhances EACH's wellbeing strategy to support the diversity of faiths and spiritual beliefs present across the region.
- Recent developments to EACHs' student placement programme are highly encouraging, particularly due to the range of roles being supported. The introduction of student support practitioner to ensure that students are adequately supported is also promising.
- Continued improvement to the Point Prevalence data capture is clearly a valuable development in terms of its propensity to capture reliable data across the system.
- The continued provision of a monthly Journal Club, incorporating different teams, appears to be a valuable way of engaging staff in developments in both research and clinical practice.
- It is encouraging that there are currently no waiting lists for services.

Is there anything that can be improved?

- Whilst all concerns and complaints made by children, young people and their family members were resolved locally, there is still scope for EACH to consider why the highest percentage of complaints focused on standards of care.
- We appreciate EACH's recognition that the majority of complaints were received at The Nook because families accessing its services are suitably encouraged to raise their concerns. However, if this open and timely reflection is promoted so readily at The Nook, then it would be valuable to see comparable approaches enacted by staff within EACH's other services.
- Whilst we recognise the complexity of care that EACH staff administer, the fact that 30% of service user incidents related to medicines management suggests a need for improvement in this area.
- We commend EACH on their desire to capture feedback from children, young people, and their families. We would be interested to see further evidence of the diverse and creative ways in which EACH capture the views of children and young people who are non-verbal, or who do not wish to share the views verbally. Based on our own experience running young people's forums, we also recognise that children and young people value sharing their experiences of services with each other to feedback and co-produce improvements.

Listening to the voices and lived experience of patients, service users, carers, and the wider community is a vital component of providing good quality care. By working hard to evidence that lived experience we hope we can continue to support the encouraging work of EACH.

Dr Kate Mahoney

Research Manager, Healthwatch Essex

19th June 2024

EACH Response:

Many thanks for your considered feedback and suggestions for improvement, all areas where we continue to evolve, learn and improve. We pride ourselves on being a learning organisation with a focus on continuous quality improvement.

We thank you for your offer to support us with improving the patients and families voice and would welcome the opportunity to discuss this further with you.

Christie Beecroft will be in contact to set up some time.

We also received feedback from your colleague Scott Tatum and we are grateful for both.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

Healthwatch Norfolk

Review of 2023/24 Quality Account EACH

Healthwatch Norfolk (HWN) welcomes the opportunity to review the draft East Anglia's Children's Hospices (EACH) Quality Account for 2023/2024 and to comment on the quality of the services commissioned locally to meet the needs of residents in the Norfolk area.

Name of provider	Comments
Readability	
Is there an executive summary/CEO statement?	Yes
Is the document well laid out, easy to read?	Yes
Is there a glossary?	No
Is the document available in different formats? e.g. electronic, hard copy, Braille, other languages	Unknown, only a written version seen.
Are priorities for the past year clearly identified?	Yes
Have the priorities been achieved?	Yes
Are the priorities for the forthcoming year clearly identified?	Yes
Are the following areas included	
Patient safety?	Yes
Clinical quality and effectiveness?	Yes
Patient experience including the family & friends test?	Yes

Incident reporting & never events?	Yes
Complaints?	Yes
Workforce?	Yes
Audits including participation in national audits?	Yes
Data quality?	Yes
Feedback from CQC?	Yes. All three sites are rated "Outstanding", no CQC visits in this reporting year.
New services?	Yes
CQUIN?	?
PLACE results?	?
18 week target (where applicable)?	N/A
IG Toolkit compliance?	?

Any other comments/observations:

This was a detailed, comprehensive and high quality account reflecting the work of a very well regarded organisation. No specific patient/family feedback has been sent to HWN. We would welcome the opportunity to discuss further involvement.

Good points to highlight are:

- a clear and forward-looking strategy with the child/family at the centre of everything you do.
- note the importance of developing Wellbeing support to both children/families and your own staff.
- impressive clinical education, especially:
 - rotational programme for NQNs involving NNUH and NCH&C.
 - development of nurse apprenticeship and nursing associate training.

-transition services.

-a clear Clinical Education Strategy.

-development of a research nurse role and transition role.

-participation in audits, communicating learning and changes to practice.

-learning from complaints/comments/compliments and putting changes into place.

-importance of communication with staff and families. Note the development of Family Forums with access either in-person or remotely. Numerous other forms of feedback mechanism. Note that two trustees have been users of your service.

-strong evidence of staff involvement with maintaining and developing clinical standards.

-involvement with the wider clinical systems across East Anglia, providing specialist input at all levels.

Concerns:

None.

Questions:

1. Note the high uptake of “mandatory training”. Is this of high quality and where appropriate face to face rather than on-line?

2. What is the level and availability of medical support to your nursing teams?

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. We would appreciate the opportunity to meet with the appropriate Quality Lead at regular intervals.

Alex Stewart

Chief Executive Officer

June 2024

EACH Response:

Many thanks for your considered and positive feedback and we of course would love to meet with you to discuss our work and Christie Beecroft will be in contact to set that up.

In relation to your questions, yes, we feel our mandatory training and clinical education is of high quality with more and more being face to face and clinical education being focused on the care

floor working alongside our staff. We have a growing clinical education team and work both internally with our teams and externally with the wider system including Norfolk.

As you know we are an advanced skilled Nurse lead service, we also have medical support Via our Medical Director and the managed clinical network, which our medical Director chairs. We also have a supportive GP practice contract for each one of our hospice locations.

Look forward to meeting with you soon.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

Feedback Statement EACH Quality Account – 2023-24

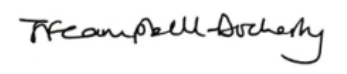
Thank you very much for sending us your Quality Account for 2023-24. Our thoughts are below:

1. We note the progress made with the 2023 -24 priorities.
2. We note the appointments to new positions within EACH and are particularly pleased to see the plan to reintroduce a transition lead role to enhance the offer at the Nook. This supports the work we are doing across Norfolk and Waveney for young people approaching transition age. We are also pleased that there is a plan to develop care assistants in terms of the nursing associate and nursing apprenticeship programme and the new student support practitioner role alongside this. It is good to see there is positive behaviour support training being delivered to the care team with champions being able to support in practice.
3. We note the plan for preceptorship programme but feel that backfilling of senior carer posts with the newly qualified nurses does not necessarily develop their knowledge and skills effectively.
4. We are pleased to continue to work with EACH on the Norfolk and Waveney Education Programme and note the positive work taking place across clinical education within the organisation. The ICB has particularly enjoyed working with the clinical education lead who always demonstrates expertise and passion.
5. It is notable that there is no mention of the significant change within the Senior Leadership Team at EACH.
6. We note the ambitions for care over the next four years and the priorities for improvement in 2024-25. We look forward to seeing the positive impact of these areas.
7. Within the key priorities section, there is no priority related to the improvement of quality and safety for the lead child which is unexpected.
8. In the audits and evaluation section, no reference is made to clinical audits having taken place to ensure the quality and safety for babies, children and young people. On page 18 the audits are listed but it would be helpful to see key findings and what changes have taken place as a result of them.
9. The report references Quality Visits by both Trustees and external partners. It would be helpful to know how many visits were carried out and what the key findings were.
10. The data regarding the number of referrals to the service is useful, however it would be helpful to have the data from the previous year to understand any trends.
11. We note 15 deaths at the Nook. A further breakdown of place of death would be informative. It is not clear from the data provided whether EACH was able to respond to every end-of-life care request for children in Norfolk and Waveney.

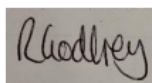
12. We value all services provided by EACH. There is a strong focus within the report on wellbeing and mental health and although it references hours of care and wellbeing, it would be helpful to have a breakdown of nursing, end of life care, short breaks, physical therapies, symptom management and wellbeing services and how these are being delivered.
13. The report refers to the Wellbeing Review, it would be helpful to understand what the key findings were and the plans for implementing them.
14. The report talks about open engagement with and feedback from families. It would be helpful to understand how many families you have engaged with at the Nook and the different methods families can use.
15. The report makes reference to a plan to continue to develop and grow the service over the next three years. It would be helpful to see the plan.
16. Within the Complaints and Concerns section, we note the majority of complaints are related to the Nook. We see this as a positive that families are encouraged to share their concerns. All services users should be encouraged to feedback whether their experience is positive or negative. It is good to see the implementation of continuous improvement interventions. A comparison with the previous year's figures would be helpful.
17. The Level 3 children's safeguarding training is at 86% which is below your target level of 90%. Some narrative could be included to explain why this is lower. It would also be informative to understand the compliance with level 2 children's safeguarding training for non-clinical staff.
18. The Human resources section does not include staff turnover figures. This would add context to the report.
19. Whilst the report contains a significant amount of interesting work, it is challenging to extract the quantitative and qualitative data needed to inform the ICB about areas of improvement and of those requiring further scrutiny. The length of the report and the difficulty in extrapolating information make it hard to fully appreciate the excellent work done by EACH.

We look forward to continuing our excellent relationship with the team at EACH and working together to improve palliative care for children, young people and their families in Norfolk and Waveney.

Once again, thank you for such a comprehensive annual report.



Jane Campbell-Docherty
Senior Clinical Lead for Complex Cases (CYP)
NHS Norfolk and Waveney ICB



Rebecca Godfrey
Programme Manager CYPM Team
NHS Norfolk and Waveney ICB

EACH Response:

Thank you for your commentary on our Quality Account.

I have responded to your points as below:

1. We note the progress made with the 2023-24 priorities.

Thank you.

2. We note the appointments to new positions within EACH and are particularly pleased to see the plan to reintroduce a transition lead role to enhance the offer at the Nook. This supports the work we are doing across Norfolk and Waveney for young people approaching transition age. We are also pleased that there is a plan to develop care assistants in terms of the nursing associate and nursing apprenticeship programme and the new student support practitioner role alongside this. It is good to see there is positive behaviour support training being delivered to the care team with champions being able to support in practice.

We will welcome the opportunity to work with you and the wider system further around transitions.

3. We note the plan for preceptorship programme but feel that backfilling of senior carer posts with the newly qualified nurses does not necessarily develop their knowledge and skills effectively.

The preceptorship program is initially focused on the nursing students who are known to us and with a significant training focus from the clinical education team. We are retaining our Care assistants on the workforce although due to their course commitments as associate students their time with us will be reduced. We are very proud that within a short period of time we have our Nurse Associate, Nurse Cadet and Preceptorship programs off the ground and that cycle will enable us to develop our workforce over time.

4. We are pleased to continue to work with EACH on the Norfolk and Waveney Education Programme and note the positive work taking place across clinical education within the organisation. The ICB has particularly enjoyed working with the clinical education lead who always demonstrates expertise and passion.

Our clinical education team are focused, driven, and enjoy working with your teams.

5. It is notable that there is no mention of the significant change within the Senior Leadership Team at EACH.

We had reported on this in last year's report, which had a focus of consolidation, but this year has been more focused on moving forward with new appointments and developments within our teams.

6. We note the ambitions for care over the next four years and the priorities for improvement in 2024-25. We look forward to seeing the positive impact of these areas.

We will share these with you at our quarterly meetings during the year.

7. Within the key priorities section, there is no priority related to the improvement of quality and safety for the lead child which is unexpected.

We feel that the key priorities will have a direct or indirect impact on quality and safety of the lead child with a focus on continuous quality improvement. With our 3-year plan there will be a particular focus on family voice to ensure continuous quality improvement.

8. In the audits and evaluation section, no reference is made to clinical audits having taken place to ensure the quality and safety for babies, children and young people. On page 18 the audits are listed but it would be helpful to see key findings and what changes have taken place as a result of them.

All audits are to ensure the quality and safety for BCYPs. Key findings and recommendations were excluded to reduce the length of the report. We are happy to share recommendations with you.

9. The report references Quality Visits by both Trustees and external partners. It would be helpful to know how many visits were carried out and what the key findings were.

Visits are carried out by the main ICBs and trustees and all findings are collated, acted upon and monitored via our program board and CGC, we would be happy to share with this you.

10. The data regarding the number of referrals to the service is useful, however it would be helpful to have the data from the previous year to understand any trends.

We are also happy to share these with you.

11. We note 15 deaths at the Nook. A further breakdown of place of death would be informative. It is not clear from the data provided whether EACH was able to respond to every end-of-life care request for children in Norfolk and Waveney.

We are happy to provide you with a breakdown. We were able to support all requests.

12. We value all services provided by EACH. There is a strong focus within the report on wellbeing and mental health and although it references hours of care and wellbeing, it would be helpful to have a breakdown of nursing, end of life care, short breaks, physical therapies, symptom management and wellbeing services and how these are being delivered.

We are currently working on developing better information systems to be able to give more details on all our services.

13. The report refers to the Wellbeing Review, it would be helpful to understand what the key findings were and the plans for implementing them.

The head of wellbeing and spiritual care has now been appointed and will take forward the priorities which is to review the component parts of the service and develop a wellbeing strategy.

14. The report talks about open engagement with and feedback from families. It would be helpful to understand how many families you have engaged with at the Nook and the different methods families can use.

Attendance at the Nook family forum has been low, with usually one or two parents in attendance despite an online attendance option. The Service Manager is now attending face to face groups and events delivered in the hospice building to meet with families directly in a more informal capacity. Families are also encouraged to feedback during the admission and discharge processes and during regular review meetings. We are filming content for our website to show the different feedback options which will include new initiatives such as the use of QR codes positioned on posters in the building, on postcards handed out at events and on the website. A whole strand of our new 3 year is dedicated to the CYP and family's voices and we will share this with as indicated above.

15. The report makes reference to a plan to continue to develop and grow the service over the next three years. It would be helpful to see the plan.

We are currently working on our plan for the next 3 years, which will go through Mex and then the board. We will be happy to share that with you once all finalised and agreed.

16. Within the Complaints and Concerns section, we note the majority of complaints are related to the Nook. We see this a positive that families are encouraged to share their concerns. All services users should be encouraged to feedback whether their experience is positive or negative. It is good to see the implementation of continuous improvement interventions. A comparison with the previous year's figures would be helpful.

We can share information over the last few years with you.

17. The Level 3 children's safeguarding training is at 86% which is below your target level of 90%. Some narrative could be included to explain why this is lower. It would also be informative to understand the compliance with level 2 children's safeguarding training for non-clinical staff.

We are happy to share this with you.

18. The Human resources section does not include staff turnover figures. This would add context to the report.

We will include this for next year's report and happy to share.

19. Whilst the report contains a significant amount of interesting work, it is challenging to extract the quantitative and qualitative data needed to inform the ICB about areas of improvement and of those requiring further scrutiny. The length of the report and the difficulty in extrapolating information make it hard to fully appreciate the excellent work done by EACH.

We have tried to shorten and enhance the details of the report within the current guidance and will continue to do so. We would welcome further discussions with you about how we further enhance this report.

We are very grateful for your ongoing support and relationship and look forward to meeting you again at our next quarterly meeting.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

East Anglia's Children's Hospice draft Quality Account 2023/24 – ICB feedback

Thank you for sharing the draft quality account for 2023-24, which various members of the Hertfordshire and West Essex Integrated Care Board (HWE ICB) have reviewed, and the feedback has been collated which we hope is helpful.

The quality account is very well detailed and laid out with clear strategic objectives. It outlines assurances related to progress made in a range of areas regarding clinical improvement priorities for 2023/24. The quality priorities are clearly defined and categorised according to the key questions from the new CQC Assessment Framework: Safe, Well-Led, Caring, Effective, and Responsive. Progress highlighted against priorities that were set out for 2023/24 and improvements are evidenced throughout the Account.

We would like to commend East Anglia's Children's Hospice on their achievements, including:

- Maintaining a CQC rating of 'Outstanding' for all three hospices and providing support to 532 life-threatened children and young people throughout the year.
- Delivering a total of 92,142 hours of care and wellbeing support for families, including those who are bereaved.
- Positive feedback from service users regarding the Wellbeing groups and events, with 95% of service users reporting that they achieved their goals by attending the groups.
- Utilising virtual technology to deliver various clinical, mental health, and wellbeing interventions to children, young people, and their families, including activities, groups, and events.
- Hosting East of England Children's Palliative Care Managed Clinical Network (MCN) to support for the delivery of 24/7 children's palliative care in collaboration with system partners across the East of England region.
- Active participation in local clinical audits, applying audit feedback for continuous learning and practice improvements, and sharing the findings with the wider team.
- Piloting the second care manager model at The Nook and with the successful recruitment of three new senior physiotherapists to lead physical therapy and hydrotherapy services.
- Strengthening the leadership team and creating career development opportunities within the existing workforce with the appointment of a new Head of Nursing and Therapies, a new Head of Performance and Delivery, and a new Head of Wellbeing and Spiritual Care.
- The completion of the Decision-making framework and receiving positive staff feedback regarding decision-making processes.

Looking forward to 2024/25, the ICB supports the hospice's quality priorities and is pleased to note the focus on making the necessary infrastructure and investment choices to ensure the workforce, training, equipment, technology, and environment are in place to deliver the best possible care to patients.



NHS Hertfordshire and West Essex Integrated Care Board (HWE ICB) response to the Quality Account of East Anglia's Children's Hospice (EACH) 2023/2024.

NHS Hertfordshire and West Essex Integrated Care Board (HWE ICB) welcomes the opportunity to provide this statement on the East Anglia's Children's Hospice (EACH) Quality Account for 2023/24. The ICB would like to thank EACH for preparing this Quality Account, developing future quality priorities, and acknowledging the importance of quality at a time when they continue to deliver services during ongoing challenging periods. We recognise the dedication, commitment and resilience of staff, and we would like to thank them for this.

HWE ICB regard EACH as an essential partner in care for children and young people with life limiting illness and their families. 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.

It is positive to see the achievements on the 2023/24 quality priorities, notably the 24/7 end of life care and symptom management service for the baby, child or young person which is supported by the East of England's Children's Palliative Care Managed Clinical Network (MCN). The ICB acknowledges the contributions made by the teams within the MCN towards the development and implementation of standardised approaches and documentation. The ICB commends the MCN in delivering the Children's Palliative Care Conference in May 2023 which received excellent feedback from delegates on the presentations given by national and international speakers along with the contributions from parents of children with life-limiting conditions at the event.

The ICB would like to recognise the hospice's efforts towards ensuring necessary infrastructure and investment choices are made to provide the workforce, training, equipment, technology, and environment to deliver the best possible care.

The ICB are pleased to see that priorities for 2024/25 are baby, child, young person and family focused, and will enable the hospice to achieve its strategic objective of capacity and capability expansion. Service development based on learnings from patient and family experiences and outcomes is welcomed.

During the year the ICB have been working closely with EACH gaining regular assurance on the quality and safety of provision to ensure a positive patient experience. Looking forward to 2024/25, the ICB supports EACH's quality priorities and progress of the 4-year strategic plan. The ICB 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.



Nadean Marsh
Assistant Director of Nursing & Quality

Dr Jane Halpin, Chief Executive

Rt. Hon. Paul Burstow, Chair



EACH Response:

Many thanks for your positive feedback on our quality account.

We look forward to continuing to work with your teams to benefit children and their families.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

EACH Annual Quality Account

Date: 28th June 2024

The Suffolk and North East Essex (SNEE) Integrated Care Board (ICB) confirm that EACH have consulted and invited comment regarding the Annual Quality Account for 2023/2024. This has been submitted within the agreed timeframe and SNEE ICB are satisfied that the Quality Account provides appropriate assurance of the service.

SNEE ICB have reviewed the Quality Account and the information contained within the Quality Account is reflective of both the challenges and achievements within the organisation over the previous twelve month period.

SNEE ICB look forward to working with clinicians and managers from the service and with local service users to continue to improve services to ensure quality, safety, clinical effectiveness and a good service user experience is delivered across the organisation.

This Quality Account demonstrates the commitment of EACH to provide a high quality service.



Lisa Nobes
Chief Nursing Officer
Suffolk & North East Essex Integrated Care Board

EACH Response:

Many thanks for your positive feedback on our quality account.

We look forward to continuing to work with your teams to benefit children and their families.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

Mid and South Essex Integrated Care Board response to East Anglia's Children's Hospices (EACH) Quality Report 2023/24

As a commissioner of East Anglia's Children's Hospices (EACH) services locally, Mid and South Essex Integrated Care Board (MSEICB) welcomes the opportunity to comment on this quality report.

MSEICB is commenting on a draft version of this quality account, however, to the best of its knowledge, the information contained within this report is accurate and is representative of the quality of services delivered. Any queries will have been fed back to East Anglia's Children's Hospices prior to publication for consideration of inclusion, along with any missing data in the final report.

MSEICB is pleased to note the progress that East Anglia's Children's Hospices has made against the priorities for improvement that it set out last year. MSEICB can see that steady progress is being made to achieve these priorities and measures are in place to continue to drive their achievement. MSEICB notes that East Anglia's Children's Hospices acknowledged that one site- The Nook has received the highest number of complaints this year and is pleased to note the quality improvement measures that have been implemented to address the concerns raised through the complaints process.

MSEICB acknowledge the priorities that East Anglia's Children's Hospices have set for 2024/25 as part of the four-year strategy:

- 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 influence over service delivery and development.
- 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.
- Wellbeing- Development of a strategic plan for wellbeing.
- Sustainable resource- Development capacity and demand modelling to influence future staffing and wider care resources.

Sincere thanks go to East Anglia's Children's Hospices and all its staff and volunteers for their hard work and dedication that has been evident over the last year. MSEICB would once again like to congratulate East Anglia's Children's Hospices for all that it has achieved given the backdrop of increasing pressure and uncertainty which continues to impact all healthcare services.

In conclusion, MSEICB considers the East Anglia's Children's Hospices Quality Report for 2023/24 as providing an accurate and balanced picture of the reporting period. MSEICB will continue to seek assurance on performance and delivery of care by regular monitoring through agreed contract processes.



Dr Giles Thorpe
Executive Chief Nursing Officer
Mid and South Essex Integrated Care Board

June 2024

EACH Response:

Many thanks for your positive feedback on our quality account and recognising the importance of the four key areas of improvement that we had developed in our ongoing care strategy.

We look forward to continuing to work with your teams to benefit children and their families.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)

Cambridgeshire & Peterborough Integrated Care Board

Stakeholder Feedback – East Anglia Children's Hospice (EACH) Quality Account 2023/24

Cambridgeshire and Peterborough Integrated Care Board (ICB) has reviewed the Quality Account produced by East Anglia Children's Hospice for 2023/24.

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.

This supporting statement is in relation to the care and services that the hospice provides for Children in Cambridgeshire & Peterborough.

The provider supported 532 life-threatened children and young people during the year. The hospice is impressive, with excellent care being provided for these very vulnerable and needy patients and families. All three hospices have 'Outstanding' ratings by the Care Quality Commission which is highly commended.

Whilst demand continues to be high, the service works flexibly to meet the demand. There are currently no waiting lists, however, 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. This is completely understandable; however, this should be a focus for the hospice in 2024/25.

The hospice is working towards a fully integrated transition role with network links to all adult service stakeholders. This development will be very welcome during 2024/25.

Service user feedback received by the organisation was excellent with commendations from families that are full of praise. The hospice has a positive approach to problem solving, e.g. family forums. The account highlights particular issues raised at one of the hospices with positive responses from the organisation to the themes within these complaints.

Recruitment of staff for hospice care is a national concern. Although there is no available data about staffing numbers within the account, this has not been a concern during the year. EACH have a staff development programme for existing and new recruits which is very well developed.

During 2024/25 there were three safeguarding incidents reported, however, there is no information on the themes, or the learning that was gained following these incidents to prevent recurrence. However, Safeguarding is a high priority, and the Safeguarding Matters newsletter is a positive way to update the workforce and keep Safeguarding high on the agenda.

EACH have engaged with all teams across the ICB during the year. Specifically joint work on preparing for the implementation of the Patient Safety Incident Response Framework (PSIRF). The ICB will continue to work with and support EACH through transition to PSIRF and beyond.

EACH contributed to two research projects in 2023-24, recruiting 19 patients to the Children's Palliative Care Outcome Scale (CPOS) Study and providing five sets of patient data reviewed as part of another study on Midazolam prescribing in paediatric care. This is almost twice the level of research recruitment than the previous year, which is a significant achievement. EACH is planning for a designated research nurse and development

opportunities to participate in research in 2024-25, which is a very positive and welcome development.

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 2023/24.



Carol Anderson
Chief Nursing Officer
Cambridgeshire & Peterborough ICB

EACH Response:

Many thanks for your feedback on our quality account.

We acknowledge your suggestions about additional content in our Quality Account which will be fully considered for next years report.

Pól Toner RN
Director of Care
East Anglia's Children's Hospices (EACH)