

EACH Quality Account

2022-2023

The EACH Vision

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

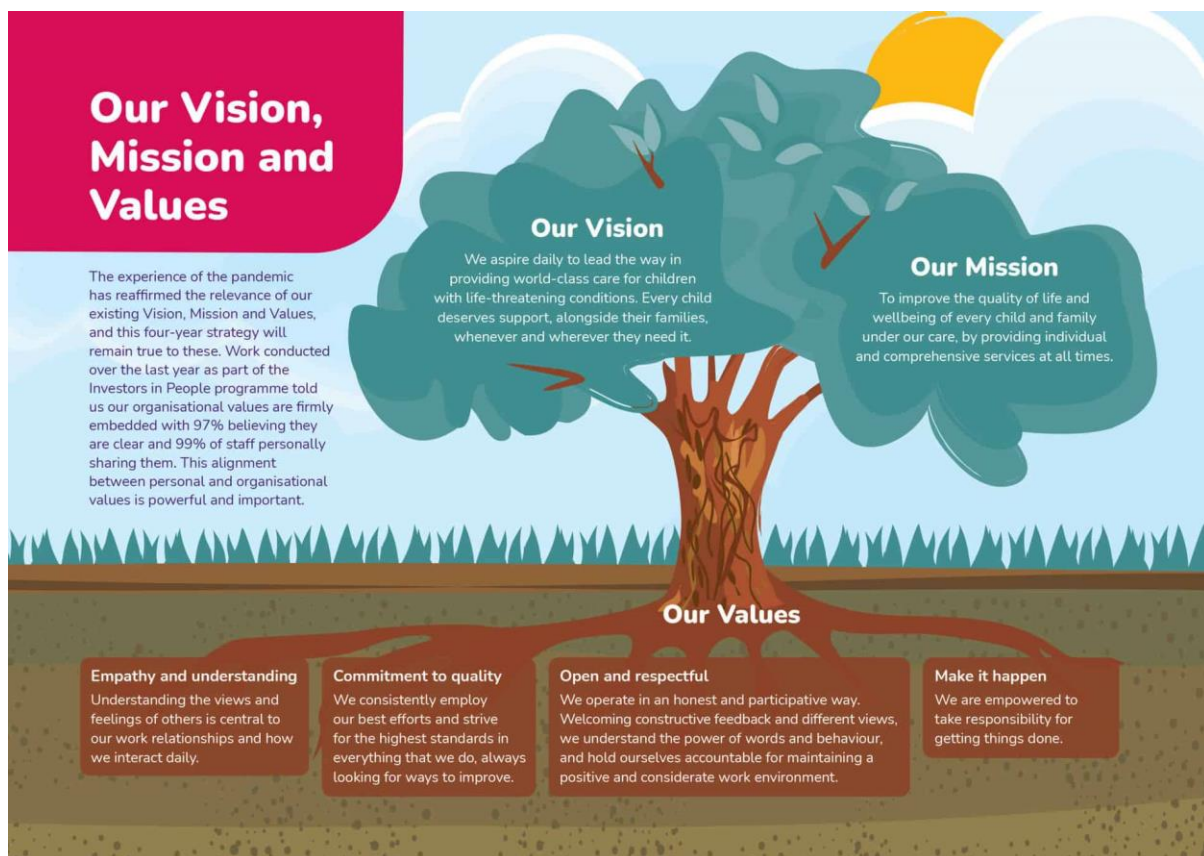


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Part 1. Introductory Statement

On behalf of the whole team at EACH, we are delighted to present the organisation's Quality Account for 2022-23.

We are extremely proud all three of our hospices are assessed as 'Outstanding' by the Care Quality Commission and equally proud we supported 532 life-threatened children and young people during the last year. We delivered a total of more than 72,000 hours of care and wellbeing support for families, including those who are bereaved.

This year, referrals to our care service increased by 17%, with more than half of the end of life care provided to children and families we met for the first time.

Whilst staff absence, recruitment challenges and the unpredictability of end-of-life care demand continued to impact our ability to deliver as many short breaks as we would like, we have been able to provide 16% more than last year. Our ambition remains to further increase our capacity to respond to the increasing demand for both end of life and short break care.

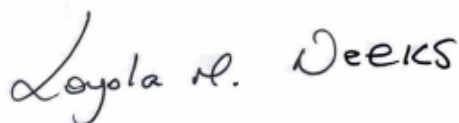
This year continued to be one where we needed to be flexible and responsive in our approach to service delivery. It was also the year when we could truly start

planning for the future as we began implementing Stepping Forward, the organisation's four-year strategic plan. Regular, open engagement with families is a vital part of our service delivery approach, including an annual programme of Family Forums.

It is important we continue to grow our service as we drive our four-year strategy forward. This means ensuring the necessary infrastructure and investment choices are made, providing the workforce, training, equipment and environment to deliver the best possible care. A strategy that grows capacity and capability.

We continue to make great strides in attracting and recruiting the best workforce we can and developing and supporting everyone to fulfil their potential. We also had a few key changes of personnel during the year, with a new Director of Care, and since year-end, two new Interim Assistant Care Directors. These changes have seen us say goodbye to excellent team members, while creating opportunities and new ideas to build on the legacy of those who went before us. We will continue to go from strength-to-strength.

As ever, we are indebted to our generous communities, supportive organisations, staff and volunteers, 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
Trustee
Chair, Clinical Governance Committee



Pól Toner RN
Director of Care

22nd June 2023

Part 2. Priorities for Improvement for 2023/24 and Statements of Assurance from the Board – to be updated

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 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 (CYP) 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.

AND the CYP is less than 18 years of age.

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

In exceptional circumstances EACH may offer a service to CYPs and their families who live outside these areas if it is deemed 'safe' to deliver the care required and there is no other service available to meet CYP and family 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 baby, child or young person 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 our three hospices at Milton, Cambridge, The Nook Hospice in Norfolk and The Treehouse in Suffolk, in hospital and in the wider community. Care is delivered by our hospice based multi-disciplinary teams which includes Nurses, Care Assistants, Therapists and our specialist Symptom Management Nursing Service, all supported by our Administration and Facilities team. Staff are trained to deliver care wherever it is required.

EACH Wellbeing Service

The Wellbeing Service is based at each site and consists of art and music therapists, counsellors, family support practitioners, play specialists, child and family practitioners, family spiritual care lead/practitioners and a groups and events co-ordinator. Each of the teams are led by senior and experienced wellbeing practitioners who also contribute to the locality leadership, maintain a caseload and offer Management and Clinical Supervision, lead on 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.

We deliver 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 and equity of service, the wellbeing leads meet regularly to discuss how to best develop and take forward psychological interventions, whilst managing fluctuating demand and making best use of the staffing resources that we have across all three sites.

- **End of life and post death care**

The team prioritise 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 the 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**

Wellbeing leads have worked together with the team to optimise and expand the wellbeing delivery post covid. The pre-covid groups have been reinstated with a number of innovations and an increase in universal events for bereaved and non-bereaved. The groups and events are needs led and developed via a Logic Model with defined goals in relation to outcomes and impact. They are evaluated and this data is used to develop our group work model. Support groups are offered to pre-bereaved families, including the lead child. Bereavement support groups are offered to families, including siblings and grandparents. This work is hugely supported by our Groups and Event Co-Ordinators. The footfall at groups and events during this period was 2,381.

Some events are offered to all family members and some specifically for pre-bereaved families, like the Christmas Panto and Dream Night, and others for bereaved families, like Memory Day, Remembering with love and Baby Loss Awareness Week.

- **Teaching and training**

In addition to these family interventions the wellbeing team contribute to a wide range of teaching and training both internally and externally including the palliative care training and requests from other directorates in supporting bereaved families.

- **Volunteers**

The Wellbeing Service is supported by a growing team of volunteers who engage in the preparation and delivery of our groups and events, supporting families to utilise facilities on a self-care basis, outside of admission. Volunteer drivers play a crucial role in supporting families to access the service.

- **Audits and Evaluations**

The EACH wellbeing service robustly audits and evaluates all of the interventions and sessions we provide. The outcomes of these audits overwhelmingly show that we are able to offer an appropriate level of intervention for an appropriate amount of time. To ensure that the psychological and psychotherapeutic intervention is of

the highest level, each wellbeing staff member receives robust clinical and management supervision. Further training and learning is encouraged and aligned to the various professional bodies that support staff.

- **Spiritual Care**

The Spiritual Care aspect of the wellbeing service has developed over the year and there is now a practitioner at each site and a Spiritual Care Lead. The allocation to this aspect of care is 3.5 days per week. The team have devised a training session on spiritual care and are working on creating clarity around what success looks like for spiritual care within EACH.

- **Staffing**

We recruited two counsellors to the team, to existing vacancies, and this supported the gap in the provision of counselling, including bereavement counselling and couples counselling. The Arts Therapists and Play Specialists continue to maintain a caseload whilst providing sessions during short break stays and at various groups. All of our therapists undertake systemic assessments.

The introduction of Family Support Practitioners to undertake a Holistic Assessment and conduct reviews has been hugely positive. Having a single point of contact at each site to lead on the initial engagement and introduction to the hospice has been beneficial for both newly referred families and the staff team around them.

- **External agencies**

The teams have worked closely with external agencies where appropriate, including adult mental health, CAMHS, schools, perinatal health, GPs and NHS psychology and wellbeing services and the newer RAaFT service. We attend regular external meetings and have strengthened links with regional and specialist hospitals and mental health teams and wellbeing colleagues.

- **Wellbeing student placements**

The team are receiving an increasing number of requests to offer student placements. The wellbeing teams' experience and reputation supports this. During this period, we have supported students including a Genetic Counselling, Counselling, Chaplain, and Art Therapy and Music Therapy student. We are able to offer a very rich experience to students and our goal is to develop further our capacity to offer more placements.

- **Research Projects**

The EACH Clinical Governance Committee gave consent for EACH to participate in two research projects, including one with The University of York and SPARK Project which focused on the emotional and spiritual care of families with children with serious or long-term health conditions, including bereaved families. Findings are due to be shared very soon. The second was with Together for Short Lives Project: 'Unlocking the door to children's hospices: Understanding the interventions that would increase use of children's hospice services'. The findings will be published in due course.

- **Bereavement Care Pathway**

As part of our bereavement pathway work, in November, we launched the Norfolk and Waveney Bereavement Forum in collaboration with the Norfolk and Waveney Commissioners. Seventeen people attended the launch and membership continues to grow. EACH also joined the Norfolk and Waveney Talking Therapies Collaborative which supports a bereavement referral pathway, attached to funding. The Wellbeing Team continue to develop our Bereavement Care Pathway and have implemented a specific bereavement referral form. They are completing a proposal for a bereavement support assessment protocol and have reviewed/updated our Bereavement family Information Packs and are collating Family Information Sheets. Bereavement Support is a key feature of the Wellbeing Service and, in February, the therapists accessed Trauma Training in relation to their work with bereaved families.

Please refer to Appendix 2.

Clinical Education

Induction Training Programme for Care

A new comprehensive induction programme for care has been developed. This incorporates Clinical Skills competencies, mandatory training and the care development programme (aligned to the care certificate) for new Care Assistants and Senior Care Assistants who have not completed it, allowing them to gain the essential knowledge and skills needed in their supernumerary period (which has been extended to 6 weeks). The induction programme is delivered through a blended approach of in classroom learning, e-learning and face to face skills training. This includes three sessions delivered at each of our sites, allowing for a tri-site induction, assisting with our tri-site working ethos. Learning and the team have worked together to significantly reduce the mandatory training requirements for staff and, as part of the process, the Clinical educators will develop an Individual

Learning Plan with all new staff to create an induction program specifically for them, taking into account any prior experience and learning.

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).

The admissions competencies are currently being delivered on a one-to-one basis by the Clinical Educator, once completed this allows the HCA to progress to a senior carer, in conjunction with their extended medication training.

Positive Behaviour training will be delivered in house and we are currently short-listing candidates from the care team to become train the trainers to deliver this training and support staff on the care floor with delivery of this.

Any other role specific to training identified through incidents, staff or managers is delivered in a timely manner and these include, EpiPen, diabetes, Paediatric Early Warning Score (PEWs), oxygen, system 1 training (electronic care records) and IV training. We are currently working with specialist centres to train our educators and staff up to care for a child with Peritoneal Dialysis.

We continue to give one to one specialist training and support to those that are identified as needing it to complete their probation period.

Clinical Education Students

We continue to welcome Paediatric nursing students across all three hospices. We are currently in discussion with our local universities to open this up to first year students, with the appropriate support. We have also had a request to increase the number of students we take, due to the excellent feedback from students. We also take students across all disciplines within care.

Recently we have seen requests significantly increase from all over the country and a range of areas, including apprenticeships, nurse associates, general nursing students and medical students. Currently we will take them for a short period if we can facilitate this, but in the long term we need to investigate this further to accommodate longer placements if possible and look at the income generation/financing from the areas requesting these placements.

EACH Palliative & End of Life Care (PEoLC) Training & Education programme

Phase 1 of Clinical Education Strategy

Last year we successfully carried out a training needs analysis of our care staff and from this, identified gaps in their skills, knowledge and attitude within palliative and end of life care. From this information we were able to develop a comprehensive training and education programme to meet the staffs specific identified training needs. The training programme commenced in June 2022 and was to be delivered over ten months to all care staff. The feedback from staff has been overwhelmingly positive, and through our pre and post-learning questionnaires we can see it has been extremely effective in meeting our outcomes, upskilling the knowledge, skills and attitudes of our care staff, and investing in them and their development within the organisation, resulting in improved patient care and experience.

All new starters will have phase one of the PEoLC education and training programme covered in their induction period.

Phase 2 of Clinical Education Strategy

We are now moving onto phase two of the PEoLC training and education programme, which will begin in the later part of 2023. From feedback and evaluation of staff and facilitators we have identified six key areas that need expanding on and to be delivered at a higher level, with increased depth. We want to measure impact on practice, we plan to do this by doing a base line audit, delivering training and then a repeat audit to identify changes in practice. The essence of clinical education is to learn and ultimately impact on practice, with our skills, attitude, knowledge and confidence, to improve our BCYP and family experience within EACH.

As phase two of our strategy develops, we will also be looking at the infrastructure of the clinical education team. We want to ensure the team are meeting the need of the clinical, education, training and development of our staff. We want to give opportunities to staff and develop them into an education role and pathway as an option. This may include development roles for band 4's, 5's and 6's. We had a member of the team doing a secondment from the care floor, due to the success of the post the secondment has been made permanent.

Phase 3 of Clinical Education Strategy

We will pick four to six of the subjects we delivered in phase two and advertise them externally, with a cost, this will bring in income generation to EACH and recoup some income back into education. As well as income generation, this will also improve the profile of EACH and the services we offer. Phase three would hope to lead others to look at us as the "gold standard of palliative and end of life care and education and training".

In the future we could also explore running Simulation (SIMs) training for income generation after the success of this with EACH and our Palliative and End of life training and education programme. This takes learning to the next level, and we would be one of few centres offering this locally.

We recognise within phase three that we also want to develop and invest in our staff and that we need to source outside specialist training in this area, such as non-medical prescribing, Advanced Nursing Practice (ANP) and specialist training, investing in our staff and developing the best quality service and care to families – growing our own from within.

Norfolk and Waveney Integrated Care Board

We received match funding from Norfolk and Waveney ICB to develop and deliver a palliative and end of life training and education programme to upskill staff working in paediatrics, who may come across palliative and end of life care in the region. As part of the funding, we were able to recruit a PEOLC Clinical educator to co-ordinate and develop the program. We adapted a similar stance to what we used for EACH and conducted a regional Training Needs analysis, covering the four settings, James Paget Hospital, Norfolk and Norwich University Hospital, Queen Elizabeth Hospital and NCH & C, from this information we have developed a two-phase training and education programme to upskill staff. Phase one will run from March – July and phase two from September to December. We will hold four study days a month, at The Nook, with between 20 and 40 staff members from the four settings attending each study day. Included in the training is a tour of The Nook, to dispel some of the myths of professionals and encourage appropriate referrals.

2.2 Priorities for Improvement for 2023/24

Our priorities are informed by the year two objectives of the four-year strategic plan, the results of the Investors in People development work and our ongoing care development plan.

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 whilst investing in the people and skills necessary to realise their full potential.

The following strategic commitments have been extracted from the four-year strategic plan.

Our Strategic Commitments

- We will develop and deliver excellent palliative care services that meet the needs of children and their families, making the most effective and efficient use of the available resources.
- We will support children and families by working ever more closely with the NHS and health and social care providers, as well as other hospice and charitable organisations.
- We will inform and contribute to the evidence base underpinning children's palliative care. We aspire to be national and international sector leaders in the field.
- We will reintroduce and expand face-to-face services that families have told us are important to them. This will include the full range of services at our three hospices and in the community.
- We will develop our online and digital services to reach more children and families in ways that are convenient and accessible to them.

And 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.

Over the four years, our ambitions for care are to;

- Enhance our capacity by creating 14 new nursing care posts. This will provide more symptom management, short breaks and end of life care.
- Explore developing a long-term ventilation service working with the relevant Integrated Care Partnerships.
- Support our partners to develop better transition services across the region for young people who are leaving our care and entering the adult system. This will build on existing partnerships with adult hospices and hospitals.
- Develop the volunteer care workforce to increase our capacity to better support families.
- Develop our three hospice sites - refurbish the Milton hospice including the provision of piped oxygen, enhance the facilities at the Treehouse including hydrotherapy and family accommodation and develop the outside garden space at The Nook
- Utilise the evolving evidence base to inform our service developments.
- Act as a Research Participation Information Centre (PIC) for relevant research studies

A full copy of EACH's Stepping Forward, four-year strategy can be found at the following link: www.each.org.uk/about-us/stepping-forward/

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.

Table 1 Priorities for improvement	Desired outcome
Priority 1: Ensure BCYP and family outcomes and experiences are gathered from the seven areas of the care model (including end of life care).	Evidence discussion that feedback has been collected and impact on practice reflected on with Line Manager.

Ensure learning from outcomes is integrated into planned service developments.	
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.	<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.
Priority 3: Ensure contribution to PEO LC Phase 2 training programme through participation and/or teaching; and evaluate how the sessions have influenced practice.	Evidence discussion that participation and/or teaching, and feedback has been collected and impact on practice reflected on with Line Manager.

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 2022-23 Quality Account will be endorsed by the Board at the next meeting in June.

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 2022/23 EACH provided the following services to children, young people and families living in Norfolk, Suffolk, Cambridgeshire including Peterborough, and North East, Mid & West Essex:

- End of life care
- Symptom management
- 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, 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

End of life care and symptom management for the child, or young person, including face to face care and access to telephone support has been available at any time of the day or night, 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 and their families as well as some of the activities, groups and events such as virtual memory day, Musical Keys and Playdays. Some face-to-face events have also been held including band practice, coffee mornings, curry night, 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 2022 included:

- Regional Advice and Facilitation Team (RAaFT) launched: A new regional service for the East of England was officially launched in October 2022, providing medical consultant, psychology consultant and specialist nursing support for families across the region. The team includes specialist clinical pharmacy support to RAaFT and regional users.
- 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 April 2022. The survey provides information about the number of children with palliative care needs at a given time. This first year of data collection is considered a pilot to test the process, but this will become an annual process to produce valuable and reliable data.

There are currently 187 members of the MCN who are registered to directly receive updates and information.

63 people attended an MCN Nursing Practice Day provided by Clinical Nurse Specialists.

This year a regular monthly Journal Club was introduced. There have been six sessions, each led by a different team from across the region. Articles discussed covered topics including Palliative extubation, a review of fenfluramine, and professional de-briefing when a child dies.

Funding

All services delivered by EACH are funded through a combination of fundraising activity, retail and some funding from NHS England, NHS integrated care boards across East Anglia and Norfolk County Council.

These arrangements mean that all services delivered by EACH are only partly funded by the NHS.

We have a diverse range of voluntary income streams including corporate sponsorship, charitable trusts, community support groups, a lottery, direct mail, digital fundraising and events, alongside our regional wide retail operation.

2.3.2 Participation in National Audits

During 2022/23, 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 2022/23 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 & scrutiny of the programme is provided by the Clinical Governance Committee of the Board.

The following audits were carried out by EACH in 2022/2023.

1. Clinical Alerts
2. Medicines: Controlled Drugs
3. Medicines: Medicine Management
4. Infection Prevention and Control: Hand Hygiene
5. Safeguarding – Parental Responsibility - Documentation
6. Safeguarding – Significant Event
7. Resuscitation – Episodes of Resuscitation and Status and Documentation
8. Moving & Handling
9. Consent - Documentation
10. PEWS
11. Retention and Archive of Records
12. Transporting Service Users

Audits Undertaken

In line with the EACH Quality and Safety framework processes the following actions and outcomes were approved by the EACH Care Strategic Leadership Team and action plans were implemented and monitored through our Care Operational Leadership Team.

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

1. **Clinical Alerts** - The audit was undertaken to check the procedure for accessing and acting on alerts from the MHRA is effective as per Clinical Safety Alerts SOP CP3. The findings resulted in the following action plan:
 - Ensure the alerts are retained for seven years only to match the MHRA website
 - Ensure action taken resulting from the alerts are recorded and monitored
 - Rotate the responsibility for processing alerts the around the three localities every three months.
2. **Medicines: Controlled Drugs** - Repeat internal audit process of controlled drugs procedures to ensure that controlled drugs are being recorded and administered in line with policies and procedures.
3. **Medicine Management** - The purpose of the audit was:
 - To review that the correct process for documentation of liquid medicines for all BCYP who have medicines reconciled on admission is followed.
 - To determine if all BCYP accessing EACH inhouse care have a completed consent template for Homely Remedies, which has been reviewed or is dated within the last 12 months
4. **Infection Prevention and Control: Hand Hygiene (repeat audit)** - A new audit tool provided by the Cambridgeshire Community Services NHS Trust IPaC team was used; it included observation of staff to check if they completed the five moments hand hygiene opportunity method (before or after patient care). The next external IPaC Environment audit is due to take place in Quarter 1, 2023.
5. **Safeguarding – Parental Responsibility - Documentation (repeat audit)** - The purpose of the audit was to ensure the parental responsibility for the lead children who use EACH service is known and documented in the care records (SystemOne).
6. **Safeguarding – Significant Event** – The purpose of the audit was to audit, the accessing and effectiveness of the Significate events tab and documentation of actions agreed upon from safeguarding supervision to ensure procedures in the safeguarding SOP are being followed following the implementation of the significant events tab.
7. **Resuscitation – Episodes of Resuscitation and Status and Documentation**
There were no resuscitation events recorded in 2022, between 1st January and 31st December 2022.

8. Moving & Handling

The audit is to ensure we work safely and constantly at best practice for our children and staff.

9. Consent – Documentation (repeat audit) - The audit was completed in order to ensure valid consent on information sharing, and receiving care and emotional and mental health interventions is obtained and recorded in the care records.

10. PEWS - The audit was developed to assess the completion of the PEWS document across all three sites.

11. Retention and Archive of Records Audit - The locality ESMs inspected records held locally for records of archiving and destruction of records. The ESM based at Milton worked with the Head of HR to audit records held on Cascade and Accounts to visually check the various books for retention period including destruction dates.

12. Transporting Service Users

The Transporting Service User audit is completed quarterly.

2.3.4 Participation in clinical research

The number of patients receiving NHS services provided or subcontracted by EACH in 2022/23, who were directly recruited during that period to participate in research approved by a Research Ethics Committee (the EACH Clinical Governance Committee) was 10. (6 CPOS; 4 Fathers)

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.
- The health of fathers of children with a life-limiting condition. University of York.
- CoPPAR network (Collaborative Paediatric Palliative Care research Network) University of York.
- The SPARK Project (sponsored by The University of York), How do the NHS and children's hospices meet the pastoral, spiritual and religious needs of children and their families, including those bereaved.

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.

External Professionals and Organisations – examples of feedback

‘The past six-months have been truly joyous, and we have been touched by the kindness, support and warmth that you have all shown us during our time here. EACH Milton is a very special family, and we feel immensely blessed and privileged to have had precious opportunity to work with you all, to help deliver the very rewarding and outstandingly compassionate care that you all provide to the families that we work with’. *GP Trainee Professional*

‘The months spent caring for X and their family alongside EACH’s involvement felt really positive and supportive’. *External Professional via SMNS Matron*

‘Sad news indeed. Thank you everyone for all your hard work and coming together to work collaboratively at such short notice to support (CYP) and their family’. *External Professional - Consultant in General Paediatrics and Paediatric Oncology Shared Care*

‘Thank you so much for letting me know. This is very sad news. My thoughts are with family. It has been very much appreciated how you have all kindly been keeping everyone updated on how CYP was doing this last year. Thank you. *External Clinical Nurse Specialist*

‘Thank you so much for looking after CYP and their family, I know they were very grateful for the care’. *Paediatric Intensive Care Consultant*

‘Thanks to all for your care for this poor family in what turned out to be a rapid final phase, which clearly presented a number of challenges’. *Consultant Paediatric Oncologist*

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

EACH did not submit records during 2022/23 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 2022/23.

2.3.8 Clinical Coding Error Rate

EACH was not subject to the Payment by Results clinical coding audit during 2022/23 by the Audit Commission.

Part 3. Review of Quality Performance

Over the last 12 months, EACH cared for 532 children and young people. This is an increase from 499 children and young people in 2021-2022 and is as a result of an increased number of new referrals and also may be related to CYP living longer with their conditions.

The snapshot number of families with lead children/ young people using services at 31.03.2023 was 385. In addition, there were 1173 bereaved families including 175 individual family members receiving targeted level interventions from an EACH therapist. Bereaved families benefited from a range of family events and activities including memory day.

The total number of referrals in 2022/23 was 155; this is an increase from 2021-22 (n=133), 2020-21 (n=90) and 2019-20 (n= 108). The reason for this increase is unknown. *As services have opened up following the pandemic, relationships with referring provider organisations improving and the inception of the regional RAaFT (Specialist Children's Palliative Care Team) there is renewed and greater awareness of EACH resulting in increased referrals.*

There were a total of 54 deaths during 2022/23, which is more than in 2021/22 (n=50) and 2020-21 (n=35) and the same as 2019/20 (n=54). The figures were lower in 2020-21 as a result of covid lockdown and different ways of working that year. Wellbeing support can also be provided to families and referrals made post death of their child.

Under half (41%) of the deaths were neonates and babies under the age of one. Whilst there was a slightly higher % of children in the 5-12 age group, the number of deaths in the other age groups are similar.

Service Demographics April 2022– March 2023

	Milton	The Nook	Treehouse	TOTAL
Total New Referrals for year	53	52	50	155
Total Deaths for year	14	29	11	54
Total No. Lead Children for year	200	170	162	532
Total No. Family members who had active referrals for Wellbeing support or mental health interventions	121	218	149	488

Whilst demand continues to increase, 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 have short breaks cancelled to provide the nursing capacity needed.

3.1 Review of priorities for improvement 2022/23

The priorities identified in the last Quality Account 2021/22 are recorded below followed by a response which reports progress on these.

Table 2 Priorities for improvement	Desired outcome
Priority 1: Enhance our capacity to provide an increased amount of short break care whilst maintaining our end-of-life care commitments, by investing in eight new 'nursing care' posts.	
RESPONSE: All of the posts had been filled and we are looking at what further may be required.	
Priority 2: Invest in our people, led by the Investors in People insight, to address the key areas of focus for EACH, Care	

<p>Directorate wide and specific care teams.</p> <p>These are:</p> <ul style="list-style-type: none"> • Simplifying reporting lines and decision-making approaches • Enhancing staff wellbeing as we emerge from covid. • Enhancing career development and skills development pathways to meet the workforce needs of the strategic plan 	
<p>RESPONSE:</p> <ul style="list-style-type: none"> • Staff recognition awards in place. • Working on meetings reduction and closer to care decision making. • Wellbeing continues to be a priority. • Education plan in place and new process for educational/ career development will be enhanced. • Succession planning work is also being developed at pace. 	
<p>Priority 3: Re-establish our face-to-face wellbeing and hydrotherapy services</p>	
<p>RESPONSE:</p> <p>Established now with New Physiotherapy posts recruited to.</p>	
<p>Priority 4: Develop our three hospice sites</p>	
<p>RESPONSE:</p> <p>The site development scoping projects for Milton and The Treehouse are in early stages and will be led by the Director of Care with the Service Managers and the new Facilities Manager.</p> <p>The rest and reflect garden at The Nook is being fully funded and managed by Greenfingers, the national charity which funds gardens for hospices. The garden designs are complete, and a contractor has been appointed. The project team are currently awaiting feedback from the council as to whether planning permission will be required. The outcome of this will inform the timescale for starting on site.</p> <p>EACH continues to enjoy a very positive experience of working with Greenfingers.</p> <p>The Director of Fundraising and Communications is leading on this project with the support of the management team at The Nook.</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 believe that a concern or complaint is an opportunity to improve our care, so treat both concerns and complaints 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 is 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. There was a decrease in the number of complaints/concerns from 26 to 13 this year.

Please see table below.

Number of CYP / family member related concerns/complaints

Service	2021/22	2022/23
Milton	2	3
The Nook	19	6
Symptom Management	1	0
The Treehouse	4	4
Total	26	13

Summary of themes of CYP / family member related concerns and complaints in 2022/23

Theme	2021/22	2022/23
Communication	7	5
Service User Information	0	1
Amount of care and support	2	1
Standards of care	15	6
Transition process	2	0
Total	26	13

Examples of changes to practice from the complaints include:

- As a result of the incident involving a parent not consenting to their child's care in EACH, we are currently developing a process for first visits by newly referred families which includes a staged approach to introducing families to the service, and ensures that where applicable, both parents have consented.
- The Long Term Ventilation Policy and Tracheostomy SOP have been updated following a review of the evidence base for tracheostomy management.
- The eligibility process was discussed by the leadership teams and it was agreed that local discussion should take place to determine what part parents play in the process and how any decisions would be communicated before decisions were made.

All concerns and complaints were resolved locally with oversight from the EACH Care Operational Leadership Team. Seven complaints and concerns were resolved and upheld, five were resolved and not upheld, one was resolved and partially upheld.

3.2b Commendations

EACH received over 109 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 send you a quick email to thank everyone for an amazing placement, I was truly touched by the kindness of all the staff at Milton. I have learnt so much on my placement and have found everyone to be so helpful, patient and accommodating to teach me and provide me with lots of different

experiences. Special thanks to X for being an amazing practice assessor and helping me to sign off my competencies'. *Nursing Student*

'Thank you so much for all your help.

We really do appreciate you all and everything you all do for us'. *Family Member*

Short Break Care

'Family wanted to send a warm thank you to everybody during their hospice journey. They told us that they felt 'The Nook was their bubble' and that they 'felt really safe with us'. The sibling upon leaving said "I want to stay forever". Mum emphasised that she would be forever grateful for the care X received and for everyone being amazing, and showing such empathy and going the extra mile. X's family expressed how grateful they were for their amazing meal before they left the hospice, and also for the sandwiches that XX made them to take home with them. Family said this was another stress they didn't need to worry about when they got home, as they hadn't got any food in the home. Mum thanked our wonderful facilities team and said she was so thankful for their kindness, and for going the extra mile to make sure their clothes and room was cleaned and for 'putting up with the brother's mess in the room' *Reported by a Bereaved Family Member to a member of staff*

'I just wanted to thank all the X and Each staff who were involved in organising and caring for XX during our recent break. XX had a wonderful time at EACH, she enjoyed a break away from home and said everybody was lovely to her, plus you provided hours of playing monopoly. As a family we were able to enjoy activities that we can't usually take part in and had time with the boys which was really important. We also had a good rest too. Thank you for making our break possible'. *Family Member*

'I just wanted to say a huge thank you to all for the care and attention paid to X at her recent two-day respite at the hospice. She clearly had a lovely time. A lot of thought had been put onto the activities she did and she was very relaxed and settled when she got back which was lovely to see. It also meant that (my husband) and I could take her sisters out to do all the things we can't normally do like going down the slides at the swimming pool and going to the cinema. Thank you...(my husband) and I are very appreciative'. *Family Member*

'I can't thank you guys enough for being so helpful and so quick in your actions tonight. I truly, truly appreciate it you are amazing I'm so glad we have you guys'. *Family Member*

'We are writing to thank you very much for the monumental effort that you all put in to enable a safe overnight stay at the hospice for our son X. We really appreciate

all the coordinated efforts with home visits, test runs and liaising with school, social care OT and learning disability team as well as joining X's EHCP review. As fellow healthcare professionals, we really admired the collaborative working and realise there was a huge amount of background effort that we didn't always see. Fingers crossed, this will lead to more collaborative working for other children and the plans that have been put in place for X will work again in future'. *Family Member*

End of Life Care and Bereavement Support

'Thank you so so much. You're all amazing and helped us make every single day count with X'. – *Bereaved Family Member*

'To everyone at The Nook - The biggest thank you for everything you offered X and everything you're still offering us even though he's no longer here. Some of you feel like extended family. You are incredible, you don't even realise the happiness that you bring to families. There are no words to describe how epic you all are. You left us with memories that will last a lifetime. We'll forever be grateful for you being there to offer X the best care during his final days. The Nook is simply magical'. *Bereaved Family Member*

'To everyone at EACH. Thank you for all you have done for us and X over the last eight months. We cannot explain how this has enabled us to process what was going on, but also helped us make it the best it could be and given us memories that will last a lifetime. Your care, compassion and support helped us navigate our way through. We are now trying to adjust to a new way of life which is difficult, we will always hold EACH very close to our hearts. A million thank you's would never be enough'. *Family Member*

'It has been almost eight months since our darling X left us. Sometimes it feels longer and other times it feels like yesterday. We just wish to express how thankful we are to you for everything you did for us during X's life and, what you continue to do since she passed away.

From our very first Zoom playdays, to our very very special sleepover.

We will never forget our happier stays at The Treehouse. In particular our first and final family Christmas weekend stay when XX was three weeks old. The fun we had trying to get X and XX's handprints on the elephant picture (which now hangs so proudly in our kitchen) is a particular fond memory.

It is heart-breaking that we 'get' to come to the bereavement days, but we did find it so comforting to remember X in this special way. Thank you'. *Bereaved Family Member*

'This was the only part of Christmas that directly was about our son, the evening was beautiful, thank you so much (Remembering with Love @ The Nook)' *Family Member*

'On behalf of my family I am writing to record our sincerest heartfelt thanks and gratitude for the way in which both our ten-month, X and immediate Family were cared for during our stay at the East Anglia's Children's Hospice. From the nurses to the care staff to Julie and her team in the onsite dining facility, as well as other support staff, every single person we encountered displayed a genuine and sincere concern for our collective well-being doing whatever they could to remove as much of the burden and 'weight' of the situation as possible. This allowed us to focus on devoting as much quality time as we could to X with all members of immediate family able to spend significant quality hours in the hospice. Of particular note was the way in which staff took our five-year-old under their collective wing spending many hours with them during our week's stay keeping them stimulated and occupied making an incredibly difficult situation easier to cope with and with obvious lasting benefits since we've returned home. From our lay perspective the balance the hospice staff were able to achieve between the demands of X care, the inclusion of us as parents in decisions, whilst simultaneously looking after the wider needs of our immediate family, including subtle interventions before we recognised the need, appeared to be superbly executed on a daily basis regardless of which staff members were on shift. As a result, the staff at Milton created an atmosphere akin to a single entity placing its arms around a family in desperate need of tender loving care following what turned out to be a very traumatic three week stay in Addenbrookes. For that we can never thank you enough and will remain eternally grateful. With sincerest gratitude and respect'. *Bereaved Family Member*

'I just wanted to thank you all for the support and kindness you have shown us all. We are all devastated but you have helped us a great deal. Sorry my words don't seem enough'. *Family Member*

'We're always so overwhelmed with the bereavement support available from EACH'. *Family Member*

Clown Doctors

'Just wanted to say a huge thank you for arranging our session with the Clown Doctors yesterday 😊 It was really lovely and created lots of much needed smiles and laughter!' *Family Member*

Transition:

'We just wanted to thank you all for everything you've done for our family over the last couple of years. The Treehouse has been a great help to us and we've all enjoyed our time with you and we're sad to be leaving. You all do an amazing job. Thank you'. – *Family Member*

Wellbeing groups and activities

'Dream night was incredible!!!!!! We were holding back tears all evening. We don't like zoos but all the effort that was put into it to make it special for families was just simply amazing!' – *Bereaved Family Member*

'I just wanted to say thank you for inviting the boys on sibling days. They really loved the clip and climb day and felt very reassured that they were not the only children that have/had a poorly sibling or have lost a sibling. It was our first time back to the hospice since losing X and although I had a cry in the car I knew it would be good for them. Thank you again for looking after them'. *Bereaved Family Member*

Help at Home Service

'In just two weeks X has taken a huge amount of pressure off our shoulders. Jobs that I also put to the bottom of the list are being completed, and to a very high standard! We are very, very thankful to X for giving up her time to help us'. *Family Member*

Memory Day

'A thousand thanks for Saturday.....to all the truly wonderful people at EACH. It was a very moving but amazing occasion'. *Family Member following Memory Day*

'Thank you for the photo and for the band which we received yesterday. We all enjoyed the memory day especially some familiar staff. We will forever be grateful for the support we received. We call the hospice our home as we spent so long with you guys'. *Bereaved Family Member*

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 following:

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, the 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.

Examples of learning from clinical incidents or changes to practice included the following:

- recognising we should always use a professional translation service to ensure important information is accurately provided to families when they are not fluent in English. This was following an incident when a family refused a translator preferring to use a family member.
- consider providing safe areas where children can play in the grounds. This resulted from an incident when concern was raised about the safety of resident siblings riding their bikes in the hospices grounds while unsupervised.

- reviewing training on controlled drugs following an increase in the number of incidents.
- the evidence base for checking the tightness of tracheostomy tapes has been updated to check in three places instead of one, around the nape and sides of the neck.
- ascertained that Gabapentin should now be destructed as a schedule three CD drug.
- staff require additional training on controlled drugs

Through the various ways noted above, staff were reminded to:

- delete BCYP's photographs from hand held devices following an audit where some had not been deleted
- not to take personal medication in the care area after several incidents involving tablets being found (although it is unknown who the tablets belonged to).

The above reminders to staff have been effective as no further incidents relating to these issues have been reported.

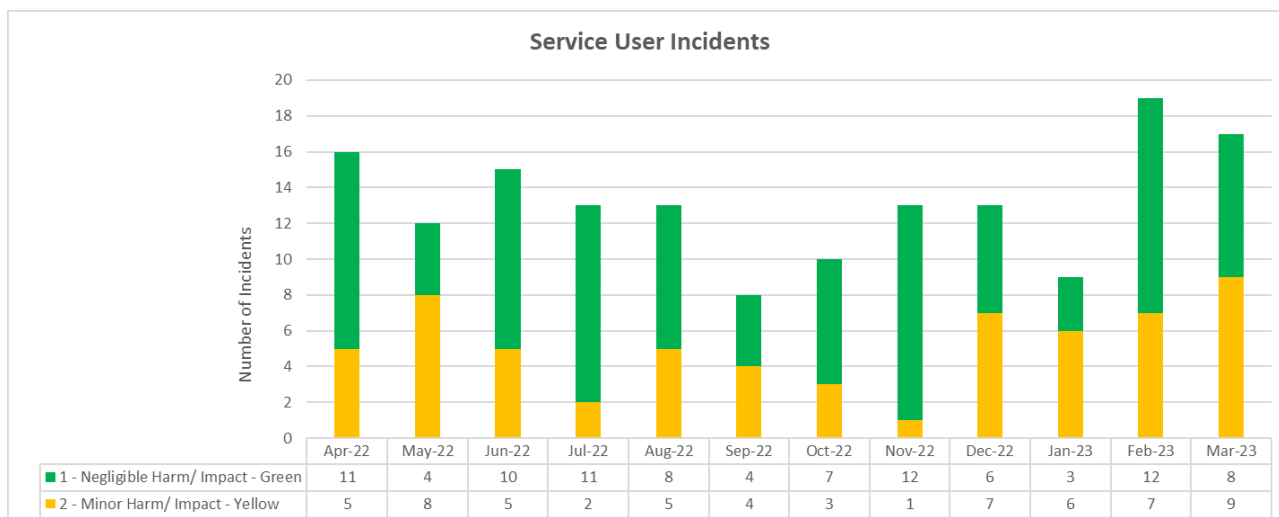
Family Information Leaflets have been translated into Polish, Lithuanian, Portuguese, Arabic and Urdu, and can be found on the EACH website at the following link: [Translated family information leaflets - East Anglia's Children's Hospices / Norfolk Cambridgeshire Essex and Suffolk \(each.org.uk\)](https://each.org.uk/translated-family-information-leaflets-east-anglia-childrens-hospices-norfolk-cambridgeshire-essex-and-suffolk)

Incidents that related to a CYP/Family member who use EACH services

Incidents 1 April 2022 – 31 March 2023

In 2022-23, there were a total of 158 green and yellow rated incidents completed (including 59 relating to medicines). This is less than the 174 green and yellow incidents (including 69 relating to medicines) recorded in 2021-22

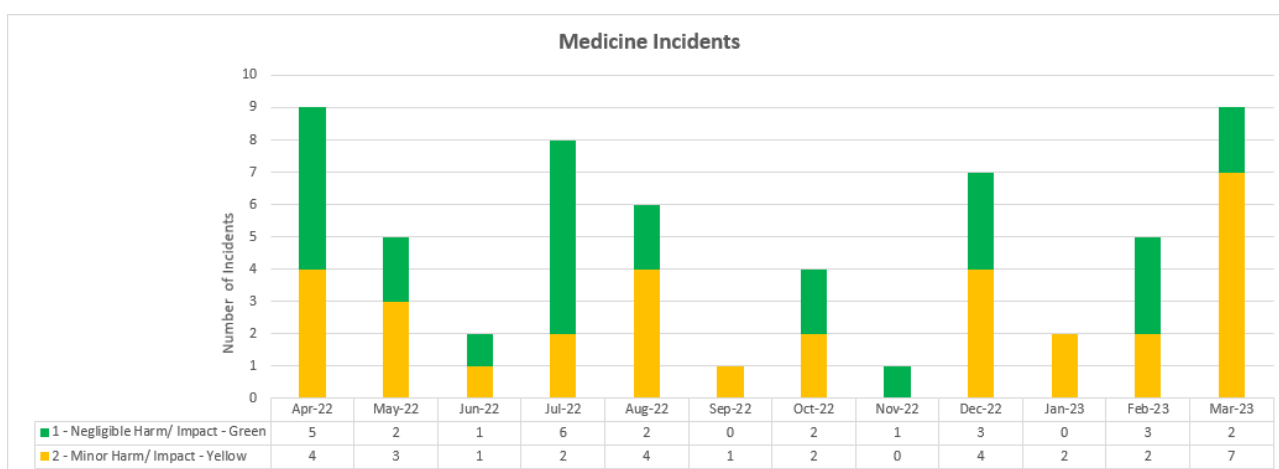
There were zero (0) resuscitation or notifiable controlled drugs incidents and zero (0) notifiable clinical incidents and zero (0) red rated incidents during 2021/22.



The highest number of incidents 37% (n=59) related to medicines management; 5% (n=3) of these incidents related to reconciliation of medicine processes and 47% (n=28) to medicines administration. The number of medicines management incidents are lower than last year (n=68).

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 no 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 1st April 2022 – 31st March 2023 are as follows:

Title	Compliance %
Resuscitation and Anaphylaxis	96%
Moving and Handling	96%
Infection Prevention & Control	96%
Safeguarding Children Level 3	94%
Safeguarding Adults Level 2 e-learning	100%
Management of Oxygen & Medical Gas Safety	91%
Fire Safety	90%
Food Hygiene e-learning	93%
Data Security Awareness e-learning	100%

The management team continue 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
Nursing 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

3.2d (iii) External Practice Development Groups

Care staff participated in the following external groups:

The East of England Managed Clinical Network (MCN) Norfolk, Suffolk, Cambridgeshire and Peterborough, Essex, Hertfordshire, Bedfordshire, Luton and Milton Keynes. This is chaired by the EACH Medical Director and the Lead Nurse in the network is the Nurse Consultant Children's Palliative Care Dr Linda Maynard and steering group is attended by EACH Matrons.

Together for Short Lives Advisory Council. The Director of Care continued as a member of the TFSL Advisory Council until September 2022.

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 was chaired by the Director of Care (until September 2022) and is attended by the Medical Director and Nurse Consultant. The county-based networks are attended by the Nurse Consultant, 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. Until September 2022 the Director of Care, as Chair of the Children's Palliative Care Forum, was also CYP PEOLC Lead. The Nurse Consultant Children's Palliative Care currently deputises as CYP PEOLC Lead.

National Palliative & End of Life Care Programme Children & Young People's Advisory Board. The Director of Care and Nurse Consultant (in RCN vice chair role noted below) were invited to join this group.

<p>Royal College of Nursing: Children & Young People Palliative Care Community. The EACH Nurse Consultant is vice chair of this group.</p>

<p>CoPPAR network (Collaborative Paediatric Palliative Care Research Network) Steering Group University of York. The Nurse Consultant is a steering group member and the EACH Research Nurse is funded through this collaboration.</p>

<p>Together for Short Lives / Association of Paediatric Palliative Medicine national research group. This is attended by Nurse Consultant and The EACH Research Nurse.</p>

3.2.d (iv) Scholarly Activity

Care staff had academic work accepted for journals and presentation at national and international conferences and meetings as follows:

- Michelle-May Wright, Katie Chapman, Peter Honig. Holistic Needs Assessment or Holistic Assessment, What's in a name? Presented at the East of England Palliative and End of Life Care Strategic Clinical Network – Sharing Good Practice Conference. June 2022.
- Jules Gibson-Cranch. This isn't going to hurt. Presented at Together for Short Lives National Conference. September 2022.
- Dr Linda Maynard. Outcomes in Children's Hospices Workshop. Presented at Together for Short Lives National Conference. September 2022.
- Dr Linda Maynard. Neonatal Symptom Management. Presented at Monthly Mondays. November 2022.
- Dr Linda Maynard. East of England CYP Palliative & End of Life Care. Presented at PEOLC System Leads Meeting. March 2023.
- Shirley E. Jones; Dr Katherine Bird, and Dr Linda Maynard. Managing intractable pain with neuraxial infusion at home: Advancing Nursing Practice in Paediatric End of Life Care. International Journal of Palliative Care Nursing (2023 March in press).
- Maynard L.; Cannon C.; Rideout J.; Lynn K; Daniels S; Lynn J; Weaver S. Supporting Parents of Children with Palliative and Complex Health Care Needs in a Time of Crisis: A Health and Social Care System-wide Response Poster presentation at Global Children's Palliative Care International Conference Rome May 2022.
- Maynard L.; Sartori P. ; Cannon C.; Perez C.; Cattaneo E. Developing a Regional Children's Specialist Palliative Care Service: Analysis of caseload and Consultant Physician activity between 2010 to 2020. Poster

presentation at Global Children's Palliative Care International Conference Rome May 2022.

- Maynard L and Brooks D. Developing and implementing a Training Needs Analysis (TNA) to better understand the learning and development needs of a multi-professional children's palliative care (CPC) workforce. Poster presentation at Global Children's Palliative Care International Conference Rome May 2022.

3.2d (v) External Study and Conferences

EACH supported 21 applications from care staff to undertake study days, extended study learning and conferences during the reporting period, both in person and virtual. Examples included

- Conferences for Music Therapy, Respiratory Care for Children with Neuro-disabilities, ANTT, Together for Short Lives, OT/PT, Mental Health & Palliative Care
- Certificate in Education & Learning
- English Language

3.2d (vi) Student Placements

During this quarter, the following placements have been provided:

- **Milton** – Ten nursing students from Anglia Ruskin University in first, second or third years. Placements ranged from four to ten weeks.
- **The Treehouse** – Nine nursing students from University of Suffolk in second or third years. Placements ranged from one to four weeks.
 - One elective placement from University of Surrey
- **The Nook** - Five nursing students from University of East Anglia in second or third years. Placements ranged from two to 12 weeks.

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 provides two posts working in children's palliative care. These are based at Milton Hospice and the doctors work with the CARE Team and Symptom Management 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.

3.2d (vii) Commissioned Training

53 professionals benefitted from the following training and education events provided by the Managed Clinical Network which is 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 4.57% which is below comparable benchmarks in the NHS. The average sickness absence rate for the whole of EACH for the period 1st April 22 – 31st Mar 23 was 4.34%. Care staff absence was slightly higher than the EACH benchmark as a result of a covid peak in December 2022.

The latest NHS data (published May 2023) put the rate for Community Provider Trusts at 5.68% and 5.23% for Community Provider Trusts in the East of England. This is the closest type of provider to benchmark against.

Source: [NHS Sickness Absence Rates, January 2023 - NDRS \(digital.nhs.uk\)](https://digital.nhs.uk/resources/identifiers/nhs-sickness-absence-rates-january-2023)

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 children, young people and family members who use EACH services can bring to the organisation are recognised and positively valued by EACH. Acting on service user feedback is important to EACH and the principle of 'you said, we did' is built into service user engagement strategy.

We seek feedback from and involve the children, young people and families in several ways including family forums and having a Trustee who was a user of EACH services. Families are encouraged to give feedback via a range of means including the family section on the website, surveys, comments slip in the family newsletter and Facebook and Twitter.

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

All families engage in a holistic assessment following their referral to EACH to identify their personal goals for involvement with EACH and to consider their different areas of need. Families identify what is most important to them and their priorities for care and support which 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, keep in touch to check that the family are happy with the type and level of support they are receiving. It is also an opportunity to learn if needs and goals have changed.

EACH welcomes children, young people and family members who use EACH services who wish to be involved in awareness or fundraising initiatives by use of their photographic images, audio and /or visual recordings and family stories or involvement in fundraising events. The use of this information is discussed with children, young people and family members who use EACH services ensuring their consent is fully informed and documented.

Children, young people and families also could be involved in research projects that EACH participates in.

3.3b Family Forums

Family Forums provide the opportunity for families to share their feedback and views and in Quarters One and Two were hosted by the Director of Care, the Service Managers at each locality have led the forums for the remainder of the year.

They are held every two months on a day and at a time which best suits the families who attend. Attendance is primarily face to face, however the option of attending via Teams also exists.

The forums provide the opportunity to hear from families about what is working well, what they have concerns about, to be updated on what is happening in EACH and in their own locality service and provides the opportunity to provide feedback on proposed developments. It has also provided a very useful opportunity to hear about the experiences and issues for families wider than EACH to feed back into the wider health and social care sector.

Although attendance at The Nook Family Forum remains a challenge, there has been consistent representation by mums and parents with children currently using EACH services at The Treehouse and mums, dads, bereaved parents and parents with children currently using EACH services at the Milton Family Forum. However, we are continuing to consider ways of increasing the attendance, for example, using the EACH social media to advertise the forums and having information available at existing groups and events.

Some of the things that the forums have advised on this year included:

- The 'I wish you knew' campaign was presented at The Treehouse and Milton forums.
- A representative from Marketing and Communications attends the forums to gain feedback regarding the EACH website and the information that is available.
- Contributing their feedback and suggestions around the delivery of groups and events.
- Feedback has been shared around hydrotherapy and family swims at The Nook.
- Families at The Nook have had the opportunity to contribute to the decorating of the bedrooms.
- The proposed plans for the Rest and Reflect garden and play area at The Nook have been shared.
- Families were asked for feedback around the wording that was being developed for the CPOS Research Survey Questions.

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

There is a weekly organisational update communication to staff from the Chief Executive and care staff also receive regular updates from the care management team via Care Matters, Medicines Matters and Safeguarding Matters newsletters. Each of the three hospices produces a locality weekly newsletter for staff. EACH wide communications meetings are also held three to four times annually with the opportunity to meet with the Management Executive (MEX) members, cover key topics & raise questions.

Investors in People

EACH achieved Investors in People (IIP) Silver accreditation in October 2021 and we continue to review team level action plans to follow up on focus areas.

The IIP assessment process will be reviewed during 2023-24 by the EACH Executive Team.

Yammer

EACH uses Microsoft's Yammer, an internal social media platform for EACH staff only. Content includes organisational news and key information for sharing with colleagues. All staff can post to the platform, comment on news stories and work

together in specific discussion groups. The site also provides links to useful websites and resources, such as pension information, the EACH Strategic Plan and the Employee Handbook.

Line Managers

Line managers are responsible for ensuring that 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.

Line Managers hold regular team meetings to ensure that staff are kept up to date with developments within EACH on subjects that affect their teams.

They are also expected to 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

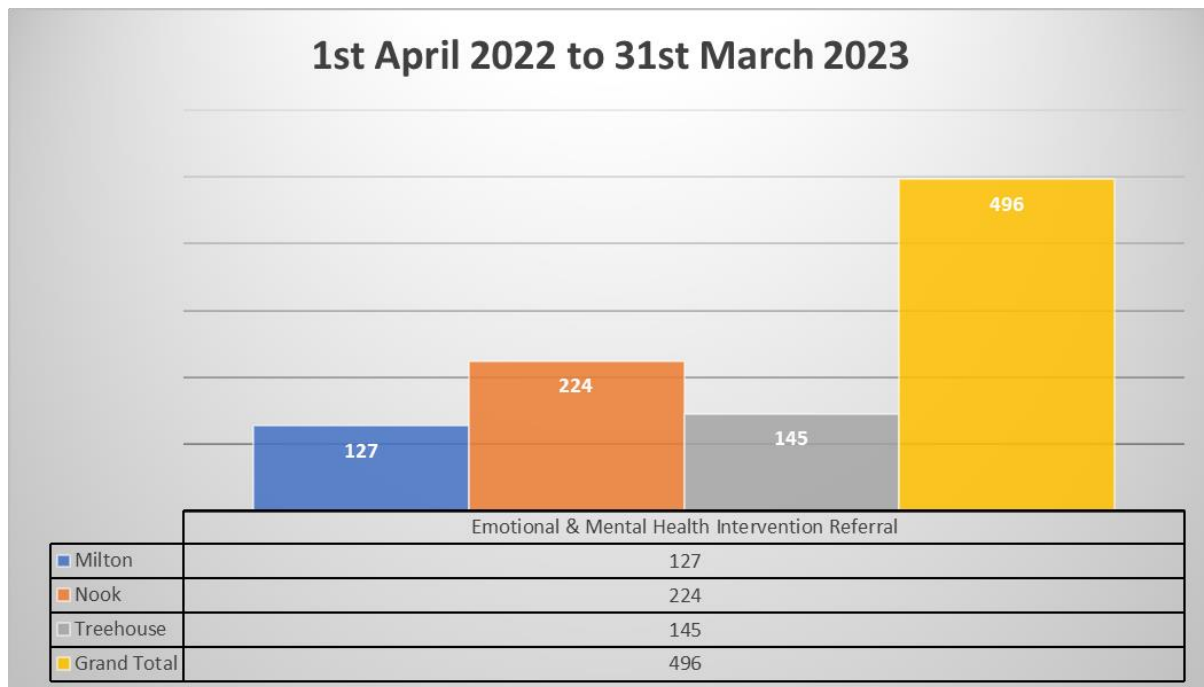
EACH provides services across Norfolk, Suffolk, Cambridgeshire and Essex. This Quality Account has been sent to Integrated Care Boards and Healthwatch in the above counties to provide the opportunity for comment and a statement. The list of those who were sent a copy of the Account is tabled in Appendix 3. Responses received are included in Appendix 4 along with the EACH responses.

Appendix I Commissioners and Healthwatch contact details

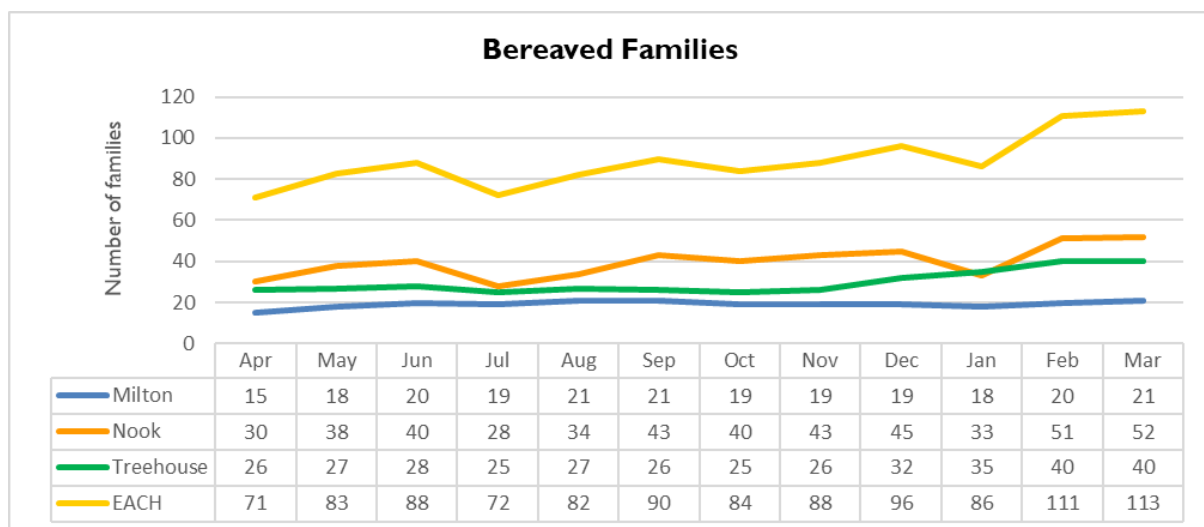
ICB area	Integrated Care Board (ICB)	ICB Contact	Healthwatch contact
Norfolk & Waveney	Norfolk & Waveney ICB	Clare.angell@nhs.net Rebecca.godfrey1@nhs.net	Alex.stewart@healthwatchnorfolk.co.uk Chief Executive Tel: 0808 168 9669
Suffolk & North East Essex (SNEE)	SNEE ICB	Anthea.Christodoulides1@nhs.net <hr/>	Andy Yacoub Chief Executive Info@healthwatchesuffolk.co.uk Tel: 01449 703949
Cambridgeshire & Peterborough	Cambridgeshire & Peterborough ICB	Delyth.richardson@nhs.net Karlene.allen2@nhs.net	Julian Stanley Chief Executive Julian.stanley@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 Tel: 0300 500 1895
West Essex	Herts and West Essex ICB	Rosalind.French@nhs.net smita.rai1@nhs.net	

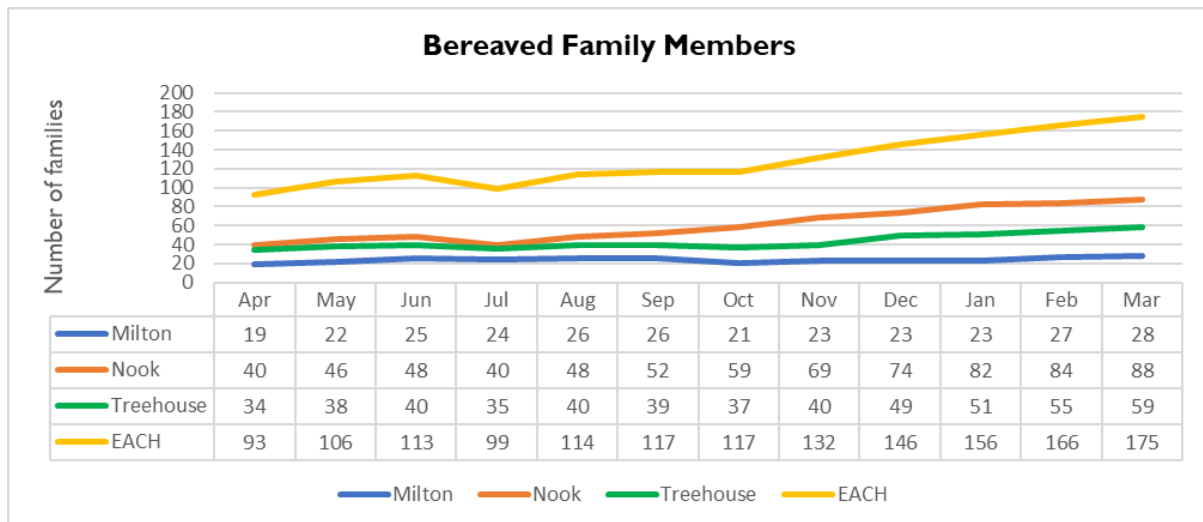
Appendix 2 Wellbeing Service data

Number of all open referrals for the Emotional & mental health caseload Q1 to Q4

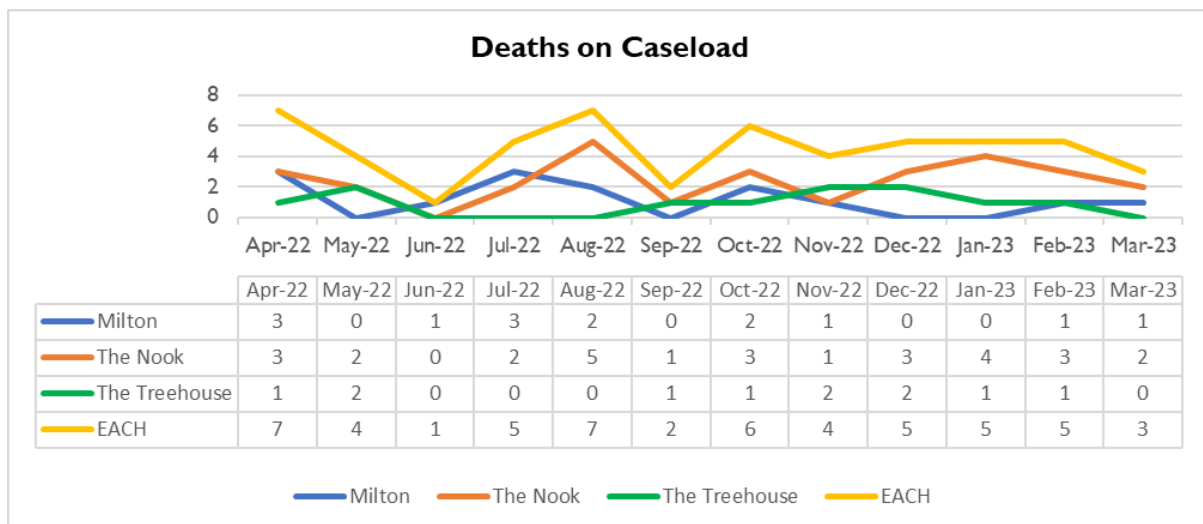


Number of bereaved families and family members on caseload for Q1 to Q4 (taken from the Q4 performance report).

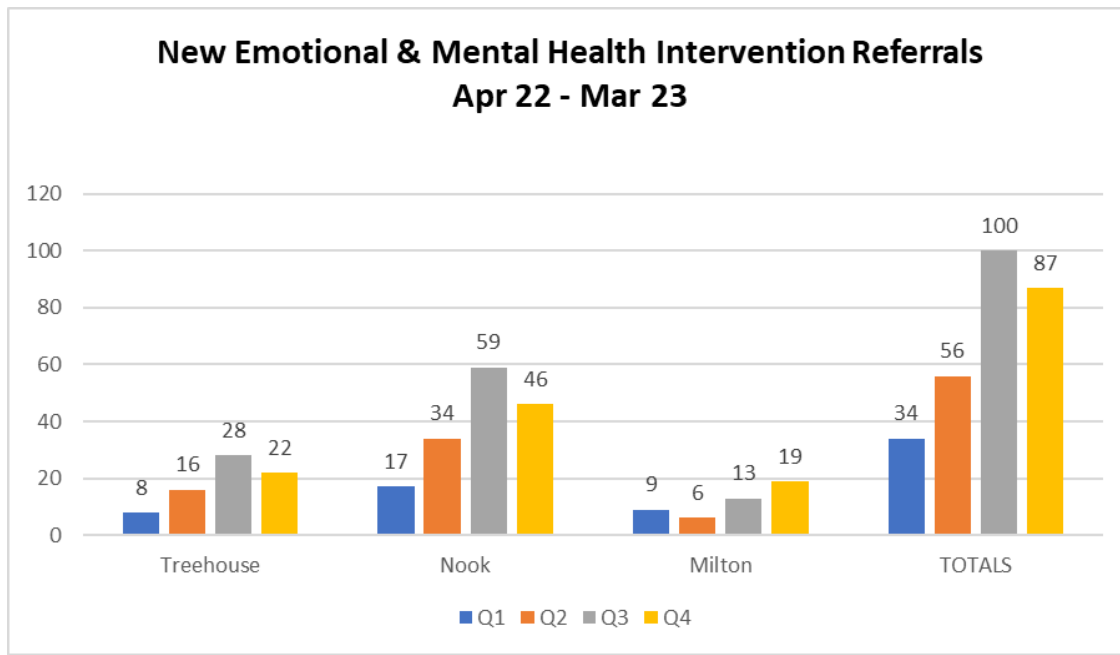




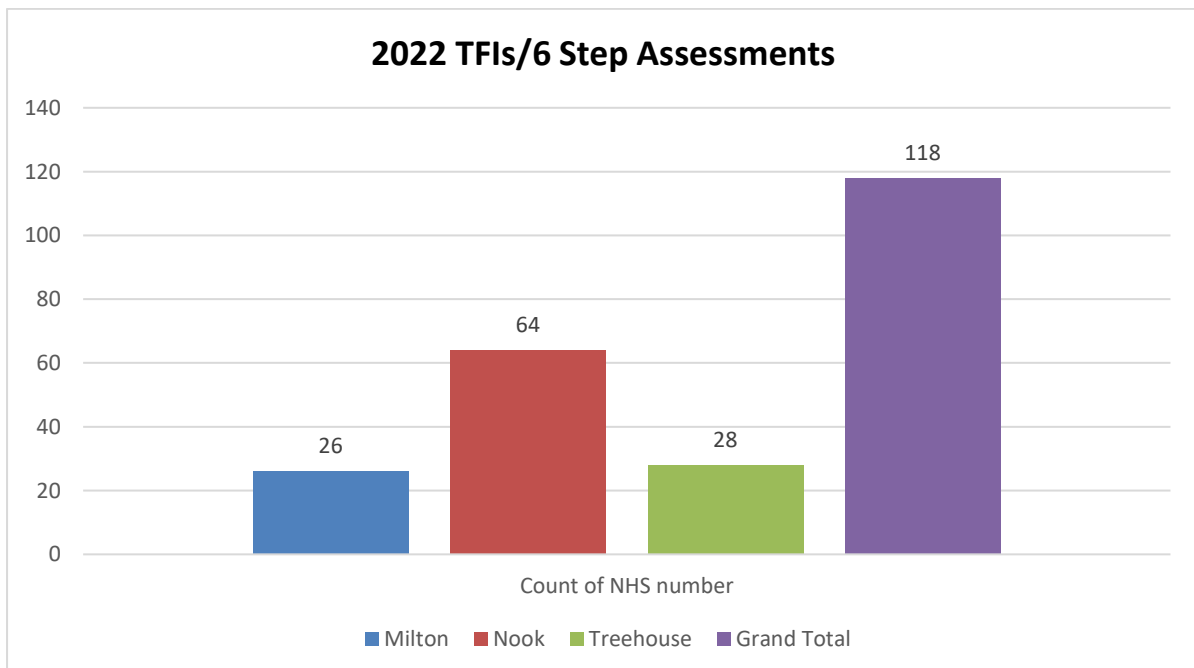
Deaths on caseload for Q1 to Q4 (taken from the Q4 performance report)

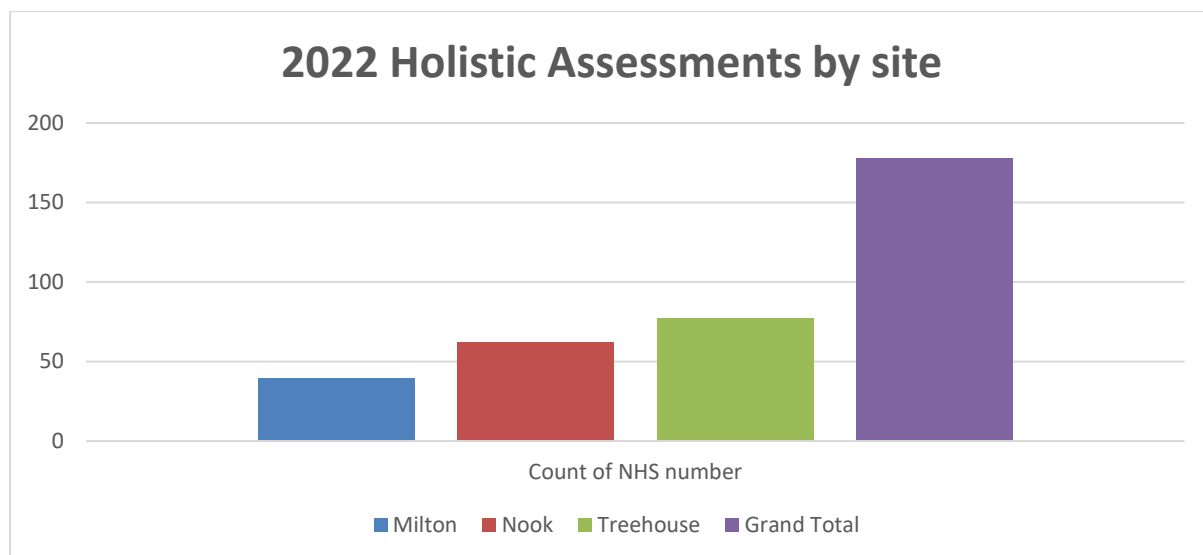


New Emotional & Mental Health Interventions for Q1 to Q4



New Individual E&MHI Referrals	Q1	Q2	Q3	Q4
Treehouse	11	16	28	22
Nook	30	36	59	46
Milton	12	8	13	19
TOTALS	53	60	100	87





Appendix 3 Commissioners and Healthwatch Responses

The following responses were received.



East Anglia Children's Hospices (EACH) Quality Account 2022/23

Statement from Healthwatch Cambridgeshire and Peterborough

Healthwatch Cambridgeshire and Peterborough welcomes the opportunity to comment on the Quality Account for East Anglia Children's Hospice (EACH).

Healthwatch Cambridgeshire and Peterborough is aware of the family-centred support that EACH provides for children, their families, and carers in an exceedingly challenging financial climate. For EACH to maintain and increase support for children and families over the last twelve months is a significant achievement.

We congratulate EACH on the launch of the Regional Advice and Facilitation Team (RAaFT). Also, for the new regional service for the East of England supplying medical consultant, psychology consultant and specialist nursing support for families across the region.

In addition, we commend the development of the palliative care survey, undertaken in 2022, involving collaboration and partnerships with acute, community services and children's hospices,

Healthwatch Cambridgeshire and Peterborough is pleased to support EACH. Our role is to amplify the voice of families, children, and young people in whatever way we can, and relay feedback – both good and bad to key service providers and decision makers.

The Healthwatch information and guidance service will continue to signpost members of the public to EACH for support and our engagement team and community researchers remain keen to promote community awareness, engagement, participation, to undertake targeted research projects, surveys and focus groups on behalf of EACH, to garner independent feedback from parents, carers, and families. We send EACH our best wishes for the year ahead.

EACH Response:

Thank you for your swift and positive response.

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

Feedback on the draft Quality Account for East Anglia's Children's Hospices (EACH) 2022/23 from Hertfordshire and West Essex Integrated Care Board.

Date of Submission - 21.06.2023

Section	Feedback
General feedback	<ul style="list-style-type: none"> ▪ The quality account is well presented and makes an easy and understandable read. Good detail and clear explanation are provided in all sections of the report. ▪ The quality priorities are clearly set out and we agree with the priorities and the principles that sit behind them. ▪ It may benefit to do a review of the acronyms used in the account as some acronyms are not initially outlined in full.
Section 1	<ul style="list-style-type: none"> ▪ Positive to hear that there has been successful recruitment and more short breaks than last year were provided. We were pleased to read that you have taken the feedback from families when developing the strategic plan. We commend the achievement of the investors in people award and consideration given to staff feedback.
Section 2	<ul style="list-style-type: none"> ▪ It is good to see that priorities for 2023/24 have been informed using different sources and that the organisation hopes to grow in capacity and capability. The strategic commitments are baby, child, young person and family focused. ▪ In the review of the services, we are pleased to note the achievements in 2022 and the partnership working that EACH supports. We value the openness and transparency demonstrated with regards to the section on funding. ▪ The ICB is pleased to note that at the time of the report, there were no patients on waiting lists. We note that EACH has had to cancel short breaks to maintain capacity as required. ▪ From an Infection Prevention Control (IPC) perspective given the increased focus on this area over recent years we are pleased to note the following including a few suggestions for minor amendments to the account if possible. <ul style="list-style-type: none"> • We are pleased to note that learnings from Covid, used in conjunction with 'What Matters Most to Children and Families' has shaped services, including continuation of online wellbeing support. • Good to note use of a new audit tool based around the World Health Organisation's (WHO) 5 moments of hand hygiene. It may be useful to include findings and action plans from this audit and any other IPC audits that are undertaken. • Including details on IPC governance, monitoring and compliance with the 2021 National Standards of Healthcare Cleanliness and response to



	anti-microbial stewardship would help make the IPC report comprehensive.
Section 3	<ul style="list-style-type: none"> ▪ The priorities for 2023/24 and successful progress against these are clearly outlined. ▪ There is good information provided on numbers and themes for complaints and incidents. We are pleased to see examples of learnings from patient complaints and incidents that have led to improvements. ▪ Addition of patient feedback provides good insight to experience of service. ▪ Inclusion of staff academic work accepted for journals and presentation demonstrates continuous learning and improvement.



NHS Hertfordshire and West Essex Integrated Care Board (HWE ICB) response to the Quality Account of East Anglia's Children's Hospices for 2022 /2023.

NHS Hertfordshire and West Essex Integrated Care Board (HWE ICB) welcomes the opportunity to provide this statement on the East Anglia's Children's Hospices (EACH) Quality Account for 2022/23. The ICB would like to thank the hospice for preparing this Quality Account, developing future quality assurance priorities and acknowledging the importance of quality at a time when EACH continues to deliver services during ongoing challenging periods. We recognise the dedication, commitment and resilience of staff and volunteers 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 HWE ICB have been working closely with EACH 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 EACH Quality Account has been reviewed and checked against data sources, where this is available, and confirm this to be accurate and fairly interpreted to the best of our knowledge.

When reviewing the progress highlighted against priorities that were set out for 2022/23 clear improvements are evidenced. Achievements against the 4-year strategic plan and the quality priorities, including increase in short break care, investment in people initiatives, prioritisation of staff education and wellbeing, and promoting closer to care decision making are reflected in the positive feedback from the patients, carers and families.

The ICB are pleased to see that priorities for 2023/24 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.

The ICB recognises the challenges experienced by the hospice in 2022/23 and we look forward to a continued collaborative working relationship as well as building on existing successes and collectively taking forward needed improvements to deliver high quality services for this year and thereafter.



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

Dr Jane Halpin, Chief Executive

Rt. Hon. Paul Burstow, Chair



EACH Response:

Thank you for your positive feedback on our quality account; and we too look forward to our continued partnership.

Pól Toner RN

Director of Care

East Anglia's Children's Hospices (EACH)

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

Quality Account 2022-2023

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 encouraged to see that EACH have successfully provided 16% more short breaks than last year, despite continuing to negotiate staff absences due to Covid-19 and the unpredictability of end-of-life care.
- EACH are clearly committed to listening to the perspectives of those who use their services. This is evidenced by their consultation of families prior to the development of their strategic plan.
- It is also valuable that staff have been readily consulted as part of EACH's strategic development.

- The expansive range of services provided by EACH is encouraging, particularly the support that it offers to families bereaved of a baby, child or young person not previously known to EACH before their death.
- EACH's optimisation of its wellbeing delivery following the Covid-19 pandemic is positive, particularly given the innovations made to groups that existed before the pandemic, and the increase in events for bereaved and non-bereaved families and individuals.
- It is encouraging to see the positive results that EACH have received in its robust audits of all interventions and sessions.
- We welcome the development of the Spiritual Care element of EACH's wellbeing service.
- The staff feedback received by EACH for their Palliative & End of Life Care (PEoLC) Training & Education programme is promising and sets a positive precedent for the introduction of Phase 2 of the Clinical Education Strategy.
- It is impressive that EACH achieved an Investors in People Award at their first attempt.
- As advocates of lived experience, we are encouraged to see that EACH's strategic commitments are underpinned by a desire to foreground the experiences and perspectives of the children and families that they support. EACH are, for example, aiming to contribute to the evidence base underpinning children's palliative care, and are continuing to reintroduce their face-to-face services in line with families' requests.
- It is encouraging to see staffs' level of involvement in academic publications and research presentations at an international level.

What is disappointing to see?

- It is disappointing to see that there are occasions where families' short breaks have had to be cancelled to ensure adequate nursing capacity.
- Whilst it is promising that there has been a significant reduction in CYP/family member-related concerns and complaints in 2022/23, it is disappointing that 'communication' and 'standards of care' remain common topics for complainants.
- It is disappointing to see that staff had to be reminded not to leave personal medication in the care area.

- It is also disappointing that EACH were obliged to review training following an increase in the number of incidents relating to controlled drugs. We do recognise that the training review reflects EACH's learning from these incidents but they should not be subject to increase again.

Is there anything that can be improved?

- Healthwatch Essex recognise EACH's capacity to work flexibly to meet the demand generated by increased referrals. It is encouraging that there are no waiting lists for services. However, we would like to see EACH's flexibility improve, potentially in terms of staff numbers, so that families do not need to have short breaks cancelled to ensure adequate nursing capacity.
- 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 a high percentage of complaints are focused on communication and standards of care.
- We commend EACH on their desire to capture feedback from children, young people, and their families. We would be interested to hear more about the ways in which children and young people are engaged with to capture their perspectives. Can children who may not wish to provide verbal feedback or are unable to do so, to express their views through creative methods like collaging, drawing, painting, or sticker work, for example?
- There is scope for EACH to diversify their recruitment and engagement techniques to ensure the involvement of more families at the Nook Family Forum.

Listening to the voice and lived experience of patients, service users, carers, and the wider community, is a vital component of providing good quality care and by working hard to evidence that lived experience we hope we can continue to support the encouraging work of EACH (East Anglia Children's Hospices).

Dr Kate Mahoney

Research Manager, Healthwatch Essex

22nd June 2023

EACH Response:

Thanks for your feedback. Occasionally we do need to cancel planned care to ensure adequate staffing ratios. We have robust systems in place to cover staff absence including an active staff bank. Sometimes we divert our staffing resource towards end of life care which can be unpredictable and it is not always possible to continue to deliver all planned care concurrently. Our staffing establishment has been increased for 2023-2024 and includes additional Nurse and Care Assistant posts. We continue working hard to recruit into our vacancies.

Although there has been a reduction in complaints and concerns we acknowledge that the common themes remain 'communication' and 'standards of care'. There are limited sub options in our incident reporting system and the other reporting options are 'service user information', 'amount of care and support' and 'transition process' which are more specific cause groups and less applicable for most concerns raised. I agree that it is disappointing that we had to remind staff not to leave personal medication in the care area. It is unknown if the tablets found belonged to staff as service user families access the care floor.

All incidents including medicines management are reviewed each week by our Operational Leadership Team and also quarterly by the Medicines Management Quality and Safety Group to consider shared learning across our three hospices, trends and additional action required. Additional training was introduced in response to incidents involving CDs. EACH are also reviewing CD specific competencies.

Our aim is to increase Nurse and Carer numbers at all three sites. This will reduce the likelihood of EACH cancelling sessions and increase our ability to retain planned care alongside end of life care provision.

We are currently reviewing service outcome measures to collect service user feedback for our range of services. Previously we have used alternative methods such as collaging, posters and drawings.

We are currently reviewing the terms of reference for our family forums and have started inviting families input via our quarterly family communications and spreading the work of the family forums at our larger face to face events.

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

Feedback Statement
EACH Quality Account 2022/2023

- 1.0 Thank you very much for this very thorough and comprehensive Report.
- 2.0 We note the progress that has been made with the 2022/23 priorities
- 3.0 In some of the areas of the report, it is not clear whether the level of staffing relates to all three sites or individual sites.
- 4.0 It is incredibly positive to see all the work taking place on clinical education, in particular the positive impact the PEoLC Training and Education Programme has had for staff. Regarding the Essential Role Specific Training it would be helpful to understand if clinical staff are trained following incidents rather than ensuring the whole clinical staff team are trained appropriately.
- 5.0 We are pleased to be working with EACH on the Norfolk and Waveney Education Programme but note that this is being delivered across the Norfolk and Waveney system not the region.
- 6.0 We note the ambitions for care over the next four years and the priorities for improvement. We look forward to seeing the positive impact that increased capacity will have on symptom management, short breaks and end of life care.
- 7.0 We note that the number of complaints for the Nook has decreased from 19 in 21/22 to 6 in 22/23. It is helpful to see a summary of the themes however would be useful to see this broken down by each Hospice.
- 8.0 It is positive to see the increase in referrals from last year, which might indicate improved understanding of the palliative care service that is offered.
- 9.0 It is good to see that none of the incidents reported fell into the amber or red category and that there was a decrease in green and yellow incidents from the previous year. It is worth noting that an increase or maintenance of the number of incident reports is not necessarily a negative factor as it demonstrates openness within the organisation.
- 10.0 On page 15, under the review of the services, you refer to “universal level” emotional support – this is not described or defined and therefore not clear.
- 11.0 On p.23, under Priority 1, there is a referral to “nursing posts” in inverted commas. This implies that they are not necessarily qualified nurses, and it would be good if this could be clarified, or the inverted commas removed.
- 12.0 There is a huge amount of work in this report, which is interesting, but it is difficult to extract the quantitative and qualitative data that informs the ICB of any areas that

have improved or that may require further scrutiny. The length of the report and trying to extrapolate the information make it more difficult to do justice to the excellent work done by EACH.

- 13.0 The CYPM team within the ICB is concerned that there has been a recent exodus of the very experienced senior management within the care team at EACH. There is a brief reference to this but no information about the plan going forward and how the staff team will be supported at a time of significant change.

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
Senior Clinical Lead for Complex Cases (CYP)
NHS Norfolk and Waveney CCG

Rebecca Godfrey
Programme Manager CYPM Team
NHS Norfolk and Waveney CCG

EACH Response:

Many thanks for your feedback,

I've numbered the relevant response accordingly to your feedback

Responses:

3. The additional 14 nursing care posts over 4 years referred to on page 14 relates to the whole care directorate, covering the three sites. This would include but not restricted to Nurses, CA, Clinical Educators.

4. Training initiated following specific incidents may be delivered as a refresher for staff and should complement and reinforce existing training.

7. We are currently reviewing the content of our reports and appreciate this feedback.

10. This would refer to support offered to all family members before and into bereavement such as conversations with families, phone calls and support offered outside of targeted sessional work where active referrals are in place for wellbeing support or mental health interventions.

11. The posts refer to 1 x Nurse and 1 x Care Assistant at each site plus an increase in over Clinical Educator and Physiotherapist hours.

12. This is timely feedback. We are currently reviewing the content of our full breadth of reports to ensure that they meet the needs of the intended audience. We are mindful that some are more heavy on qualitative data and will be considering content moving forward.

13. There is no doubt that there has been significant change within the senior level of the care directorate, over the last year. Internal interim appointments are in place, with substantive recruitment to begin soon. The change has created some real development opportunities for staff and we are very excited about the future; care teams have been regularly briefed on these arrangements and locally the teams are being supported by their locality leadership teams.

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

