

EACH Quality Account

2020-2021

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.

This document can be made available in other formats on request from karen.self@each.org.uk

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Part I. Introductory Statement

In response to the wide ranging COVID 19 lockdown initiated on 23 March 2020, the delivery of EACH care services changed rapidly to ensure the safety of vulnerable children and their families and to comply with the mandatory stay at home guidance.

Whilst emergency and end of life care continued at home and in the hospice, all other face to face care and support activities paused and then were relaunched as a virtual hospice, delivering our wellbeing groups and activities, counselling and therapies using video on line platforms, by phone or through accessing activities videos through the EACH website.

To support the NHS hospital bed capacity and help keep very vulnerable children safe, a small number of children were transferred to the hospices or received their treatment with us at one of the hospices. In addition, the work of the specialist symptom management nursing service meant that 178 hospital admissions and 215 calls to GP services were prevented. This was critical to both families and the NHS at a time when it was at its busiest.

Staff and families adapted incredibly well to the situation we found ourselves in. But for families, as weeks became months, the toll of COVID and lockdowns became more evident. Families talked about their worries about who would care for their child if they became ill, the anger at not being able to access PPE for their local care staff which meant they were left on their own caring for their child 24 hours a day. Newly bereaved families struggled with not having the funeral they wanted for their child and not being able to be with their family and friends when they needed them most. Families were feeling isolated and alone.

Whilst we were able to provide support on line it was clear that we needed to provide more planned short breaks as well as emergency care as soon as it was safe to do so. During the Autumn of 2020, we were able to start offering this vital element of our service in the hospice and at home, for both day and overnight care.

We have also learned that for some families having access to online support suits them better than having sessions at the hospice or in their home and we will be continuing to offer this choice moving forwards.

The events of the past year have not only reminded us of the importance of the services we provide to children and their families but also how they can easily be forgotten in a system designed to care for the many rather than the few, and yet these few children are some of the most vulnerable and have the most complex health care needs.

Tracy Rennie

Tracy Rennie
Director of Care & Deputy Chief Executive
1st June 2021

Part 2. Priorities for Improvement for 2021/22 and Statements of Assurance from the Board

2.1 About EACH

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

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

Our Mission

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

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

- holistically
- centred on the family
- to all eligible families in East Anglia with 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 or 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- see Appendix I.

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.

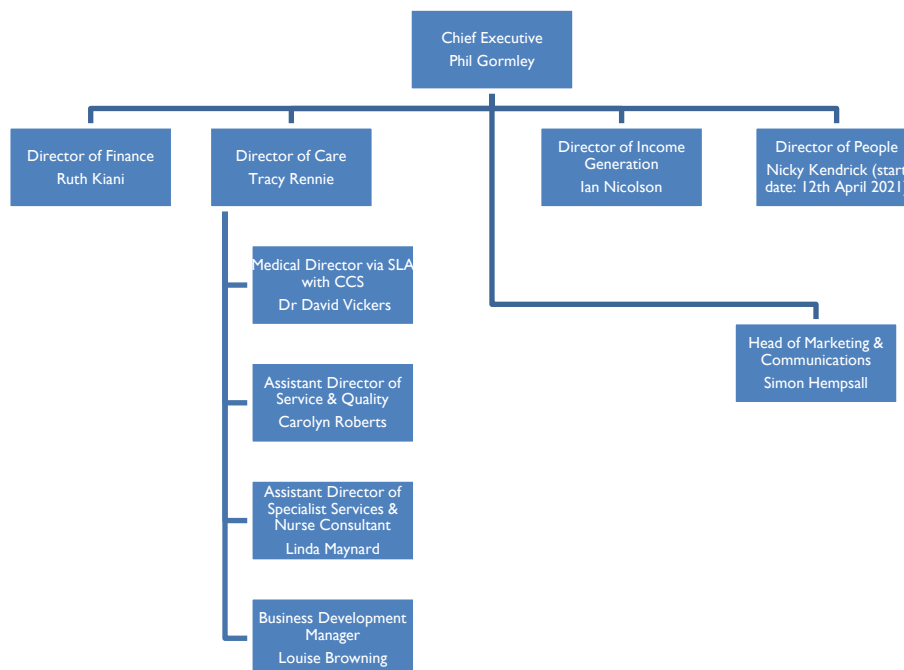
AND the CYP is less than 18 years of age.

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. Symptom management and specialist advice is provided across EACH by the charity wide Symptom Management Nursing Service and the East of England Children's Palliative Care Managed Clinical Network of Specialist Paediatricians and Nurse Consultant.

The Management Executive and Senior Care Management and Leadership structure for 2020-2021 is shown below. Phil Gormley started in post as the new CEO on 1st August 2020.



2.2 Priorities for Improvement for 2021/22

Our priorities for improvement are detailed in Table I. In these unprecedented times, the primary objective for EACH this year is to re-establish our operations and ensure organisational sustainability in the short and longer term, as we respond to the impact of the COVID-19.

We will keep the following under review, recognising this is an evolving situation, and updating our aims as required to respond to the needs of the organisation. This includes sustainability of our service provision, our workforce and our finances.

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 I Priorities for improvement	Desired outcome
Priority 1: Define the service delivery elements of the 3-year strategic plan	A sustainable care service delivery model is defined, informed by the changing care landscape of increasing complexity and demand.
Priority 2: Sustain nursing capacity to deliver end of life care and short breaks provision by increasing the nursing resource and improve recruitment and retention rates for nursing staff	Service Quality Improvement: To have the ability to deliver end of life care as well as an increased volume of short breaks by: <ul style="list-style-type: none"> • increasing the nursing team to 27 nurses and 27 senior/ care assistants. • Care Assistants undertaking additional skills to care for children/ young people whose conditions are stable.
Priority 3: Restate the approach to elements of the service	Improved quality & service user experience: Service specifications are developed for: <ul style="list-style-type: none"> • wellbeing therapies, groups and events • short breaks • physical therapies • hydrotherapy to better inform stakeholders of the services which are available, and they can expect to receive from EACH, ensuring equity and consistency across all the three hospice services
Priority 4: Improvements to care practice & processes	Improved quality & service user experience including: <ul style="list-style-type: none"> • more timely reviews of holistic needs assessments to ensure needs and goals are known and plans agreed to achieve these • greater accessibility to services for those with sensory deficits and behavioural support needs by ensuring all on line activities are fully accessible, providing staff training and improving care plans.

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.

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 2020-21, EACH provided the following services to children, young people and families living in Norfolk, Suffolk, Cambridgeshire and 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

During the report period, it was not possible to provide the hydrotherapy service due to the COVID-19 pandemic restrictions.

Care was delivered by our three-hospice based multi-professional teams at The Nook hospice in Norfolk, Milton, Cambridge and The Treehouse, Suffolk and by our EACH wide Symptom Management Nursing Service consisting of a Nurse Consultant, Matrons and Clinical Nurse Specialists. Staff are trained to deliver care wherever it is required.

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.

In addition to our usual services, EACH contributed to the wider regional responses to the pandemic.

To support NHS hospital bed capacity and help keep very vulnerable children safe, a small number of children were transferred to the hospices or received their treatment with us at one of the hospices.

The Milton Hub Crisis Care Service was established. This is a system wide collaboration that includes the Cambridgeshire and Peterborough Clinical Commissioning Group (CCG), Cambridgeshire and Peterborough Combined Authority, Cambridgeshire Community Services NHS Trust and Cambridgeshire and Peterborough Foundation Trust. The Milton Hub provides short break crisis care at the Milton hospice for families of children with complex health care needs living in Cambridgeshire and Peterborough some of whom may not be EACH service users, using the Milton workforce together with other nurses and care assistants from within the local health system.

As part of the end of life care hub (led and coordinated by St Elizabeth's adult hospice) in Suffolk EACH temporarily amended the age criteria for EACH service so that referrals for young people up to the age of 25 years on the end of life pathway could be considered for care. EACH counsellors also undertook some bereavement sessions to support the end of life hub.

During the pandemic we have learnt that the use of virtual technology has been possible to deliver clinical and mental health and wellbeing interventions to children and their families, as well as activities, groups and events such as virtual memory day and music group. We have also used the technology to have virtual meetings and training and to enable staff to work from home. Examples of virtual activities and support are Fishy Physio Fun, Play days, Musical Keys, Clown Doctors Clinic, Baby Massage, Parents night, Transition event (with Arthur Rank adult hospice), Bereavement Coffee Morning at Xmas.

Delivering core care services virtually has resulted in:

- The opportunity to develop service user engagement and co-production
- Quicker responses for families and decision making
- Decreased travel for families and staff resulting in saving time and travel expenses
- Increased resources for families to access to support their wellbeing on the EACH website
- Increased collaboration and communication with external partners including joining the local and regional networks to support each other for example securing the procurement of Personal Protective Equipment.

EACH hosts the East of England Children's Palliative Care Managed Clinical Network (MCN). This consists of the Children's Palliative Care Consultant, paediatricians with specialist palliative care expertise and a Children's Palliative Care Nurse Consultant. The purpose of the MCN is to provide:

- access to specialist medical advice 24/7
- clinical leadership to promote the provision of high-quality children's palliative care across universal, targeted and specialist services wherever and whenever it is required by children and their families across East Anglia.

The MCN brings together professionals and organisations to promote education and skills development, partnership working amongst those who support families throughout their experience of caring for children and young people with life-threatening illnesses and those with complex health care needs. The active education programme is available to all levels of interested professionals.

During 2020/21, the MCN provided specialist medical telephone advice, overnight and at weekends, to the EACH Symptom Management Nursing Service providing 24/7 care and support to families living in Norfolk, Suffolk, Cambridgeshire and North, Mid and West Essex. This meant that 178 hospital admissions and 215 calls to GP services were prevented. This was critical to both families and the NHS at a time when it was at its busiest.

The income generated by the NHS services reviewed in 2020/21 represents 100% of the total income generated from the provision of NHS services by EACH.

All services delivered by EACH are funded through a combination of fundraising activity and funding from NHS England, local NHS organisations and one County Council.

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

2.3.2 Participation in National Audits

During 2020/21 no national clinical audits and no national confidential enquiries covered NHS services provided by EACH.

The national clinical audits and national confidential enquiries that EACH was eligible to participate in during 2020/21 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 a programme of local clinical audits. The following were carried out by EACH in 2020/21.

1. Clinical Alerts
2. Medicines: Controlled Drugs & Medicine Administration Records (MAR)
3. Medicines Reconciliation Audit
4. Infection Prevention and Control: Hand Hygiene
5. Infection Control standards during COVID-19
6. Nutrition
7. Safeguarding - Safer Recruitment
8. Resuscitation

Audit Findings

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.

1. **Clinical Alerts** – The audit provided assurance that the process is effective.
2. **Medicines: Controlled Drugs (CD) & MAR** - There were no areas of significant concern noted. The CD book for the most part is completed as per policy. The

quality of recording in comparison to the 2019 audit was improved but with some of the same errors continue to be noted e.g. contemporaneous recording in the care record after CD administration. This has been addressed by highlighting the importance of capturing the efficacy of medicines to staff during training. The consistent recording of weights on the MAR chart were much improved over previous years.

3. **Medicines Reconciliation Audit** – There was an improvement from the previous audit e.g. increased inclusion of the NHS number on documents. There were no areas of concern.
4. **Infection Prevention and Control: Hand Hygiene** - There were no areas of concern found.
5. **Infection Control Audit of National Covid Infection Control Arrangements**- No areas of concern were found. It was recommended that some signage was enhanced on the care floors and office areas.
6. **Nutrition** – There were no areas of concern. However, it was noted that the nutrition care plan could be improved to include portion sizes.
7. **Safeguarding Audit of EACH Safer recruitment standards** - The records of all starters between November 2020 and February 2021 (n=15) were audited including application forms, pre-employment checks and completion of induction mandatory training. Compliance ranged from 86% (13 out of 15 records) to 100%. There was an immediate action to check the professional registration of two employees which was completed which no further action required. It was recommended that the Human Resource team guidance and processes be updated, and training provided. This has been completed.
8. **Resuscitation** – There were no resuscitation incidents during the reporting period. Whilst the audit standards were met, it was recommended that the content of resuscitation SI template and processes associated with recording of information and decisions are reviewed to aid ease of reference.

2.3.4 Participation in clinical research

The number of patients receiving NHS services provided or subcontracted by EACH in 2020/21, who were directly recruited during that period to participate in research approved by a Research Ethics Committee (the EACH Clinical Governance Committee) was 6.

Over the past 12 months EACH has participated in the following research:

- Children’s Palliative Care Outcome Scale (CPOS) Delphi Study. Kings College, London and Cicely Saunders Institute of Palliative care.
- The SHARE STUDY: How to **S**upport children with a life-limiting condition and their **pAR**ents during the COVID-19 outbreak?: understanding **E**xperiences, information and support needs, and decision-making University of Southampton, York University, the Martin House Research Centre, Together for Short Lives,

Southampton University Hospital NHS Trust and Leeds Teaching Hospitals NHS Trust

- Feasibility of a randomised clinical trial of transmucosal diamorphine vs. oral morphine for breakthrough pain in children and young people with life-limiting conditions (DIPPER study) Looking at the best needle-free, pain medicine for young patients (short title) University College London (UCL)
- Crisis Prevention rather than Crisis Management; the Health of Mothers of Children with a Life-Limiting condition. York University and the Martin House Research Centre

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

The Norfolk & Waveney Continuing Care Contract with EACH for the financial year 2022/23 did not set a CQUIN payment framework.

2.3.6 What others say about us

Care Quality Commission

EACH is registered with the Care Quality Commission (CQC). The CQC has not taken any enforcement actions against EACH during the year 2020/21. EACH has not participated in any special reviews or investigations by the CQC during 2020/21.

In February 2021, the CQC engaged with EACH as part of their new transitional monitoring approach. The approach was adapted to regulate services during COVID to monitor risk using the key lines of enquiries specifically for hospices. The CQC found no areas of concern.

External Professionals and Organisations – examples of feedback

'I would also like to thank everyone for their excellent care and support for X and his family over what has been a long palliative phase of his illness.' (Consultant)

'Thank you every-one for the care and support you gave X and his family through this very difficult time for them. He was well looked after by the collective team.' (Consultant)

'Can I just say thank you to everyone for all your care to X and support to his family. His illness was long-drawn out and his symptoms were challenging but I think together we were able to give him and his family really good palliative care. I'm sure we will all miss him.' (Consultant)

'We have such a good working relationship with EACH and have always found their experience and support invaluable.' (Nurse)

'I would like to thank everyone for working together so well to care for this young person and support her family. In spite of the current circumstances I think the teams, esp. SMNS, CCNT and lovely GP, have provided excellent end of life care for this young person and her family.' (Consultant)

'I just want to say a big thank you to you all for this invaluable learning experience and being so supportive as a team. Thank you for making me a better doctor!' (GP Trainee)

'I wanted to email you to feedback regarding how supportive the LTV [long term ventilation] team and I'm sure other team members (behind the scenes that we may not communicate with) have been during the pandemic.

We all changed the way we worked from early on in the pandemic and your team helped facilitate these changes to keep the LTV co-hort safe in the community. They have supported us in various ways including the use of video appointments with some of our vulnerable patients with a staff member in the home, facilitated training for families member that couldn't come into Addenbrooke's due to visiting restrictions and various other ways.

So in conclusion a thank you for their support and continued support in the future'. (Nurse)

'Firstly, thank you so much for your email; I am very pleased that X was able to come for a much needed stay in the EACH 'Hub' last week and I hope that all went well. I've heard some very positive feedback from our carers of how much they enjoyed coming to EACH and how welcoming everyone was. Would you please convey our sincere thanks to your team for making this work so well'. (Charge Nurse)

'I want to start by thanking you for having me work with your team. They were so welcoming and supportive whilst I was getting to grips with how the service worked. I really enjoyed my time with the staff and those wonderful children and it was such a great experience for me to be able to actually interact with children and learn some techniques and approaches I wouldn't otherwise know. The chef made me an absolutely delicious lunch, which was very much appreciated and everyone was very caring of each other, there were regular drink checks (to ensure everyone either had a drink or was given one). It is just an overall lovely place to work and I think your team really enjoy their work'. (Healthcare Assistant)

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 & Protection Toolkit.

NHS Number and General Medical Practice Code Validity

EACH did not submit records during 2020/21 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 have attained the standards required in the NHS Data Security and Protection Toolkit for 2020 /21.

2.3.8 Clinical Coding Error Rate

EACH was not subject to the Payment by Results clinical coding audit during 2020/21 by the Audit Commission.

Part 3. Review of Quality Performance

Over the last 12 months, EACH cared for 458 children and young people. This is a decrease from 472 children and young people in 2019-2020 and is as a result of fewer referrals during the early stages of the pandemic. 259 family members received virtual and face to face

wellbeing interventions. In addition to this, families benefited from a range of family events and activities including memory day.

During the reporting period, there were 90 children / young people referred to EACH, a total decrease across all three localities from the previous year (n=108).

We provided end of life care and support to 35 children or young people and their families. This is significantly less than the previous year (n=54). Less end of life care was provided to babies under the age of 1 and children aged 1-4 years. As a result of lockdown, fewer referrals were made from the hospitals for neonates and babies under 1 year. In addition, for some of the children aged between 1 and 4 years it is possible that shielding helped to keep them well and free from infection.

Service Demographics April 2020– March 2021

	Milton	The Nook	Treehouse	TOTAL
Total New Referrals for year	35	27	28	90
Total Deaths for year	14	16	5	35
Total No. Lead Children for year	172	148	138	458
Total No. Family members (receiving wellbeing interventions)	75	126	58	259

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 2020/21

The priorities identified in the last Quality Account 2020/21 are recorded below followed by a response which reports progress on these.

Table 2 Priorities for improvement	Desired outcome
<p>Priority 1 -: Re-establish the delivery of our range of services for all families, as soon as it safe to do so, including new and innovative ways of working.</p>	<p>Deliver face to face specialist care</p> <ul style="list-style-type: none"> • End of life care & symptom management according to CYP / family choices • Crisis face to face care • Resume Help at Home service • By providing different ways for families to have experiences together in COVID secure ways e.g. families using facilities available in Hospice and grounds <p>Develop a virtual hospice approach</p>

	<ul style="list-style-type: none"> • Provide virtual wellbeing support and therapies via website, phone or on-line platforms • Virtual engagement with service users <p>Monitor Workforce capacity, prioritising service delivery accordingly</p>
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RESPONSE

All service elements except for hydrotherapy have been available to families, albeit it in a different way as a consequence of the pandemic.

We have continued to deliver urgent and end of life care across all settings which required ongoing dynamic risk assessment; designating COVID secure areas in the hospice building using ‘red’ and ‘green’ zones in the early stages and moving to pathways as the guidance was updated. Care procedures were adjusted to ensure staff and patient safety; correct use of PPE for different settings and type of caring interventions, developing video consulting systems for children with unstable and deteriorating symptom management needs and facilitating COVID testing for children who exhibited symptoms.

For families who wished for their child to have care at the end of their life in one of the hospices, we were able to manage our space safely to enable the families to stay and visit. This was extremely valuable for families at a time when there have been restrictions initiated in hospitals.

Planned short breaks were re-established in the hospice and the family home during the Autumn of 2020. This has included providing 889 overnight stays and 200 day care sessions in the hospice buildings and 101 community based sessions.

EACH’s immediate response included enabling ways for staff to ‘keep in touch’ with families on their caseloads. An important tenet in children’s palliative care, well understood in EACH, is that every interaction with a child or family member provides an opportunity for emotional health and wellbeing support. Maintaining this connection primarily through Family Coordinator calls has been key to building family resilience and coping.

Counselling and therapy interventions for service users across the age range have developed virtually (on line or by phone) after ensuring staff competency and adapting our IT systems. Anecdotal evidence demonstrated acceptability for service users who have engaged whole heartedly; some expressing a preference for the ‘difference and distance’ that a virtual on line consultation offers.

Therapists and counsellors have also developed a library of open access resources for service user emotional health and wellbeing support which are accessed through the EACH website including short activity videos and signposting to other useful links.

During the early part of the year, family pages website hits increased from 2,750 in February to 3,074 in May. 4,079 recorded in April. Google analytics showed an interesting trend of weekly spikes in activity which likely meant that users were checking back every week. A comparison of the top five pages accessed in May and in February had observed the inclusion of the Wellbeing resources for families which received more hits than the three main family pages did pre COVID. As a result, new and different resources have continued to be added to the family website pages.

In addition, EACH worked with the health care system to provide capacity and also to help manage clinical risk for the most vulnerable children. For example, in order to support NHS hospital bed capacity and to facilitate ongoing clinical management in a COVID free environment, two children were transferred from hospital to The Nook for commissioned overnight care; one received 64 days of care prior to discharge home.

Another child received their intravenous treatment intravenously at one of the hospices rather than in the hospital setting as the hospital setting was perceived unsafe by the clinical team.

As for many other health care and hospice organisations, the recruitment of nurses remains a key challenge. This impacts on our ability to deliver the volume of short breaks that we need to deliver. A priority for the coming year it to implement a range of measures to attract and retain nurses and to upskill our Care Assistant workforce to be able to increase the amount of nursing care that we offer.

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 33 to 25 this year.

Please see table below.

Number of service user concerns/complaints

Service	2019/2020	2020/21
Milton	13	4
The Nook	9	10
Symptom Management	1	5
Treehouse	10	6
Total	33	25

Summary of themes of service user concerns and complaints in 2020/21

Theme	Number
Communication	15
Amount of care and support	3
Standards of care	7
Total	25

Examples of changes to practice from the complaints include:

- Ensuring staff use body maps to record marks and skin integrity.
- Implementing a quality standard for when the nurse should attend the family home outside office hours.
- Implementing the use of virtual platforms to make clinical assessments when required.
- Ensuring Advance Care Plans are in place for all children and young people who are at end of life.
- Improving the written information about the service EACH provides at the end of life and after death to families and external professionals.
- Providing a freephone number for families and having an alternative contact telephone number for families accessing the SMNS nurse on-call in the event they are unable to do so via the Telephone Answering Service.

All concerns and complaints were resolved locally with oversight from the EACH Care Operational Leadership Team. 8 complaints and concerns were partially upheld, 9 were upheld, 7 were not upheld, 1 was not resolved initially as the parent temporarily withdrew their child from EACH services but they have since re engaged with the service.

3.2b Commendations

EACH received many commendations throughout the year 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.

'Parent expressed her thanks for all the support our team provided. She was very 'anti-hospice' from previous difficult experiences, so to hear how she has found our input beneficial was really heart-warming. Parent discussed that the reassurance of having someone to discuss things with and the timing of our involvement meant that we were supportive without being intrusive.'

Short Break Care

'X wants to say a big thank you for his stay! Thank you for all the hard work you put into organising it and to everyone that cared for him in that difficult PPE. We are so, so grateful. The way home from dropping him off I felt like I could metaphorically breathe out a bit for the first time in months! We really needed the break!'

'Thank you for everything. Thanks for having us. Thank you for all the support. Thank you for giving us amazing memories. Thank you for being an amazing team.'

End of Life Care and Bereavement Support

'X family have asked if could say a huge thank you to everyone who they have had contact with – either directly or indirectly. They told me today that these days have been very precious to them and that they are very grateful for all the support they have been given, they said it will be remembered by them for a long time to come. They left the hospice today, earlier than planned by their choice saying that they felt ready to go now.'

'I wanted to say a big thank you to the nurses who tended to my grandson. Sadly, he passed away in December. They were fantastic at what they were doing trying to keep him comfortable. I will miss him, but know he is at peace now. Could you thank the Clinical Nurse Specialists and the Music Therapist for helping with my grandson's care. We didn't see all of the palliative care nurses, but the care that we did see when we went to visit was absolutely fantastic.'

'Thank you so much for everything, you and the team have been so lovely and supportive and it's meant a lot at a really difficult time.'

Transition:

'We would like to take this opportunity to thank you all at EACH for a fantastic and thoughtful present for X. We have taken some pics of him opening them and he was very happy with all the goodies and the brush went down extremely well. A special thanks to the Music Therapist for putting some lovely music together which works soooo well. We have used it already a couple of times and I can see many more happy relaxing hours for the future for this young man. As we venture into a new chapter into this mans life we take with us some fond memories with the team and hope we can stay in touch.'

Wellbeing groups and activities

'Thank you so much for inviting us to use the play park yesterday. The children spent 5 hours there playing hide and seek in the fairy garden (sensory garden) and had so much fun on the play park. X has suddenly deteriorated and stopped walking and standing over lockdown this injection of fun was just what we needed. I had been a little worried we would have been stuck if it rained but the pergolas were perfect shade for us and would have kept us dry. We would love to come back over the holidays if there are spaces but fully accept lots of others may take you up on your offer. The

kids were so tired this morning I managed to clean my house and put on three loads of washing. Thank you for providing us a safe space in all the COVID chaos’.

Virtual Memory Day

‘Thankyou so much for the virtual Memory Day. It was still beautiful but in a very different way. A lovely time to reflect on my precious daughter. My family and friends also loved watching it’.

‘THANKYOU for putting together a virtual service for us to watch. It is a lovely way to remember my great niece and also her grandad (my brother). I have always enjoyed our day at Milton each year and a huge THANKYOU for the amazing food and ideas for the children that you all do’.

‘I would just like to say a huge thank you to everyone involved in the virtual memory day video. Although we couldn't have the usual memory day, I am so grateful that you have taken the time to offer an alternative way to remember our loved ones during this unusual time. Please pass on my thanks and gratitude to everyone for their hard work every year and keeping the memories alive of those we have lost’.

Virtual Clown Doctors clinic

‘Thank you, so nice to see someone different’.

‘Thank you, really brightened our day’.

‘Thank you for making us smile - really nice and she recognises your voices. The Clown Doctors are a significant part of our lives we have a catalogue of memories of photos with them taken at Treefest etc’.

‘Thank you, this has been lovely - so nice to do something different when we are at home so much’.

‘How good was that, that was great, thank you, X is in her own world but she enjoyed it’.

‘There's been a lot of crying and sadness in this house this week but that was so special for us all’.

‘Thank you to the Clown Doctors, that was really lovely. X was falling about laughing’.

3.2c Incidents and Accidents

EACH has 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:

Clinical intervention, Consent communication confidentiality, Documentation (care records), Infection control, Manual Handling, Medication, Medication Controlled drugs, Medication Homely Remedy, Pressure Sore, Resuscitation, Self-harm

Service User 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 service user information incidents by the Information Governance Management Group.

All service user 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: Staff were reminded to:

- check the list of controlled drugs list following an incident when a drug was not signed into the controlled drugs locked cupboard.
- check with a senior nurse if medication should be given or not following an incident where antibiotics had expired.
- sealed bottles of medication must be recorded on the reconciliation form.
- ensure Medicines Administration Records are tidy after a drug was missed due to several entries being crossed out.
- discuss ground rules at the start of virtual groups.
- complete body maps upon admission and discharge.

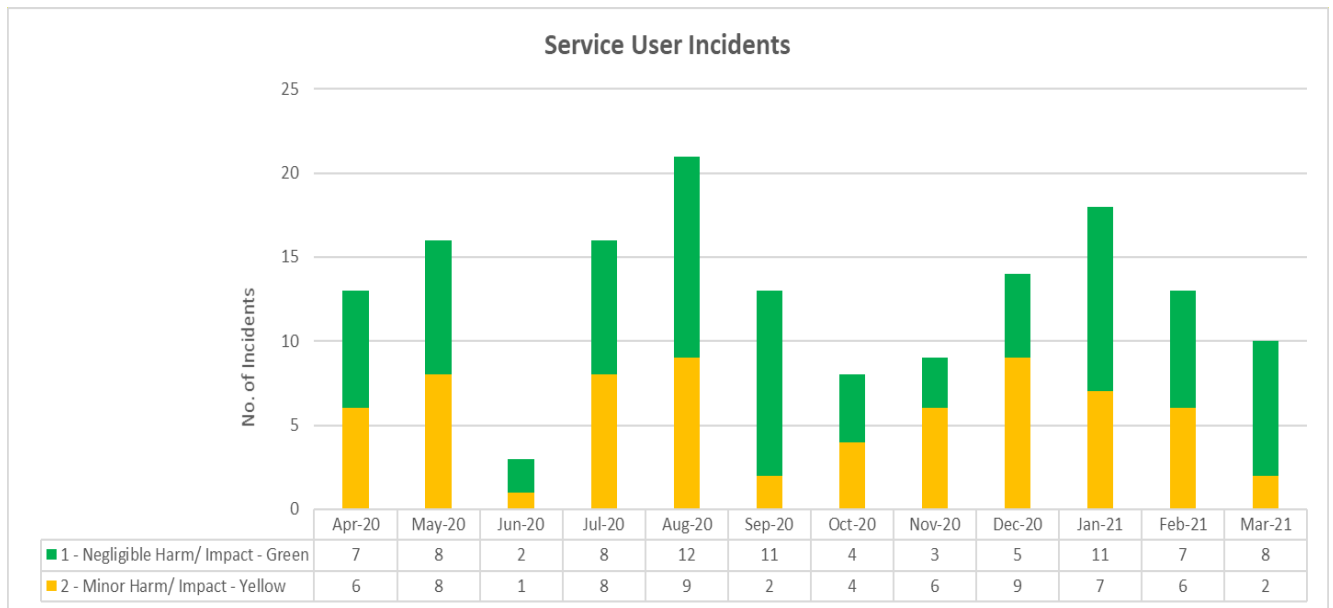
The above reminders to staff have been effective as no further incidents relating to these issues have been reported.

In addition, due to a trend in incidents highlighting that several moving and handling care plans had not been fully completed the Physical Therapies team started checking care plans prior to admissions and worked alongside the care staff to ensure they were completed correctly. The care staff reported that this was supportive and incidents relating to this issue have decreased. It also highlighted the complexity of the care plan templates and it is planned to review them this year.

Total Service User Incidents | April 2020 – 31 March 2021

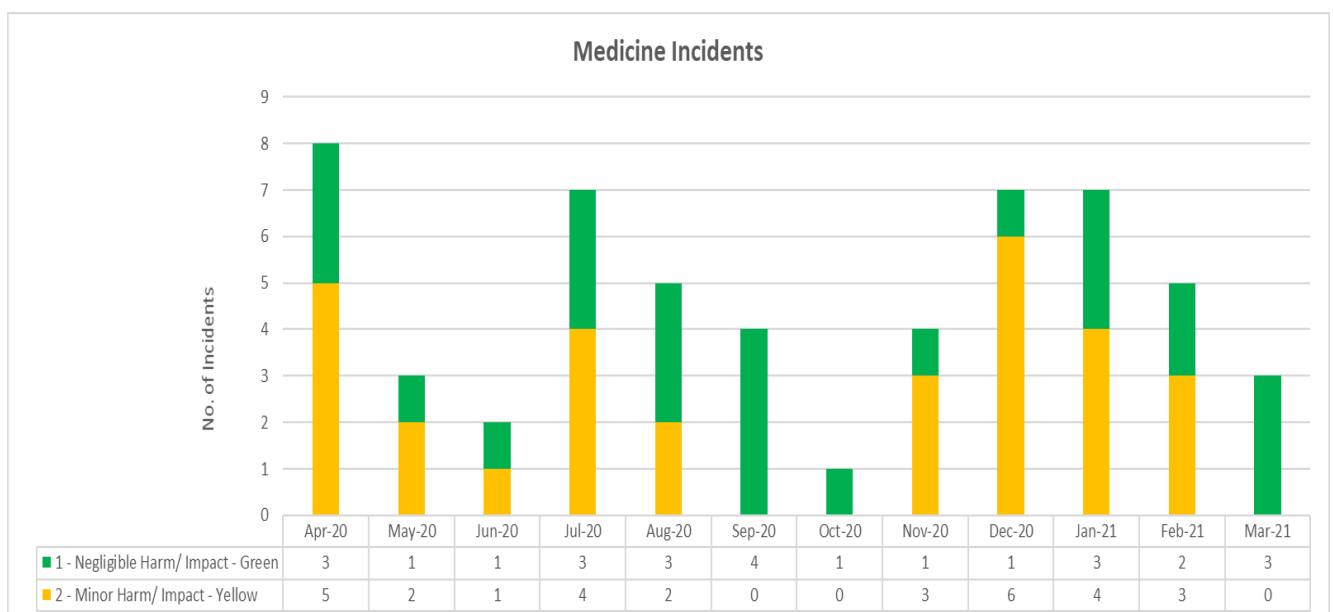
There was a total of 154 service user incidents including near misses across the whole care service, during the reporting period. This is a decrease from the previous year total of 229 service user incidents. It is likely that this was due to a decrease in short breaks service activity due to COVID-19.

There were zero (0) resuscitation or notifiable controlled drugs incidents and zero (0) notifiable clinical incidents during 2020/21.



The highest number of incidents 36% (n=56) related to medicines management; 21% (n=11) of these incidents related to reconciliation of medicine processes and 43% (n=24) to medicines administration. The number of medicines management incidents are lower than last year (n=84).

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.



3.2d Staff knowledge, skills and practice development

Due to COVID-19, the mandatory training programme was revised to ensure face to face training sessions were only delivered if essential. These were delivered within COVID secure arrangements. All other training was delivered virtually or via e-learning. For example, the Introduction to Palliative Care and Working with Service Users in EACH induction days for new staff were delivered virtually.

The education team developed a comprehensive training programme for care staff to complete including updating clinical skills and use of Protective Personal Equipment (PPE).

The evidence of learning and development activities carried out by staff demonstrates EACH's commitment to this aspect of quality assurance.

3.2d (i) Annual mandatory training

Annual mandatory training was provided to care staff in the following areas. EACH has a compliance standard of 90%

The levels of compliance for the year 1st April 2020 – 31st March 2021 are as follows:

Title	Compliance
Resuscitation and Anaphylaxis	92%
Moving and Handling	90%
Infection Control – Level 2	90%
Safeguarding Children Level 3	95%
Safeguarding Adults Level 2	93%
Management of Oxygen	90%
Fire Safety	89%
Food Hygiene	100%
Data Security Awareness	98%

The members of staff who had not completed training by end of March 2021 are in the process of doing so.

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 Group (corporate)
Physical Therapies Group

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

- Review operational risk

- 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 attended and participation in the following external groups:

<p>The East of England Managed Clinical Network (MCN) Norfolk, Suffolk, Cambridgeshire and North and West Essex. This is chaired by the EACH Medical Director and is attended by the Nurse Consultant Children’s Palliative Care and EACH Matrons.</p>
<p>Together for Short Lives Advisory Council. The Director of Care continued as a member of the TFSL Advisory Council.</p>
<p>East of England Children’s Palliative Care Forum and county based palliative care networks. These are responsible for developing and implementing the priorities of the managed clinical network. The regional forum is chaired by the Director of Care and attended by the Medical Director and Nurse Consultant. The county based networks are attended by the Nurse Consultant, Matrons and Service Managers.</p>
<p>East of England Palliative & End of Life Care Strategic Clinical Network. The Director of Care and the EACH Medical Director attended this in their capacity as chairs of the CYP Palliative Care Forum and MCN respectively.</p>
<p>East of England Regional Action Group for Young People. This is attended by an EACH Service Manager or Young Person Co-ordinator.</p>
<p>Royal College of Nursing: Children & Young People Palliative Care Community. The EACH Nurse Consultant is vice chair of this group.</p>
<p>Together for Short Lives / Association of Paediatric Palliative Medicine national research group. This is attended by Nurse Consultant.</p>
<p>Library and Information Service Manager and Nurse Consultant are members of the editorial team for the Together for Short Lives publication: Synopsis. This includes summaries of current research and evidence based practice articles</p>
<p>National Children and Young People Hospice LTV Forum. This group is chaired by the EACH Respiratory Nurse Specialist and attended by EACH Long Term Ventilation Nurses.</p>

3.2.d (iv) Scholarly Activity

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

- End of Life Discussions. How to do this well. Talking parents through death Norman, C presented at the Northern Ireland ECHO Knowledge Network Meeting

- EMERGENCY RESPONSE End of life care symptom control guidance for use in the COVID-19 East Anglia Managed Clinical Network (April 2020). Maynard, L and Sartori, P
- Neonatal Palliative Care and Symptom Management. National Neonatal Network. Maynard, L

3.2d (v) External Study and Conferences

EACH supported 13 applications from care staff to undertake one day training and extended study learning and development activities and attendance at virtual conferences during the reporting period.

Examples include: Reflective supervision, national long-term ventilation, postural management for daily life, paediatric parental nutrition, enquiries and explanations to enable wellness, Together for Short Lives conference, non-medical prescribing, respiratory care of children with neuro-disabilities, safe uncertainty, narcissism and echoism, paediatric epilepsy, aquatic therapy and understanding impact of bereavement on community.

3.2d (vi) Student Placements

Owing to the COVID-19 lockdown student placements were put on hold however, since short break care has resumed EACH has provided placements for three nursing students from the University of Suffolk over a period of 19 weeks.

3.2d (vii) Commissioned Training

216 external professionals benefitted from training and education events provided by the Managed Clinical Network which is hosted by EACH as follows:

- Management of Intravenous Therapy for Nurses
- Management of Subcutaneous medication Therapy for Nurses

3.2d (ix) Human Resources Indicators

Sickness absence

During the report period, the average sickness absence rate for care staff was 2.82%. The average sickness absence rate for the whole of EACH for the period 1st April 20 – 31st Mar 21 was 2.02%. The latest NHS data (published November 2020) put the rate for Community Provider Trusts at 4.14% and 3.54% for Community Provider Trusts in the East of England. This is the closest type of provider to benchmark against.

Staff Stability Index

The Staff Stability Index for the Care Directorate was 87% at the end of March 2021. This has been compared with the latest NHS data for Community Provider Trusts (published December 2020) which put the rate at 81.8% and 77.6% for the East of England.

At the end of March 2021, the nurse vacancy rate across the three hospice localities was 41% (n=11 out of 27 whole time posts). There was one vacant Clinical Nurse Specialist post (n=1 out of 9.5 whole time posts) and no Care Assistant vacancies (n =0 out of 27 whole time posts)

Recruitment of children's nurses remains a chronic issue and we continue to have a strong focus on this working on initiatives to engage and retain staff which feed into the wider organisation strategy around staff engagement, reward and benefits. This includes implementation of pay progression for care staff in 2021/22 and increased unsocial hours enhancement pay rate for Sunday and bank holiday working. We are also continuing to enhance the Care Assistant role to reduce reliance on nurses and revamping our approach to recruitment including raising awareness of the benefits of working at EACH, media and recruitment campaigns, webinars and virtual tours.

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

EACH believes that service users have a 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 service users 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.

Families views are sought in the development of EACH services, for example families were invited to complete an online family survey to gain their feedback on the services EACH provided during the COVID-19 pandemic to ensure we were continuing to meet their needs. Examples of feedback received from families are noted earlier in section 3.2b.

All families engage in a holistic needs' assessment following their referral to EACH to identify their 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. An EACH family co-ordinator, who is a member of the team, is allocated to every family. They contact the family every 3-6 months to check how well the family feel their goals and outcomes have been achieved, and their level of satisfaction with the service they have received. It is also an opportunity to learn if needs and goals have changed.

EACH welcomes service users 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 service users 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 Forum

The Treehouse Family Forum met twice during the reporting period. The forum provides opportunity to receive feedback from families and to test out service developments and proposed changes to ways of working. Some of the areas the Forum has been involved with this year were:

- Family Zone on the EACH website.
- Media permission process.
- Family Memory Making
- On-line events

In the past membership and attendance at the forums in Milton and the Nook has been more of a challenge, and it is planned to introduce new look virtual forums in June 2021.

To make it easier for families to attend, the forums will be held virtually, for approximately one hour, online via Microsoft Teams, at a time to suit as many families as possible (this can include evenings). Meetings will take place every two months.

The Forums will provide the opportunity for families to share your feedback and views directly with the Chief Executive and Director of Care. This may include hearing family experiences of services, to input to and help shape future EACH care service delivery, or to help raise public understanding and awareness of the needs of families and the role of children's hospice services.

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.

During the locality team meetings there are sessions on staff wellbeing and staff are also invited to complete a wellbeing poll, based on The NHS 'how are you feeling' toolkit, during tri-site team meetings to monitor how supported the teams are feeling.

Care staff also have opportunity and are actively encouraged to submit their ideas to develop the service to the Care Operational Leadership Team. These ideas are discussed during weekly meetings and feedback is given to the member of staff.

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.

Investors in People

This year it has been agreed that EACH will work to achieve the Investors in People accreditation which will measure how well EACH lead and support our staff compared to other organisations. The aim is to develop a meaningful workforce strategy and culture to engage staff in improving service user experience and make EACH an employer of choice.

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 key 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.

3.5 Statements from Lead Commissioners and Healthwatch

EACH provides services across Norfolk, Suffolk, Cambridgeshire and Essex. This Quality Account has been sent to Clinical Commissioning Groups 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 2.

Responses have been received from NHS Cambridgeshire & Peterborough CCG, Healthwatch Cambridgeshire & Peterborough and a joint response from the Suffolk and North East Essex CCGs. These are included in Appendix 3.

Appendix I Conditions which may require palliative care (East of England 2016)

1. Life-threatening conditions

- In these conditions curative treatment is possible but may fail. Palliative care services are generally not involved during active treatment unless there are very specific needs e.g. for emotional support or short breaks, which cannot be met by other services.
- Palliative care services are usually needed if curative treatment fails and may be given alongside experimental therapies.
- Cancer and leukaemia are the most obvious examples, but children with congenital heart disease or renal or liver failure may follow this pattern.

2. Life-limiting conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and facilitating participation in normal activities.

- Examples include conditions such as Cystic Fibrosis and Duchene Muscular Dystrophy
- Children with these conditions usually live well into adulthood and rarely require palliative care input during childhood.
- A few children, whose disease progresses unusually quickly e.g. CF with progressive respiratory failure during adolescence, may benefit from access to symptom management and palliative care planning. This may include parallel planning during transplant assessment.

3. Life-limiting conditions which are progressive and without curative treatment options, treatment is exclusively palliative and may extend over many years

- Examples include Mucopolysaccharidoses, metachromatic leucodystrophy, Krabbe's disease, SMA type I and many very rare genetic and metabolic conditions. Children with a progressive clinical picture but no definitive diagnosis may also fit this pattern.
- Children with these conditions often need a wide variety of palliative care services at different times

4. Life-limiting conditions which are irreversible but non-progressive associated with severe disability leading to susceptibility to health complications and the possibility of premature death.

- Examples include severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury
- These children may have long periods of stability but may have chronic symptoms and pain syndromes and may also be at risk of acute deterioration

- Families may benefit from access to short breaks and emotional support plus symptom management and anticipatory planning

5. Children who have not responded to maximal intensive therapy (PICU or NICU) for a variety of conditions may be referred for palliative care support for withdrawal of intensive treatment.

- These children may need careful symptom management and transfer to home or hospice
- Families will benefit from access to emotional support
- A significant number of children survive withdrawal of intensive treatment: they and their families will need on-going symptom management and support

Palliative Care (supportive and end of life care) - A Framework for Clinical Practice in Perinatal Medicine BAPM (2010) - Candidate conditions for perinatal palliative care.

Category 1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly.

Category 2. An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. severe bilateral hydronephrosis and impaired renal function.

Category 3. Babies born at the margins of viability, where intensive care has been deemed inappropriate.

Category 4. Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, e.g. severe hypoxic ischemic encephalopathy.

Category 5. Postnatal conditions which result in the baby experiencing “unbearable suffering” in the course of their illness or treatment, e.g. severe necrotizing enterocolitis, where palliative care is in the baby’s best interests.

Appendix 2 Commissioners and Healthwatch contact details

ICS area	Clinical Commissioning Group	Commissioning Group Contact	Healthwatch contact
Norfolk & Waveney	Norfolk & Waveney CCG	Tracy.mcclean1@nhs.net jack.murphy4@nhs.net	Alex.stewart@healthwatchnorfolk.co.uk Chief Executive Tel: 0808 168 9669
Suffolk & North East Essex	Ipswich & East Suffolk CCG West Suffolk CCG North East Essex CCG	peter.broughton@suffolk.nhs.uk lauren.howard5@nhs.net	Andy Yacoub Chief Executive Info@healthwatchesuffolk.co.uk Tel: 01449 703949
Cambridgeshire & Peterborough	Cambridgeshire & Peterborough CCG	Delyth.yates@nhs.net Karlene.allen2@nhs.net	Sandie Smith Chief Executive Sandie.smith@healthwatchcambspboro.co.uk Tel: 0330 355 1285
Mid Essex	Mid Essex CCG	Susanna Vaughan (susanna.vaughan@nhs.net)	Samantha Glover Chief Executive enquiries@healthwatchessex.org.uk Tel: 0300 500 1895
West Essex	West Essex CCG	Rosalind.French@nhs.net	

Appendix 3 Commissioners and Healthwatch Responses

The following responses were received.



East Anglia Children's Hospices (EACH) Quality Account 2020/21

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 during very difficult times.

It has been the most challenging of years for all health and care services. The adaptability of EACH to rise to these challenges and maintain support for children and families is to be commended. Healthwatch Cambridgeshire and Peterborough is aware of the development of the Cambridgeshire and Peterborough Palliative and End of Life Hub and looks forward to children and young people's services being part of this.

EACH's open approach complaints and learning through feedback is to be commended. The commitment to listening to families, children and young people is evident throughout this Account. Healthwatch Cambridgeshire and Peterborough welcomes the plan to bring virtual family forums to Milton.

Healthwatch Cambridgeshire and Peterborough offers EACH support to amplify the voice of families, children and young people in whatever way we can and sends the organisation every good wish for their future work.

EACH Response:

Thank you for your response. Your positive comments are welcomed.

Carolyn Roberts

**Assistant Director – Quality and Service
East Anglia's Children's Hospices (EACH)**

23rd June 2021

Dear, Helen

Email: lesleydeacon@nhs.net
Web: www.cambridgeshireandpeterboroughhccg.nhs.uk

Re: Quality Accounts Acknowledgement

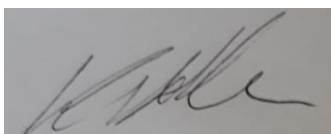
Thank you for submitting your quality accounts for Year 2020/21.

We acknowledge receipt of your accounts and have reviewed the content.

EACH is commended for continuing to deliver urgent and end of life care across all settings with dynamic risk assessments during Covid, updating and amending pathways, adjusting some procedures in ensuring quality care. EACH have established a clear outline of Priorities for Improvement for 2021/22 focusing and outlining the four priorities a sustainable care service deliver, the service, service user experience to determine holistic quality of the service.

We would like to take this opportunity to thank all staff for their hard work, dedication and professionalism throughout the Covid pandemic.

Yours sincerely,



Karlene Allen

Deputy Director Maternity and Children's Commissioning /Deputy Chief Nurse

EACH Response:

Thank you for your response. Your continued support of EACH is acknowledged and appreciated.

Carolyn Roberts

**Assistant Director – Quality and Service
East Anglia's Children's Hospices (EACH)**

Response from Lauren Howard, Senior Contract Manager, North East Essex CCG on behalf of the Suffolk & North East Essex CCGs:

Thank you for sending this through. Peter [Broughton] and I have now reviewed this document. We would also just like to confirm we have sent this on to our quality team who have not as yet responded, however, as we were aware of your deadline of today we wanted to provide our comments in the meantime. When the quality team respond, we will of course forward on any comments they may have.

It is evident you have adapted well during COVID and helped avoid admissions and calls towards other areas of our health system, the CCG appreciates your hard work throughout the last 18 months.

In relation to the managed clinical network the CCG recognises the importance of this access to 24/7 specialised medical advice and the clinical leadership promoted wherever required.

You have clearly identified your key priorities for improvement which demonstrates your commitment to continuous improvement. As above, we feel comment would best be made by our quality colleagues.

Its great to see the number of complaints have decreased, the highest trend of complaints appears around communication, we wondered whether you feel this number has been impacted by COVID? In relation to the standard of care complaints, is there any further information you can share on this, for example are all standard of care complaints centred around the same areas?

Having read the statements from families who have used the service it is evident what a difference you make to families which is fantastic to see.

We are extremely grateful for the information shared with us and we very much look forward to continuing work with you over the next year.

EACH Response:

Thank you for your response. It is possible that communication may have been impacted by COVID as some families have felt more isolated and our normal methods of providing care, support and communications have been disrupted.

With regards to the concerns and complaints raised about standards of care, there were no specific themes or areas. One related to care at end of life including an issue with making contact with us and an understanding of the service that we provide as part of the network approach. Several concerns were raised by one family in relation to their child whose individual needs are complex. We have been working with the family to resolve these.

Carolyn Roberts
Assistant Director – Quality and Service
East Anglia’s Children’s Hospices (EACH)

Statement from West Essex Clinical Commissioning Group

West Essex Clinical Commissioning Group is responsible for commissioning hospice care from East Anglia's Children's Hospices (EACH) for children and young people with life limiting illness in west Essex.

Completion of a Quality Account can be challenging for hospices as some of the required information is data collated for acute hospitals. However, there are other data sets that can be used to reflect the hospice service.

West Essex CCG works closely with EACH as an essential partner in care for children and young people with life limiting illness and their families. The involvement of EACH in supporting children's timely discharge from hospital to their preferred place of care is invaluable.

The production of this year's Quality Account has been challenging for all providers, the Department of Health and Social care considered an extension for publication to the deadline of 30.06.21 (a significant extension to the time frame was enabled in 2020), however confirmation was received in May that there would not be an extension this year.

NHS West Essex CCG would like to commend and thank all the staff and volunteers that work for East Anglia's Children's Hospices in relation to their response to the Covid-19 pandemic. Staff responded with professionalism, energy and adaptability. Their team work and continued energy has enabled the care of children, young people and their families to continue during the challenging time of the pandemic.

In April 2020 three of EACHs locations were rated as 'Outstanding' by the Care Quality Commission (CQC) this is an incredible achievement.

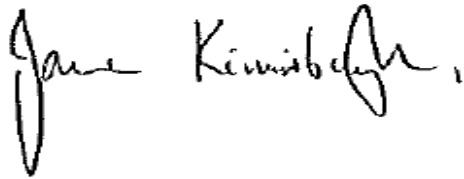
EACH has included progress on their priorities from last year, the information explains what was achieved and that the on-going priorities will be carried over into the coming year.

The priorities for 2021/22 have been identified and relate to the organisation's recovery from the COVID – 19 pandemic, getting back to "normal" and improved services for children and young people and caring for staff.

Whilst the organisation did not need to take part in any national audits within the year, there are explanations of changes to care that have been made as a result of local audits.

We confirm that we have reviewed the information contained within the Account and checked this against data sources where these are available and it is accurate in relation to the services provided. Some of the data that is required to include a comparison of the organisations results to the highest and lowest scores of other organisations has not been included because there is no national data set for hospices in terms of palliative care. We have reviewed the content of the account; it complies, on the whole, with the prescribed information as set out in legislation and by the Department of Health.

The CCG would like to extend its thanks to all the East Anglia's Children's Hospices staff for their dedication and commitment to the people they care for and how they have provided compassionate, supportive care to people through the pandemic.

A handwritten signature in black ink that reads "Jane Kinniburgh". The signature is written in a cursive style with a large initial 'J'.

Jane Kinniburgh
Director of Nursing and Quality
Hertfordshire and West Essex Integrated Care System
June 2021

EACH Response:

Many thanks for the statement; your positive comments and continued support to EACH are appreciated.

Carolyn Roberts

**Assistant Director – Quality and Service
East Anglia's Children's Hospices (EACH)**

Healthwatch Norfolk Statement East Anglia Children's Hospices Quality Account 2020-2021

Healthwatch Norfolk (HWN) acknowledges the services provided by the East Anglia's Children's Hospices (EACH) cover the East Anglia region, and welcomes the opportunity to review the draft EACH Quality Account 2020-2021.

Part 1 Deputy Chief Executive Statement

The opening statement acknowledges the rapid changes to the EACH care services due to the Covid-19 lockdowns and restrictions in place for the year under review. HWN notes the prevention of 178 hospital admissions and 215 calls to GP services due to the work of the specialist symptom management nursing service, which supported the NHS bed capacity during the challenging and critical times of the pandemic.

It is interesting to read that the virtual hospice has been well received and will continue to be offered as part of the service going forwards.

Part 2 Priorities for Improvement 2021-2022

There is a clear mission statement, with services being delivered wherever they are needed. There is an organisational leadership structure chart included.

As we look to the future EACH identifies four priorities for the coming year, and beyond. The priorities are clearly laid out and have very clear desired outcomes. The priorities promise to offer a sustainable delivery model, increase the nursing resource, and improve recruitment and retention rates. Service specifications will be developed to better inform stakeholders of the available services. In addition, EACH strives to improve practices, processes, and accessibility.

During the pandemic EACH made rapid changes to both support families and staff, but also to support the NHS. During these challenging times, the increase in EACH's digital footprint has resulted in a variety of activities being available virtually. This has had multiple benefits for both families and staff, and EACH will continue to offer a virtual hospice, alongside the vital face to face care provided by EACH.

Participation in Clinical Audits

EACH has a programme of local clinical audits, with eight clinical audits completed in 2020/21. The audit programme shows evidence of recommendations, and provides comparisons to previous audits, including improvements to these audits.

Professional Feedback

HWN note that EACH engaged with the Care Quality Commission (CQC) in February 2021, as part of the CQC's new transitional monitoring approach. The CQC found no areas of concern. The inclusion of multiple statements from professionals again demonstrates a real sense of excellent external working partnerships, and the value professionals gain from working with EACH.

Data Quality

EACH completed work to ensure compliance with the Data Protection Act 2018, the National Data-Opt Out Programme, and the Data Security & Protection Toolkit.

Part 3 Review of Quality Performance

Over the last 12 months EACH has seen a decrease in referrals during the early stages of the pandemic. The service demographics are clearly laid out, and EACH make the correlation between the lower number of end-of-life care provided to 1–4-year-olds and the shielding that was in place during the pandemic, with the possibility of shielding helping to keep them well and free from infection.

Review of Priorities for Improvement 2020/21

The priority identified in the Quality Account 2020-21 is clearly tabled, and naturally focusses on re-establishing the delivery of the range of services for all families and including new and innovative ways of working. The desired outcomes include delivering face to face specialist care and developing a virtual hospice approach. The account identifies that EACH has achieved their priority and should be commended for providing such valuable care during such difficult and rapidly changing circumstances. Families have been able to stay at and visit the hospices whilst their child received end of life care, which has without doubt been invaluable during a time when hospital visiting restrictions were initiated. The outcomes demonstrate the need to keep both children and staff safe and highlights the value families place upon EACH services.

EACH have chosen to monitor further quality indicators:

Complaints and Concerns

EACH recognise that a concern or complaint is an opportunity to improve care. The report includes a breakdown of the number of service user concerns/complaints. The Nook, based in Norfolk, has received 10 complaints during the reporting period 2020/21, as opposed to 9 during the 2019/2020 period. The report includes a thematic table and identifies changes to practice following concerns/complaints. All complaints have been resolved locally.

Commendations

The account includes many commendations and demonstrates the value children, young people and their families place on the services provided by EACH. The commendations cover many aspects of the service, but all provide a sense of how much these services mean to the families, especially during such difficult and challenging times.

Incidents/Accidents

EACH shows a positive approach to incident reporting, with the resulting learning being shared across all teams. The account includes examples of incidents and the resulting learning from this. The highest number of incidents is related to medicines management and highlights the complexity of care the children and young people receive at EACH.

Mandatory Training

Compliance levels are above the EACH compliance standard of 90%, with the exception of Fire Safety, although this should now have been achieved due to EACH's training plan.

Quality and Safety Framework

The account shows EACH's commitment to robust evidence-based practice and shared learning, with participation and attendance at external practice development groups contributing to this.

Due to Covid-19 student placements were put on hold, however since the short break care has resumed EACH has provided placements for three nursing students, providing, no doubt, an invaluable learning experience for these students.

Nursing vacancy rates have risen to 41%, evidencing the chronic recruitment issues faced by EACH. EACH include various initiatives in the account on how a wider organisation strategy will benefit staff engagement, recruitment, and retention.

Involving Children, Young People and Families

EACH provide a detailed account of how children, young people, and their families can be involved in the decision-making processes, and the development of services. HWN is pleased to note the planned introduction of new look virtual forums (including evenings) and hope this will encourage greater Family Forum membership.

Staff

Staff are offered a variety of ways to communicate and share practice ideas. It is very positive to read that staff have an opportunity to talk about their wellbeing, especially as all health settings have faced such rapid changes due to the pandemic.

The account is easy to read, well laid out, and contains information on how to obtain the account in alternate formats if required.

We would welcome any opportunities to work with EACH in ensuring that the views of patients, their families and carers are central to their Quality agenda and improvement work and to make recommendations for change as and when appropriate.

Alex Stewart
Chief Executive Officer
June 2021

EACH Response:

Many thanks for your comprehensive overview of the EACH Quality Account, your comments and continued support are appreciated.

Carolyn Roberts

**Assistant Director – Quality and Service
East Anglia’s Children’s Hospices (EACH)**