

We care for babies, children and young people in the East Midlands – wherever they are. Hospice | Hospital | Home

Contents

Rainbows Vision, Mission and Values

Part One

Statement of Quality by the Chief Executive Officer

Part Two

What We Achieved in 2022/23:

- Patient Safety
- **Clinical Effectiveness**
- Patient Experience

Family Story

Part Three

Priorities for Improvement 2023/24:

- Patient Safety
- Clinical Effectiveness
- Patient Experience

Part Four

Statements of Assurance

Review of Services:

- **Financial Considerations**
- Information Governance

- Clinical Coding Error Rate
- Data Quality
- Participation in National Clinical Audit
- Local Clinical Audits
- Infection Prevention and Control
- MHRA and Patient Safety Alerts
- Research
- Transition and Youth Work

Part Five

What others say about us:

- Care Quality Commission (CQC)
- Commissioner Quality Assurance Visits
- Areas for Further Improvement
- Child, Young Person and Carer's Feedback
- Complaints, Concerns and Compliments

Part Six

Review of Quality Performance:

- Quality Schedule
- Incident Reporting
- Workforce
- Equality, Diversity and Inclusion Strategy
- Freedom to Speak Up
- Safeguarding
- Duty of Candour
- Activity Report

Part Seven

Service Improvements

- Hospital Nurses •
- Safety and Risk Briefings
- Development of the Non-Medical Workforce
- Medicines Management

Part Eight

The Board of Trustees Commitment to Quality

Part Nine

Responses to Hospice Quality Account

Appendix



Our Vision, Mission and Values

Our Vision

The Rainbows experience wherever you are.

Our Mission

Across the East Midlands we will:

- Transform care for those babies, children and young people who have a life-limiting or life-threatening condition
- Relieve the pain and symptoms associated with life-limiting/life-threatening conditions
- Support every baby, child and young person to achieve their full potential
- Create memories for families to treasure
- Provide comfort and compassion at the time of and following the death of a baby, child or young person



Our Values

...because **WE CARE** we are:

Our Values	Evidenced by
Welcoming	 We will welcome you to Rainbows with a smile and open arms. If you are a family member please make yourself at home. If you are a supporter thank you, we are so grateful to you. If you are a colleague, volunteer or Trustee we will value your contribution We will have a positive "can do" attitude, which we will demonstrate every day, through our body language and behaviour We will treat everyone as we would like to be treated and will consider others needs as well as our own, embracing and valuing differences. We will see everyone as an equally important link in the chain We will support others personally and professionally, especially when they are struggling or managing a stressful situation We will demonstrate care and compassion to everyone all of the time
Excellent	 We will work hard to be the best we can be at everything we do and we will play our part in helping others to achieve the same. We will constantly look for ways to be outstanding in all of our work. We will listen, we will learn and we will lead. We will be the best we can be in order to offer exceptional service. We will deliver care that reflects best practice and clinical excellence, and we will be outstanding across the whole of the organisation. We will actively participate in our development plans, using the appraisal process and taking personal responsibility. We will keep up to date with statutory training and access appropriate training opportunities. We will encourage people to be open about mistakes and how we can learn from them
Co-operative	 We will work together to create the best possible outcome for families, which is our single unifying goal We will take on board others' views and welcome feedback on how we could do things better We will develop trust through openness, honesty and consistency, to ensure that everyone feels safe to speak up and that people feel able to voice their views in an appropriate manner We will frame meetings and discussions with a positive message at the start and remain solution focused throughout We will demonstrate Rainbows values in all that we do and we will consider the impact that our behaviour has on others, either positive or negative

Our Values	Evidenced by
Accepting	 We will accept everyone because everyone matters. We will respect and embrace the differences amongst the diverse communities we serve We will be accepting and supportive of change, which includes seeking accurate information about the changes. We will constructively challenge proposals for change if we do not agree and offer alternative suggestions We will politely challenge inappropriate behaviour or poor working practices We will always seek accurate information and not contribute to Rainbows rumours We will accept other people's strengths and weaknesses and should not assume we are all the same
Responsive	 We will listen and we will learn. We will rise to the challenges we face and we will not give up. We will try new things and develop new services to meet increasing and changing needs We will do what we say we will do and hold others, respectfully, to account for their actions and behaviours and ourselves. Alternatively, we will provide an explanation if we are delayed or no longer able to do so We will work proactively and collaboratively, responding to different teams' needs We will constructively feedback to others and be willing to receive feedback We will try to see a situation from the viewpoint of others and respond in an appropriate way, considering what it must feel like to be in someone else's shoes
Energetic	 We will go above and beyond and we will make sure the efforts we put in matches our ambition. We hope our energy is infectious We will work together and celebrate together. We will cooperate as a team and acknowledge each other's success and achievements We will actively communicate the right information at the right time. We will be open and transparent at all times, helping and guiding each other We will show commitment to demonstrating the Rainbows values and we will aim to be the best we can be We will set ourselves stretching goals, going the extra mile where possible, to make a difference to others and to maintain the reputation of Rainbows

Part One

Statement of Quality by the CEO

This is our eleventh Annual Quality Account and covers the period between 1 April 2022 to 31 March 2023. I write this statement in the context of continuing to see and feel the effects of the pandemic, the economic crisis and social challenges currently being faced across the UK. These are challenging for most but the impact on our babies, children, young people and their families is profound and now, more than ever, they need access to the expertise and support that Rainbows offers.

As well as continuing to provide vital end-of-life care and symptom control for those children who simply do not live long enough, we have made real progress towards our challenging ambition to reach more babies, children and young people. This is part of a whole system approach and we are very proud of the work we have done with our partners and the continued expansion of our Rainbows in hospital service. This year we have been preparing to embark on the final element of our strategy 'Rainbows in the Community', aiming to continue to increase choice of place of care for our families, babies, children and young people.

Our people are our greatest asset and we recognise the current demands on our staff and volunteers. We remain committed to providing our people with the tools, resources and skills they need to be the best they can be. Their well-being is of paramount importance to us and we will continue to build on our well-being programme including the introduction of Mental Health First Aiders across the organisation. We continue to improve our communications, particularly in relation to how we tell our story to staff and how we hear about their concerns or challenges.

We have continued to invest in a large-scale IT programme, developing and expanding our digital platforms, that is transforming the way our staff and volunteers work, ensuring we can deliver high quality care in all locations. I am proud of all our staff and volunteers, the quality of care that the clinical team provide and the creativity and incredible resilience of all across the whole of the organisation; especially in their response to emerging from the pandemic and getting back to levels of activity that exceed what we were achieving pre-Covid.

We know there are challenges ahead and the impact of the current economic and social challenges is yet to be realised. However, I am confident in our ability to respond to those challenges and to deliver our ambitious plans for the future. We simply couldn't deliver our essential services without our supporters, and we would like to take this opportunity to thank them for keeping Rainbows in their hearts and minds.

To the best of my knowledge, the information reported in this Quality Account is an accurate and fair representation of the quality of services provided by Rainbows Hospice for Children and Young People. We hope you find this Quality Account both informative and useful and please do not hesitate to contact us with any questions or comments that you may have.

Jane Zurus

Jane Burns Acting Chief Executive Officer

Part Two

What we achieved in 2022/23

In line with our Strategy, Rainbows identified the following priorities for 2022/23

When our quality account was written last year, no-one expected that we would be experiencing an ongoing Global Pandemic. This, as in all health and social care services, has impacted our work programme and priorities set out last year. Our focus and priority has been to ensure the safety of our babies, children, young people, families and staff during these unprecedented times. Despite this we have made progress on all of our priorities.

Future Planning - Patient Safety

Priority 1: Implement a digital risk register using the Datix system and develop a pan organisational process

The system has been configured for Rainbows and the risks, both corporate and clinical, are being transferred from the paper-based system to the new digital system with the ability to run reports based on risk category and sub-category. Use of the system across the organisation provides a consistent approach to managing and reviewing risk.

Priority 2: Develop and implement Hospice metrics to demonstrate compliance with standards and evidence continuous improvement

Weekly data is collected by the Lead Nurse for Clinical Operations and provides information and opportunity to monitor and maintain the high standards of care provided at Rainbows. The weekly data collection includes quantitative and qualitative data about patient safety standards, clinical incidents (including medicines) and actions and learning from these, audit results and actions (including record keeping, medicine charts, tissue viability), infection prevention standards, occupancy statistics, staff and child and young person dependency assessments. The data is then collated into a monthly dashboard which is reviewed at the bi-weekly Good Clinical Governance Meeting and will be used as part of the daily review via the safety briefing and knowing how we are doing board.



Future Planning - Clinical Effectiveness

Priority 1: Embed the new Care IT system and HR database

SystmOne has been in place since February 2022 and is being used effectively to document all aspects of care delivered at Rainbows.

SystmOne Mobile was launched in November 2022, enabling staff that provide care in the home, community and other settings to ensure effective and timely documentation. SystmOne also allows all staff to access babies, children and young people's records and enables them to gain an up to date picture of plans and care delivered. The system also allows us to access a shared care record with consent of the family or young person. We have also amended and developed our policies and audit processes in line with SystmOne use.

Our HR database went live in the middle of 2022, giving staff the ability to access and manage holidays, training and absence. It gives the organisation more effective and robust data to manage HR processes and reduces reliance on manager input and improving communication.

Priority 2: Rainbows Admissions Nurses

The Admissions Nurse role has become an integral part of the Care Team. Our pre-admission service either in the family home, hospital or on the phone has allowed children, young people and families the time to ask questions and update care plans, and for the Admissions Nurse to ensure our children, young people, parents and carers are aware of what they need to do to have a smooth and quick admission on the day they arrive for a short break or hospital to home step down. The procedure on the day of admission is now done in a much more timely way with care team nurses knowing exactly what needs to be completed to finalise the admission as this is all clear on SystmOne. Our Admissions Nurse is now using SystmOne Mobile when in the family homes, again allowing the process to be more straight forward and clinically effective.

Future Planning - Patient Experience

Priority 1: Implement the "Voice of the Child" survey at Rainbows

The Voice of the Child and Young Person survey was rolled out over a three month period from April to July 2022 at the end of short residential stays.

24 surveys were completed and the results demonstrated that children and young people using the Hospice benefitted from their stays. 20 children and young people had been involved in their own admission process; all had had the opportunity to speak with staff alone; and comments indicated that interaction with staff is highly valued.

Children and young people were asked to rate their stay out of 10 and the average score returned was 8.65. Where scores could have been higher these correlated with comments about poor WiFi; the necessity for staff to input codes to watch films and the pool being out of order. All these issues have since been resolved.

The survey has been edited to gain information specific to whether stays over the weekend are rated differently to stays during the week and will be rolled out again April – July 2023.

Priority 2: Introduce NHS England Improvement 15 Steps Challenge

The 15 steps toolkit has been adapted for use at Rainbows and introduced across the organisation via team meetings. The 15 steps challenge team have been recruited and briefed via a launch and mock walkaround to develop first impressions observation skills. The first walkaround was in February 2023. The challenge forms part of our programme of continuous improvement, helping us to understand quality care from a patient or family perspective. The team is currently drawn from non-clinical teams with plans to recruit parents/carers and young people once the project is established.

C's Story

C is a 23-year-old man with Duchene muscle dystrophy who was referred to Rainbows at age 11. Until recently he had not accessed care at the hospice for seven years.

A request for support was made by his respiratory physio who had concerns with regard to both his physical and mental health.

C received 24-hour support from an agency. He advised that he had not been out of his bed or out of the house for approximately two and a half years. He receives support from carers as Mum had had a stroke the previous year and was now unable to provide his care.

He had previously attended college from age 16 and obtained Level one and two in music. He was unable to continue Level three due to the impact of Covid-19 and the colleges concerns that they could not meet his needs and keep him safe.

During this time, he was admitted to hospital with a chest infection and was advised by a medical professional that a DNAR was in place.

This led C to feel that everyone had given up on him and he had nothing to get up for. Saying he felt like "they are just waiting for me to die".

Initial discussions around the DNAR decision led C to a better understanding of why that had happened and encouraged him to create a RESPECT document which detailed what he wanted to happen when his condition deteriorates. This gave him back a sense of control of his own care and treatment which he felt had been taken away from him.

It is important within Transition to ensure parallel planning. While we needed to know C's wishes at end of life we also needed to know his aspirations and to plan for living as well as dying.

C really wanted to return to college. Saying this would give him a "reason to get up and live my life."

Rainbows Transition support worker organised a respite stay at the hospice in order to help address anxieties that C had having not left the house for a considerable time. Transport was also arranged to support this. The respite stay also enabled C to have his first bath in two and a half years as well as increasing his confidence.

College was contacted and the possibility of him re-joining his course investigated. College needed to be supported in understanding changes in his condition and the level of support he would require. Multidisciplinary team (MDT) meetings involving C, his family, care agencies, college, transport and Transition support were organised, and after extensive input, resulted in C being able to return to college.

8

Part Three

Priorities for improvement 2023/24

Future Planning - Patient Safety

Priority 1: Implementation of Electronic Prescribing and Medicines Administration (EPMA) using SystmOne

Phase 3 of SystmOne implementation July 2023 - use of EPMA to support safer medicines practice and reduce risk of errors occurring. Ability to remotely prescribe supporting future medical model and non-medical prescribing. Increasing potential to use wider pool of Doctors to support Rainbows babies, children and young people.

Priority 2: Evaluate daily Safety and Risk Briefings (SARB) to demonstrate floor to Board identification and management of risk within the Hospice.

SARB was implemented in January 2023 as a mechanism to increase staff awareness and involvement in identifying and managing risk and safety concerns within the Hospice. Aim to be proactive and pre-emptive - 'Better Decisions Together'.

Three areas are discussed daily:

- Dependency and Capacity
- · Deteriorating babies, children and young people
- Any safety events/concerns

Evaluate the impact of SARB in October 2023, to identify any key themes, learning and potential need to change the process.



Future Planning - Clinical Effectiveness

Priority 1: Grow the non-medical workforce to support the sustainability of the medical provision at Rainbows and in the wider East Midlands community

Establish a non-medical workforce that can support all babies, children and young people accessing Rainbows services across Hospice, Hospital and Community.

Recruit further Advanced Clinical Practitioners (ACPs) over the next two years, to ensure 24/7 cover is available.

Support the training and education needs of the Clinical Nurse Specialist (CNS) workforce and new CNS posts.

Invest in enhanced practice education and training to include, Cardiff Diploma in Palliative Care, Non-Medical Prescribing and Advanced Assessment.

All Nurses will be trained to enable them to verify death.

Identify training needs of the workforce to support the increasing complexity of babies, children and young people - including catheter care, intravenous medicine administration, feeding, tissue viability and recognition of the deteriorating/sick baby, child or young person.

Priority 2: Implementation of Community and Outreach Services:

Hospice at Home - Providing palliative and end-of-life care to babies, children and young people with life-threatening/life-limiting conditions within their own homes, in order to give parents/carers increased choice for place of care/death.

Working alongside/in collaboration with existing Community Teams, not replacing, to improve provision of 24/7 care at home implementation October 2023.

Locality Based Family Support Services:

Modernisation of the current service to include digital care records using SystmOne mobile, review of caseload management, referral and acceptance criteria. Family Support Services will be county-based from April 2023, delivering care closer to home and ensuring our services are easily accessible to families, babies, children and young people.

Future Planning - Patient Experience

Priority 1: 15 Steps to be implemented within the Hospice

NHS England 15 steps challenge will highlight areas for improvement across the Hospice from the perspective of family first impressions. The 15 steps team will carry out regular walk arounds looking at four key areas, to ensure our services are welcoming, safe, caring and involving, well organised and calm. Feedback will highlight positives and recommendations. An action plan following the feedback will be developed as part of our approach to continuous improvement across the Hospice.

Priority 2: Engaging Integrated Care Boards (ICBs) to support collaborative quality visits incorporating CQC inspection process to ensure high quality, safe and effective service provision

To ensure our partner organisations, including ICBs, are engaged in the work that Rainbows does - we will encourage a collaborative approach to quality site visits. The aim of these visits will be to develop a culture of an open, honest and transparent approach to inspections and ensure that we continue to deliver high quality, safe and effective services, enabling us to provide assurance to the Board, users and partners.



Part Four

Statements of Assurance

There is a legal requirement for us to report on the following. These statements identify our position as set out in the Quality Account Regulations.

Review of Services (mandatory statement):

Rainbows is a nurse-led Hospice providing care and support for babies, children and young people with life-limiting and life-threatening conditions from birth to 25 years of age and their families. Reduction of age from 30-25 years was completed in December 2022. A team of GPs and hospital/community paediatricians supports us Monday - Friday in hours with an out of hours on-call service. A full time Advanced Clinical Practitioner also supports the medical workforce.

During 2022/23 Rainbows provided the following services to the NHS

- Hospice services short breaks, symptom management and end-of-life care
- Psycho-social family support services
- Specialist palliative care advice and support
- Palliative Care Clinical Nurse Specialists in Leicester and Nottingham hospitals
- Support to the NHS, including ongoing step down services, Covid-19 vaccinations and workforce sharing

Rainbows have reviewed all the data available to us on the quality of our services. Our Clinical Quality Assurance Committee (CQAC) chaired by a Clinical Trustee, meets quarterly. The Committee is provided with reports for assurance on the quality of care we provide, including clinical incidents and clinical audit compliance. CQAC submits a quarterly report to our Board of Trustees.

All Rainbows services are funded through a combination of fundraising activity and/or contracts with Integrated Care Boards (ICB's). Where NHS and Social Care funding is secured, this only partly contributes to the costs of clinical care of children and young people. Additional costs are supported by the charity and we are dependent on our fundraising activity. This income enables us to offer enhanced services to our families, including; music therapy, art therapy, complementary therapy, family accommodation, hospitality and bereavement support. In addition, on-going supplies and provisions, costs of maintaining the Hospice buildings and gardens are also reliant upon fundraising/charitable income.

A focus of our work in 2023/24 will be to further develop our relationships with ICB's and to increase Clinical Commissioning Funding from the NHS, by continuing to support NHS services with long term ventilation needs and step down of children who are medically fit for discharge. We will also continue to develop our Rainbows in Hospital services and aim to have a Rainbows Nurse in all hospitals across the East Midlands by July 2023. We will begin to deliver increased services in the community and home setting, in line with our five years strategy - including Hospice at Home services and Locality based Family Support services.

Our strategic priorities for 2021/25 aim to extend our services to reach more families of babies, children and young people with a life-limiting condition across the East Midlands:

- Rainbows in hospital
- Rainbows at Lark Rise
- Rainbows in the community

"The Rainbows experience wherever you are"

Financial Considerations

The income provided by the NHSE grants and statutory funding in 2022/23 was \pounds 1,443,000.

The remainder (86%) of the funds needed to run Rainbows services is generated through donations, legacies, fundraising events, retail shops and lottery.

Information Governance

Rainbows have updated their information governance policies and procedures in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018; and have continued to manage personal data in line with this legislation.

Clinical Coding Error Rate

Rainbows was not eligible to submit data to the Summary Hospital-level Mortality Indicator (SHMI) during the period 2022/23. Rainbows are not subject to the Payment by Results clinical coding audit during 2022/23 by the Audit Commission.

Data Quality

In 2022/23, Rainbows collected and submitted the following:

- Internal activity/performance data including Rainbows Nurses in Hospital activity and outcomes data to Clinical Quality Assurance Committee, Corporate Governance Committee and Board of Trustees
- Baby/child/young person specific data to ICB's
- Annual data to Together for Short Lives
- Baby and child death data to Child Death Overview Panel
- Data for the Safeguarding Audit Tool

Participation in National Audits

In 2022/23 there were no audits or enquiries relating specifically to specialist children's palliative care that we were eligible for.

Local Clinical Audits

The Rainbows Audit and Quality Improvement (QI) Committee continue to meet quarterly to drive improvement across the Hospice with a consistent approach to audit with common understanding across the Hospice. We are supporting a number of audit and QI projects across the Organisation including:

- The 15 Steps Challenge
- Safety and Risk Briefings (SARB)
- Introduce a new pain assessment tool for non-verbal babies, children and young people
- The Voice of the Child Survey
- "The Pebble in your Shoe" a new improvement initiative which invites staff to identify small but impactful issues that once resolved will make a big difference to their clinical efficiency, effectiveness and in turn be passed onto babies, children and young people and their families in improvements to services and their experience.

A programme of local clinical audits is still undertaken each year as part of the on-going quality and performance monitoring and review process. These include mixed sex accommodation, hand hygiene, IPC, PPE, medication management, tissue viability and record keeping. We use national audit tools specifically developed for hospices. The audit tools have been peer reviewed and quality assessed. This allows us to monitor the quality of care Rainbows provide in a systematic way and creates a framework by which Rainbows can review this information and make improvements. 2023 will see the introduction of an updated audit of the nutrition and hydration needs of babies, children and young people admitted to Rainbows.

Local Clinical Audits (Continued)

Clinical Quality Assurance Committee (CQAC) and Corporate Governance Committee approves the audit schedule for the coming year, which includes clinical and non-clinical audit. Priorities are selected in accordance with our statutory and regulated requirements and any areas where a formal audit would inform our risk management. For assurance, audit results are reported to and discussed at CQAC and the Board of Trustees.

Medicines Management and Storage of Controlled Drugs has external oversight when it is audited by University Hospitals of Leicester pharmacy team twice a year. The outcome of most recent audit in February 2023 was good with no further action required. This is the third year running where audit compliance has been 100%.

The Continuous Quality Improvement plan provides a framework to ensure continuous improvement is a focus for the clinical teams. It is monitored through The Good Clinical Governance Committee and progress is reported to CQAC quarterly. New improvement projects are identified through a variety of sources including the "Pebble in your Shoe" initiative, Good Clinical Governance Committee, Clinical Policies Committee, staff sharing solutions forum and team meetings.

Infection Prevention and Control (IPC)

Infection Prevention and Control procedures and risk-based approach formed the bedrock of our response to the national Covid-19 pandemic with standard and enhanced precautions continuing to be part of everyday practice as we live with Covid-19, to ensure everyone using and working at Rainbows remains safe. There have been no Hospice Acquired Infections (HAI's) among children, young people and their families in 2022, including Covid-19, with a couple of isolated cases of Covid-19 in symptomatic babies, children and young people picked up through testing which were not linked and therefore deemed community acquired. An outbreak within the clinical staff team of Covid-19 occurred in December 2022 but was well managed and had limited impact upon services. We have continued to be supported remotely by Partner IPC lead at University Hospitals of Leicester - the last physical audit took place in March 2020 - the audit showed 91% compliance. This is due to be repeated in 2023 following external pressures beyond our control. However, internal monthly IPC, PPE and hand hygiene audits have continued with high compliance.

MHRA and Patient Safety Alerts

All alerts received are reviewed by the Senior Nurses to assess relevance to Rainbows. All relevant alerts received are noted at Good Clinical Governance meeting and have had appropriate action taken.

Research

Rainbows continues to develop its Research activity and has now appointed a Research Nurse, with external funding from the East Midlands Clinical Research Network, for 12 months in the first instance. Some funding has also been secured from the same source to support some research work being undertaken by the Music Therapist at Rainbows which will be the first piece of independent Research at Rainbows and it's hoped that, on completion, it will lead to a larger scale project. In 2022/23 Rainbows have participated in seven Paediatric Palliative Care Research Projects as either a Participant Identification Centre (PIC) Site or a Recruiting Site.

Rainbows continues to lead the way in paediatric palliative care in the East Midlands and continues the established links and working collaborations with:

- The East Midlands Clinical Research Network
- Together for Short Lives
- Martin House Research Centre in York

Transition and Youth Work

Transition is not a single event, but is a gradual process of supporting a young person and their family through their teenage years and into adulthood, building up their confidence and ability to manage the care and support they need. A good transition should build on the young person's strengths and wherever possible work with the young person themselves to plan for how they can meet their aspirations in life. -(Together for Short Lives (TfSL)).

The Transition Team supports 190 life-limited young people and their families across the East Midlands.

It introduces what transition is and supports the families through the challenge of moving from child to adult services in areas that include health, social care, education, respite and housing. It also supports through changes in finances and legal changes around decision making. It provides information at appropriate milestones and provides targeted support for specific issues faced by young people and their families. In order to facilitate this the team has established relationships with adult services across the East Midlands. A high priority is the transition to adult palliative care and work continues to be carried out with the 14 Adult Hospices in the area to develop appropriate support for young people at end-of-life.

Youth work at Rainbows is primarily about supporting the young person, starting with where they are at and developing a trusting relationship with them to enable them to be themselves, to feel safe and secure and to enable them to develop and explore as an individual. It is also about being a resource to share information, to advocate, sign post and to build confidence as well as offering different types of support depending on their needs. This could include 1:1 support, group work sessions, fun activities, learning and developing new skills, memory making and realising and achieving their aspirations.

Often the 1:1 work includes discussions around managing their condition, dealing with it and looking at developing coping strategies in order to build resilience. With opportunities to explore fears and anxieties

in a safe supported environment, also touching on managing grief and enabling the individual to feel safe to ask questions whatever they might be. It is also about developing confidence and self-esteem, decision making and recognising the importance of not only having a voice but the confidence to use it.

The group work sessions offer our young people an opportunity to come together and spend time with peers, developing friendships and peer support. The groups offer a supportive environment enabling the young people to talk openly and honestly about their worries and concerns, working together to problem solve and explore resolutions. The groups are needs led and the young people are the ones that take the lead on planning the sessions throughout the year ensuring it is reflective of their needs and interests, enabling them to be the decision makers.

Youth work sits within the multi-disciplinary team and contributes to the holistic care that Rainbows offers to our children, young people and families. Giving young people positive activities to do, places to go and someone to talk to.



Part Five

What Others Say About Us

Care Quality Commission (CQC):

COPE Children's Trust (trading as Rainbows Hospice for Children and Young People) is registered by the Care Quality Commission (CQC) under the Health and Social Care Act (2008) and has the following conditions of registration that apply:

• Treatment of disease, disorder or injury

Rainbows are subject to periodic reviews by the CQC and the last unannounced on-site review took place from 31 May to 2 June 2016. Rainbows are fully compliant and rated as low risk. The overall rating was Outstanding.

Rainbows are required to register with the CQC and our current registration status is unconditional. The CQC did not take any enforcement action against us and Rainbows were not required to participate in any special reviews or investigations by the CQC during 2022/23.

A CQC Direct Monitoring Assessment (DMA) was carried out in September 2022 - No areas of concern were raised.

As part of the process the CQC sent a number of questionnaires seeking feedback on our services anonymously to our families and whilst we were not able to view this feedback the CQC confirmed it was complimentary.

CQC carried out a review of the data available to them about Rainbows Hospice for Children and Young People on 2 February 2023. They did not find any evidence to suggest an inspection was required to reassess our rating at this stage. CQC's website has been updated to reflect this.

Six monthly DMAs will be carried out in 2023-24, unless evidence prompts an on site inspection.

Commissioner Quality Assurance Visits:

There have been no Commissioner Quality visits this year due to the Pandemic. Quality reports continue to be submitted quarterly to all commissioners - no concerns raised.

Areas for Further improvement

As part of Rainbows commitment to continuous improvement a new initiative has been launched within the clinical teams "The Pebble in your Shoe" looks at small change, big impact issues which will make a huge difference to clinical effectiveness and efficiency, for example ensuring equipment is where it needs to be and in working order so nurses do not need to waste time looking for equipment that works in order to do their job. This is hoped to improve working process and practice which will in turn improve the experience of babies, children and young people and their families. Initiatives will be implemented using a Plan-Do-Study-Act cycle or Rapid Improvement Project methodology.



Children, Young People and Carer's Feedback:

A formal postal family survey was not sent this year as we wanted to encourage feedback centred around specific events and stays and to be able to respond to any feedback in a targeted and timely way.

We have received 17 feedback forms in 22/23. We ask families to give us a smiley or sad face related to their feedback. We work with families, children and young people considering any suggestions and implement where possible. Here are some of the suggestions and what we did about them in a "You Said We Did" format.



Complaints, Concerns and Compliments

Complaints	0
Concerns	6
Compliments	70

The Informal complaint / concern was related to the welcome on arrival for a first stay, access to technology and expectations of the stay. Lots of learning within the care team has taken place ensuring the experience of the admission is not process driven.

The other was related to the differing care practices from home to hospice and family choice, resulting in a formal access to care records request. The family were supported by the Head of Nursing through this process.

There have been compliments over the last year. These have come from families, siblings, young people and professionals and have been captured in a variety of ways; via feedback forms, our white board, email, cards, letters and verbally. A flavour of some of our feedback is below:

"We had been in hospital for six and a half months when we visited Rainbows for the day. T was nervous when we first arrived, but it didn't take long for her to cheer up, have fun and enjoy interacting with the staff. Her favourite experience was the soft playroom. Her face lit up and her mood lifted. T has always been a cheery, happy girl but we had only seen glimpses of this during her admission. After the visit T seemed happier and not so serious. The visit gave us the opportunity to have some family time with the reassurance that T's medical needs, feeds and medication were all in hand but not in a clinical environment. We were able to sit down as a family at a table for the first time in seven months and eat lunch." - Parent of a child supported by the Rainbows Paediatric Clinical Nurse Specialist at University Hospitals Leicester (UHL).

"Staff have been amazing and so helpful, always willing to help. I love how there is a choice of food for the fussy eaters" - Mum following short break stay. "It has been the worst year of our lives but having you all here has made it that little bit easier. The amount of support that you guys have given us as a family is amazing and being able to see our son settled and relaxed and being able to get him around and do different things has really made a difference. It's something we would never have been able to do at home. You have made us feel extremely welcome and we will never be able to thank you enough" - Mum staying at the Hospice with her son.

"Flats are much better, beds comfy, TV's on the wall better for us all to see. We had a much better stay" - Mum staying in the family flats after the refurbishment.

"My children have absolutely loved today. They are always excited about Rainbows anyway, but today was different and not once did they say they are bored, which usually happens after 15 minutes at home!" - Family attending Family Fun "Safari" Day.

"I cannot thank all the staff enough for how they have been. (Our son) has been encouraged to do things that are out of his comfort zone and hopefully when he starts coming on his own he will find out who he is and not look to us for all the answers" - Family staying for first short break stay.

"Thank you for an amazing few days. We felt very comfortable leaving (our daughter) with the staff who were all fantastic. Everyone took the time to talk to us about things that will help us at home from how to lift her to sensory equipment that she may like" - Family staying in the Hospice for a short break.

"To all the fantastic staff at Rainbows. Thank you for making our first stay at Rainbows so magical for us as a family. Having the time and space to be mum's and leave the nursing stuff for a few days has meant the world to us. We have created so many memories with our little girl that we thought was not possible due to her condition. We all loved it! Thanks for looking after her so well" - Family staying for the first time.

Part Six

Review of Quality Performance

Quality Schedule

Hospice Safety Indicators

Hospice Safety Indicator	2022 / 2023	2021 / 2022
Number of patient safety related incidents/accidents, including medication errors (April 2021 – March 2022)	Total incidents = 138* Clinical incidents = 53 Near Misses = 10 Medication errors (including CDs) = 85 Controlled Medication errors = 15	Total incidents = 146* Clinical incidents = 61 Near Misses = 22 Medication errors = 85 Controlled Medication errors = 13
Number of patients who developed category 3 and 4 pressure ulcers in our care	0	0
Infection Prevention and Control rates:	0	2
Total number of children admitted with known infection. This includes:	0	0
Number of C-Dif	0	0
Number of MRSA	0	2
Total number of children who developed symptoms whilst staying at the Hospice. This includes:	0	0
Number of C-Dif/CRO	0	0
Number of MRSA/CRO	0	0

* excludes near misses

Incident Reporting (Data from Datix from April 2021 - March 2022)

The decrease in incidents from last year reflects the continuous investment in education and training in medicines management for our nurses and the robust learning and reflection that happens following every error, by the nurses involved and the medicines management meeting. It also reflects the excellent reporting culture at Rainbows. The chart below shows that our highest single area of incidents is medication which is to be expected as administration of medication is our highest risk, frequency and complexity intervention. Reporting of other clinical incidents such as reporting of equipment failure or interruption, the second highest area of incidents recorded, reflects the increase in technology dependent babies, children and young people and the development of the Long-term Ventilation (LTV) and step-down services. Reporting has meant that issues can be addressed quickly and safely in a controlled environment, supporting families to manage issues when they are discharged home.

Rainbows nurses administer in excess of 32,850 medication doses every year. The pie chart below drills down to the categories of medication errors to focus the areas for improvement as transcription, storage and administration of medications. Administration errors have remained largely consistent and reflect the volume of administrations. All 85 of the total medication errors including 15 involving controlled drugs were no or low harm minor errors. A recent "deep dive" into incidents in a particular month found a robust reporting and learning culture, good practice around picking up errors and managing errors in practice for example around missed doses, demonstrating fit for purpose checking and monitoring processes. Although relatively low numbers of errors, all errors are fully investigated and learning put into practice to minimise the same errors occurring again. Learning is shared via Top 10@10 briefing, Bi-monthly Medicines Newsletter, Team Meetings and The Good Clinical Governance Meeting.







Workforce

Mandatory Training:



Jan-23 Feb-23 Mar-23

Mandatory Training:



Equality, Diversity and Inclusion (EDI) Strategy

Equality. Diversity and Inclusion sits at the heart of everything we do. Ensuring we have a diverse workforce reflective of our community is key to our success as we encourage the new generation of talent to join our workforce but also to diversify and reach all communities and break barriers to accessing our services. EDI is key in shaping the future of Rainbows and recognising that everyone's lived experience is different and unique and that every voice is heard equally. We strive for individuals to embrace their differences and celebrate that true diversity lies in our actions and people feeling like they belong and are welcome.

We are committed to creating an environment of positive working relationships where every employee, worker, baby, child, young person and their family has the right to be treated with equality, dignity and respect. We strive to ensure we are there for everyone who needs us, and maximise our reach by learning from the experiences of others, working across all areas of EDI to develop our engagement across all communities using community networks and truly listening to a range of different voices.

We have a number of policies and training programmes in place to set out standards of conduct that must be observed by everyone at Rainbows and those who engage with us. Together we will build a culture where everyone is appreciated for their unique self and contribution. We are finalising our EDI strategy and action plan that supports and underpins the Rainbows corporate plan liaising with a number of key stakeholders across the business and we are developing a training plan around EDI, belonging, anti-racism and use of language that will be rolled out across the business including our Board of Trustees. In addition, our ambition is to create an EDI forum that is formed of both internal and external stakeholders to ensure diversity of thought as well as lived experiences. We are collecting data from across the business, particularly for those who are accessing our services and our workforce to identify where the gaps are and improvements that can be made.

EDI is a continual process and there is always more to learn - we are currently working with Inclusive Employers who are undertaking a full organisational wide audit of EDI practices across the business.

Freedom to Speak Up (FTSU)

The FTSU Guardian role is available for staff to feel safe to speak out about patient safety, as well as learning lessons by listening to those who have experiences to share, both positive and negative. The FTSU Guardian provides a yearly report to the Board of Trustees. Our Public Interest Disclosure (Whistle Blowing) Policy has been changed to include the FTSU roles and Rainbows have implemented this across the charity.

Our FTSU service is currently under review to ensure that it continues to be relevant, effective and adequately meets the needs of our staff.



Safeguarding

Safeguarding Children, Adults, Mental Capacity and Deprivation of Liberty Safeguards policies were all reviewed during 2022. Updates to procedures and learning from serious case reviews are disseminated to Rainbows staff via a robust process of training and safeguarding specific supervision sessions, and all clinical staff demonstrate their understanding and skill level through completion of 1:1 sessions using the safeguarding competency framework commensurate to their roles and based upon The Royal College of Nursing Intercollegiate Guidance for both children and adults. Safeguarding training is mandatory for all staff and delivered through a system of blended learning, combining e-learning and face to face training. Compliance has remained between 96-100% throughout 2022/23.

In November 2022 Rainbows hosted a, 'Safeguarding the Disabled Child' study day which was attended by multiple partner agencies, including Health, Education and the Police. Rainbows staff were also able to attend the event.

Rainbows Safeguarding Lead receives monthly supervision from the Head of Safeguarding for University Hospital Leicester UHL hospitals and also sits on UHL Safeguarding Committee. Rainbows Care Team receive weekly safeguarding group supervision; Rainbows Nurses in Hospitals receive monthly group safeguarding supervision and Rainbows Clinical Leadership Team receive bi-monthly group safeguarding supervision. Rainbows Family Support Team access 1:1 safeguarding supervision when required. Rainbows has two Safeguarding Link Nurses on the Care Team who are supported by the Safeguarding Lead. The Safeguarding Assurance Template (SAT) was requested by Leicester, Leicestershire and Rutland ICB in December 2022 and a virtual assurance visit took place in February 2023. Rainbows was seen to be fully compliant with the exception of two areas which received an amber rating. 1. Rainbows processes and procedures in regards to the admission of Looked After Children to the Hospice. A Looked After Children checklist has since been developed to gather relevant information and as a prompt to engage with the Local Authority when they hold parental responsibility. 2. Information regards DBS/Risk Assessment for employees whether permanent, temporary, independent contractors, volunteers, or agency/ bank staff. A working group has been established to develop robust processes and procedures. Submission of the next SAT is 31 March 2023 and there is a follow up assurance visit planned in June 2023.

Rainbows is a trusted partner within Leicester, Leicestershire and Rutland Safeguarding Children's Partnership Board and is named within the multiagency Information Sharing Agreement.

Duty of Candour

Rainbows follows the Duty of Candour Process for all incidents involving babies, children and young people in our care.



2022/23 Activity Report

In January 2023, we updated the activity that we report on to include new service activity. The graphs below show Hospice Occupancy, family support and hospital nurse activity provided by Rainbows - some data is only available from January 2023, following the use of SystmOne as a reporting tool.





Part Seven

Service Improvements - 2022/23

Hospital Nurses

There are now four Rainbows in Hospital Clinical Nurse Specialists in post with a fifth due to start within Northamptonshire Healthcare NHS Trust soon. The roles have had a significant impact upon the care of babies, children and young people within the region receiving palliative care in hospital (see appendix 3). This has been acknowledged by several awards presented to the CNSs:

- The Leicester nurses and their cardiac nurse specialist colleagues were awarded the UHL "Caring at its best" for the "We are one team and we work best when we work together' category in October 2022
- The Leicester neonatal CNS was awarded one of the first 'Recognising Excellence in Neonatal Services' (RENS) awards in November 2022 by the East Midlands Neonatal Operational Delivery Network.

SARB

Safety Huddles have been well established in the NHS for many years and offer the MDT the daily opportunity to meet for 5-10mins to identify, anticipate and discuss risks. A daily SARB (Safety and Risk Briefing) was introduced at Rainbows in January 2023 and is held directly after 9am handover to look specifically at the risks and safety issues of the clinical care in the hospice. Led by the shift co-ordinator and with the over-arching philosophy Better Decisions Together, other members of the MDT who attend include: Lead Nurse for clinical ops, CNS, ACP, GP if available, Lead Therapist. The briefing aims to:

- Discuss patients most at risk
- Anticipate future risks
- Monitor and increase cues to increase staff awareness of what is happening around them
- Integrate information to develop a comprehensive picture of the current status of patients.
- Anticipate how that information might adversely affect the current situation both NOW and in the NEAR FUTURE
- Identify potential problems or safety issues

The briefing is split into three sections:

- Dependency and capacity
- Deteriorating babies, children and young people
- Safety and risk (any events / issues occurring that may impact safety)



Service Improvements - 2022/23 (continued)

Development of the Non-Medical Workforce

Rainbows recognises the national challenges within the Paediatric Palliative Care medical workforce, we are therefore developing a sustainable workforce model incorporating non-medical roles and engaging with system and regional partners.

Rainbows has committed to developing an Advanced Practice workforce and has successfully recruited three posts with a vision for further posts over the next two years. These roles significantly reduce the reliance on Doctors for daily non-complex tasks. We have also supported a number of staff to access specialist training in Palliative Care.

Our Clinical Nurse Specialist team has also continued to grow, with Palliative Care Nurse Specialists in three hospitals and three within the Hospice Team, with plans for further posts in 2023/24.

We are increasing our pool of non-medical prescribers and staff with advanced assessment skills.

We have improved our working relationships with system partners and organisations to ensure medical responsibility remains with the child's specialist, community team or GP, who continue to be involved in the care when accessing Rainbows services.

Medicines management

Refresher training around the seven rights of medicines administration was rolled out to all nurses in 2022. The annual calculations test moved on-line with the purchase of SafeMedicate an on-line interactive resource for developing and assessing medicines calculations. Rainbows uses our Medicines Management Just Culture Framework to review all medicines incidents. They are discussed at the Medicines Management meeting bi-weekly. The National Coordinating Council for Medication Error Reporting and Prevention Index for categorising medication errors algorithm is used to assess harm and the just culture framework which looks at behaviours and human factors is applied to inform action and learning, which is consistent and fair, this is then cascaded via a number of forums / formats including: The bi-monthly medicines newsletter, "incident on a page" and "Top 10@10" team briefing.

Controlled drug (CD) incidents are reported by our Controlled Drugs Accountable Officer (CDAO) to the Local Intelligence Network quarterly and learning shared with and from CDAO colleagues across the East Midlands.

Part Eight

The Board of Trustees Commitment to Quality

The Board has an active role in ensuring that Rainbows provide a high quality and safe service in accordance with our Statement of Purpose, which is updated regularly and displayed in hard copy format at the Hospice and available on our website.

Our Board of Trustees are fully committed to providing the best service for our babies, children and young people in order to achieve our vision and aims. Rainbows has an established governance structure, which has recently been externally reviewed. A Clinical Trustee chairs the Clinical Quality Assurance Committee, with other Clinical Trustees as members.

The Board of Trustees regularly reviews the structure of meetings across the charity to ensure the appropriate committees and groups are in place with clear lines of accountability and input from Trustees as required. A recent independent review of our governance structures and processes reported a good governance structure with some areas to be developed further, which have largely been actioned. In addition, Rainbows have a comprehensive Risk Register which is monitored by the governance committees who regularly update the Board in relation to areas of high risk.

Clinical risk is managed using a 'floor to Board' approach, engaging staff in identifying and managing risk, with assurance through to the Clinical Quality Assurance Committee.

The Board has approved and supports Rainbows five year strategy to ensure we continue to deliver high quality, relevant and effective services to babies, children and young people and families across the East Midlands. The strategy has been developed in line with National evidence on the prevalence of babies, children and young people with life-limiting and life-threatening conditions. As we continue to develop and provide services away from Lark Rise, robust quality assurance processes are being developed and used to ensure families, babies, children and young people continue to receive safe and high quality care in the location of their choice.

Engagement with key stakeholders across the health and social care system remains key to ensure we are delivering a collaborative approach to children's palliative and end-of-life care.

The Board is confident that the treatment and care provided at Rainbows is of the highest quality, with an embedded culture of continuous quality improvement and learning whilst remaining cost effective and efficient.



Part Nine

Responses to Rainbows Quality Account

The Rainbows Quality Account was presented to LLR (Leicester, Leicestershire and Rutland) ICB System Quality Group in May 2023.

LLR ICB System Quality Group say:

"The Rainbows Quality Account was considered and gave updates on quality improvements for the last year and looked to demonstrate and open up areas for quality improvement in the future. ICB felt it was a good, rounded quality account.

The Chair acknowledged that Rainbows were a key player for the system in the Children & Young People's pathway."

Appendix 1

Audit Calendar 2023-2024

Marth	Clinical		Corpo	orate	Health and Safety (H and S)			
Month	Audit	Quality Improvement	Audit	Quality Improvement	Audit	Quality Improvement		
April	External Placement Audits External Controlled Drugs Audit	15 Step Challenge Voice of the Child Survey			Hospice H and S Legionella (monthly)			
May	Nutrition and Hydration Audit				Water risk assessment			
June			Lottery		Kitchen Food Safety Electrical Safety (5 yearly 2027)			
July		15 Step Challenge			Review of COSHH			
August								
September	Mattress Audit	Voice of the Child Survey		Sit and See - Data Protection	Shops - Health and Safety			
October		15 Step Challenge	Finance - Mid Year			Compliance with environmental policy		



Appendix 1

Audit Calendar 2023/2024 (continued)

	Clinical		Corp	orate	Health and Safety (H and S)			
Month	Audit	Quality Improvement	Audit	Quality Improvement	Audit	Quality Improvement		
November	External Controlled Drugs Audit External Medication Storage Audit		Fundraising		Security (External CHUBB) AC compliance (external)			
December	Uniform Audit				Risk Management policy			
January	Mixed Sex Accommodation	15 Step Challenge			Fire			
February			Gift Aid		LOLER (mini-bus tail lift)			
March	External Infection Prevention Control Audit			Sit and See - Reception	PAT testing (TR19 inspection compliance)			



Appendix 2

Clinical Audit	Outcome
	We continue to accommodate student nurses, doctors, midwives and physiotherapists and have practice placement contracts with universities from across the region i.e. Nottingham, Nottingham Trent, Derby, University of Leicester, De Montfort University, Keele, Coventry and Staffordshire Universities.
Placement Audits	A single educational audit has been completed in 2022, by Nottingham University, to be shared with academic colleagues. Clinical staff have updated their practice assessment skills via both on-line resources and visits/workshops by the variety of University tutors.
	In conjunction with colleagues from the finance team, we have been reviewing the income possibilities from this work. We estimate, that it could potentially generate £10,000 per year for Rainbows
	An audit was carried out in February 2023 by an external Pharmacy Assistant from University Hospitals of Leicester (UHL).
External Medicines Storage Audit	The audit findings were exemplary and no further action was required / no recommendations made. Of particular note was the labelling and organisation of the cupboard. This is the third year in a row that our compliance has been 100% for stock medication. Internal monthly stock audit continues to be carried out by the CNS. The annual update of nurses' signatures for purposes of ordering medicines from UHL was updated in January 2023.
Children and Adults Health	This template outlines assurance against key safeguarding requirements for adults and children and to identify areas for development or where additional assurance is required.
Safeguarding Assurance	Rainbows demonstrated compliance with the Children Act 2004 and the Care Act (2015).
Template	Safeguarding at Rainbows is managed safely and effectively. Our Safeguarding Committee meets bi-monthly and reports are presented to the Clinical Quality Assurance Committee and Board of Trustees.
Drug Storage Audit	Rainbows carry out audits every three months and have devised a tool to carry out audits, producing an action plan following each audit, if appropriate.

Clinical Audit	Outcome
Drug Chart Audit	Weekly audit of Medicines Administration Records (Drug charts) is carried out in order to monitor standards on a continuous cycle and ensure continuous improvement in practice.
	Audit carried out in February 2023 by external Pharmacy Assistant from University Hospitals of Leicester (UHL).
External Controlled	The audit noted a neat Controlled Drugs register, expired Controlled Drugs stored correctly, wastage was well documented and Controlled Drugs stored as per policy within the designated locked Controlled Drugs cupboard.
Drugs Audit	Discrepancies were logged and cross referenced in the register to the log sheet.
	The audit found our practice to be good with minor best practice recording points notes for improvement. No further action required. This is the third year in a row that our compliance has been 100% for CDs.
Infection Prevention Audit	Infection Prevention and Control audits have continued to be carried out with Hand hygiene audits and PPE audits being carried out on a monthly basis increased as necessary during community outbreaks of Covid-19. Hand Hygiene and PPE compliance remained at 100% during 2023. A monthly "walk around" audit of the clinical area identifies any concerns or environmental issues which are then addressed working with our facilities and housekeeping teams. Compliance to standards within this audit has been 98% to 100%. Partnership working with UHL has continued remotely throughout the pandemic and is returning to face to face support with a planned full audit in 2023.
Mattress Audit	A full mattress audit by an external assessor took place in 2022 with no significant issues highlighted except for some issues going forward if replacements were ever needed as several mattress types are no longer being manufactured.



Clinical Audit	Outcome
Record Keeping Audit	Rainbows continued to carry out weekly monitoring using a recognised clinical records audit template against NHS and Health care professional body standards and criteria. Audit results have varied throughout the year with an initial dip following the introduction of SystmOne electronic records (in February 2022 whereby the weekly audit was paused until May 22 to embed the new system) followed by improvement especially in relation to missing signatures on the signature tracker, and completion of tissue viability and mouth care assessments. The annual record keeping competency has been updated to include electronic record keeping and cascaded to staff to complete. This includes reflective discussions with line managers and at team meetings. Ongoing work continues to ensure accurate and complete patient records, including clear and concise evaluations of care. Day to day monitoring of records is overseen by The Lead Nurse for Clinical Operations.
	The weekly record keeping audit is broken down into sections for compliance monitoring; paper documentation, SystemOne documentation and care plans/assessments.
Mixed Sex Accommodation	Rainbows continues to be compliant with the requirement to support young people staying in a mixed sex accommodation environment as per the Mixed Sex Accommodation policy. The annual audit which seeks to ensure compliance against all standards set by the Department of Health found that due to the changes to the environment to ensure that children and young people are being cared for in a Covid-safe way, some processes were now different to those described in the policy, however children and young adults continue to be accommodated in separate areas and where this is not possible a risk assessment is undertaken and supportive / additional measures are put in place. The Department of Health requires all providers of NHS funded care to confirm that they are compliant with the national definition 'to eliminate mixed sex accommodation except where it is in the overall best interests of the patient or reflects the patient's choice'. Rainbows are committed to maintaining the privacy and dignity for males and females staying at the Hospice. Rainbows have implemented a number of processes that support the sensitive management of males and females whose bedrooms are located in the same area of the Hospice.

Appendix 3

Rainbows in Hospital - Clinical Nurse Specialists

	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	TOTAL
Total Contacts	116	248	269	309	347	154	187	142	118	149	173	201	2404
Referrals to other Rainbows services such as hospice stay or respite	5	6	3	8	6	2	4	2	1	8	1	4	50

	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	TOTAL
Palliative Care	12	47	36	71	70	41	55	33	18	72	46	51	552
End-of-Life Care	2	5	6	8	1	1	8	8	3	5	12	6	65
Bereavement Support	9	6	3	1	5	4	0	1	1	7	6	11	54
Advance Care Plan	1	12	10	8	2	7	11	9	3	8	8	6	85
Symptom Management	1	8	0	2	1	5	2	2	5	3	8	2	39

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rainbows.co.uk

This Quality Account has been endorsed by the Hospice Board of Trustees

Rainbows is registered as Cope Children's Trust in England and Wales. Registered Charity No. 1014051. Registered Office: Lark Rise, Loughborough, Leicestershire LE11 2HS.

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