



# rainbows

Brightening short lives

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

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## Quality Account 2024/2025



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## Our Vision, Mission, Purpose and Values

### Our Vision

#### The Rainbows Experience wherever you are.

We believe every baby, child, young person, and their family should have the “Rainbows Experience” throughout their palliative or end-of-life care. They should have the best possible care where choice, quality and expertise is prioritised, ensuring families can make informed decisions that are right for them. As a child nears the end of their life, they should have help and support to make treasured memories while surrounded by comfort, dignity, and love. After death, they should continue to receive support and compassion as families go through bereavement and grief.

Our support and care reaches beyond walls and locations, and we believe the Rainbows Experience should be wherever families need it to be, whether that is at the hospice, home or in hospital.

### Our Mission

We provide compassionate, expert palliative and end-of-life care to babies, children, and young people across the East Midlands.

The unique needs of each baby, child and family are the centre of everything we do, and our mission is to support them in their most comfortable and preferred setting. Working collaboratively with other professionals and volunteers, we provide care and support and create opportunities and meaningful memories through illness, death and bereavement.

### Our Purpose

Rainbows exists to support babies, children, young people and their families in life and in death. We create lasting, precious memories and provide care and support wherever a family needs us – in the hospice, at home or in hospital. For families facing the unimaginable, we provide compassionate and dignified support during dying and bereavement. Helping families to navigate their grief while honouring the memory of their child.

### Our Values

#### One Team

We are more than a hospice. We are a team that helps families and communities to thrive. Although we do this in different ways and through different roles, everyone’s contribution to the Rainbows Experience is valuable and celebrated.

#### People Centred

People are at the heart of what we do. We exist to support families experiencing one of the toughest challenges that life has to offer. We must be resilient, kind and compassionate, remembering that we are not alone.

#### Aim High

We are a diverse team made up of experts from many fields. We use this diversity and knowledge to strive for excellence in everything that we do; from the experience we provide to the communities that we support, to the way we run our charity.

#### Own It

We make a big impact in our community and beyond. Every day we ensure a consistent, quality experience for each other and those that we support. To achieve this, we align expectations with reality and respond appropriately to different situations.



**One  
Team**



**People  
Centred**



**Aim  
High**



**Own  
It**

### Part One

#### Statement of Quality by the CEO

This is our thirteenth Annual Quality Account and covers the period between 1 April 2024 to 31 March 2025.

The year covered by this Quality Account is also the final year of our current strategy. The strategy was focused on reaching many more babies, children and young people and we have made considerable progress whilst recognising there is more to do. We continue to provide vital palliative and end-of-life care for those children who simply do not live long enough at the Hospice in Lark Rise as well as through our 'Hospice at Home' service, working in partnership with other providers. Our continued expansion of our 'Rainbows in Hospital' service has also been critical in significantly increasing our reach to both those who need our care and support, and the number of other professionals and partners that we are working with. We now have nurses in all the Tertiary and District hospitals in the East Midlands. We have also hosted a Single Point of Contact for the East Midlands utilising the skills of our Advanced Clinical Practitioners and Clinical Nurse Specialists. This has improved the experience of our babies, children, young people and their families at the most challenging of times as well as ensuring other professionals can provide the best possible care and support to them.

Our greatest asset is our people, both staff and volunteers. It is their commitment and dedication and that of our supporters that makes what we do possible. We continue to focus on ensuring that our staff and volunteers are equipped to do what they do well. A highlight this year has been the introduction of our new values which has been met with enthusiasm and is enabling us to strive to be the best we can be both individually and collectively. We are also working hard to ensure that we are a welcoming and inclusive environment for all, and that work will continue. We also continue to work hard to ensure our supporters know the difference they make and how much their support is appreciated.

We have continued to invest in how we work including the use of digital solutions that improve safety and efficiency. Alongside this we have worked hard to be good stewards of all the resources we have.

It is my huge privilege to be the CEO of this incredible organisation and to work with such an amazing and committed team of staff and volunteers. They all strive to do the best they can for our children and their families, whether through the direct provision of support and care, or ensuring we have the environment and resources to deliver it.

Recent years have taught us that we can never predict what challenges the future might hold, however I am confident in our ability to respond to those challenges as we look to embarking on our new strategy. We also could not do what we do without our supporters, and I would like to take this opportunity to thank them for making what we do possible.

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 Burns  
Chief Executive Officer





## Part Two

### What we achieved in 2024/2025

#### In line with our Strategy, Rainbows identified the following priorities for 2024/2025

Rainbows continued to develop and expand its services throughout 2024/2025. Our focus and priority have been on reaching more babies, children, young people and families across the East Midlands, to ensure they have access to high quality, specialist services at the time when they need it most. Rainbows has successfully made progress on all of the priorities set out in 2024.

#### Future Planning – Patient Safety

##### Priority 1: The implementation of an electronic rota system to provide a safe staffing tool.

The launch of the electronic rota system was unfortunately unsuccessful, and the difficult decision was made to part ways with the company. Despite planning and development of what was believed to be a system that was suitable for all our clinical rota needs, once we had launched the platform it quickly became apparent that there were still going to be many workarounds needed for the system to work for us as we needed it to. The project to introduce an electronic rota system is currently on pause and is due to be re-launched towards the end of the calendar year. To ensure safe staffing levels all admissions continue to be assessed using the categories of care, and appropriate staffing levels are then put in place.

This project has now moved into the digital portfolio priorities for 2025/2026.

##### Priority 2: Implementation of Electronic Prescribing and Medicines Administration (EPMA) using SystmOne.

Rainbows EPMA digital solution is making great progress, particularly in terms of medication prescribing for BCYP within the community. In 2024, the EPMA system has successfully been tested.

The focus in 2025 is adding further functionality to enable medication prescribing for BCYP residents in the hospice settings. Activating this feature in the electronic records will improve efficiency, accuracy, and overall care for BCYP.



### Future Planning – Clinical Effectiveness

#### **Priority 1: Implement a Paediatric Early Warning Score to effectively identify & manage deteriorating babies, children and young people**

Implementing the Paediatric Early Warning Score (PEWS/H) within SystmOne is a major step towards enhancing the recognition of clinical deterioration in BCYP. The fact that it accounts for the complex health needs of these BCYP, recognising that their baseline vital signs might be outside the typical reference ranges, is a crucial feature. This individualised approach helps ensure that each BCYP's unique health needs are considered, leading to more accurate monitoring and early intervention when necessary.

By standardising how deterioration is identified and managed, the PEWS/H system ensures consistency in care, which can be especially important when managing vulnerable and medically complex children. This could lead to earlier detection of issues, better outcomes, and potentially fewer complications.

#### **Priority 2: Develop a portfolio to evidence maintenance of Advanced Practice Skills aligned with the four pillars of practice**

The implementation of a portfolio for the Rainbows Advanced Clinical Practitioners provides evidence of their advanced clinical practice but also supports the recognition and validation of their skills in the highly specialised field of palliative and end-of-life care for BCYP. By aligning the portfolio with recognised advanced practice standards, it reinforces the importance of professional growth and accountability.

The inclusion of essential evidence, supporting documentation, critical narrative, and peer review within the portfolio, ensures that it serves as a comprehensive record of the Advanced Clinical Practitioner's expertise. This kind of evidence-based approach is invaluable in maintaining high standards of care, while also facilitating reflective practice and continual learning.

Additionally, linking the portfolio to the annual appraisal process ensures that professional development and achievements are regularly assessed, providing a structure for ongoing improvement and career progression.





### Future Planning – Patient Experience

#### Priority 1: Rainbows Patient Participation and Inclusion / family experiences group

Young people, parents, and families have a crucial role to play in supporting Rainbows to improve our services and the wider children's palliative care community. As a result of the Family Support and Outreach project, the opportunity to involve parents, carers and young people in co-design and development of Rainbows' services and initiatives and to get them involved in research governance was explored over the last year. Several parents and carers answered the call to action, and they have been able to get involved with ad-hoc pieces of improvement and evaluation work. The envisioned group has not developed as we hoped, due to individual circumstances, but parents, carers and families have got involved with presenting patient stories at World Patient Safety Day, reviewing research proposals and giving us fresh eyes on local improvements at the hospice. We continue to work on further developing the pool of young people, parents, carers and family members who can be called upon to advise, contribute and consult on Rainbows service developments, quality improvements and initiatives and research.

#### Priority 2: 15 steps team to include children, young people and families

Linked to the above priority, now that the 15 steps challenge is embedded in practice with non-clinical colleagues reviewing the experience of our families of different areas with fresh eyes, last year saw us working to recruit a pool of young people and parents / carers to bring their unique perspective on the experience of Rainbows and inform the process of continuous improvement at Rainbows, representing the voice of families. We produced a leaflet explaining the initiative and presented this at the parent / carer's forum, however, due to individual circumstances it has been difficult for families to commit. We will continue to explore the opportunity for young people and families to dip in and out of the walk arounds whilst staying at the hospice and provide more informal feedback, still using the 15 steps challenge ethos, during their stays. Meanwhile 15 steps has continued with the existing team.





### Service Improvements - 2024/2025

#### Community Hubs

Between June 2024 and January 2025, we piloted our first 6 community hubs. These were located at different venues across the East Midlands including Derby, Newark and Market Harborough. The purpose of the hubs was to allow families to access some of our support and services closer to home – “The Rainbows experience wherever you are.” Once a venue was risk assessed, as suitable dates were booked and planning of activities took place based on feedback we had been given from resident families at the hospice and families attending our on-site support groups. Peer support and conversation with family support staff was especially important to the families we spoke to, so offering the three C’s of coffee, cake and chat was available at all the hubs. Other activities included crafts, music and the offer of massage from our complementary therapists for either any BCYP in attendance or parents/carers. The feedback received was excellent, as seen in Part 5, and the feedback we continue to receive will allow us to arrange each hub around the BCYP and family’s needs, including some of our specialist family support services attending such as Youth and Transition or Social Worker. We now have 16 hubs planned for 2025 including cultural hubs aimed at our under-reached BCYP and families.



#### Holistic Needs Assessment and Family Support Practice Model

Since August 2024 all newly accepted BCYP and families to Rainbows have received a holistic needs assessment (HNA) from one of the Family Support Nurses or Clinical Nurse Specialists if the BCYP is in hospital. This involves the nurses assessing all elements of the BCYP and family life and then presenting at a HNA panel made up of appropriate members of the Rainbows MDT. Recommendations are put forward by the assessor for services they feel would benefit the family most at this point in time. The HNA panel will either agree the recommendations or have further discussion about what should be offered. The discussion includes whether or not it is appropriate for a BCYP and family to receive short breaks, which is not always necessary depending on where they are in their palliative journey. A decision is made about what level of family support is required and using the newly developed family support practice model this can range from universal to specialist support. If a family is offered universal this gives them the opportunity to attend all the on-site support groups, community hubs and family fun days. Targeted family support will see the allocation of a family support worker or nurse in their locality to work with the family to achieve certain goals and targets and, if achieved, then re-assessment should take place, and the family moved back into universal services. Our specialist services such as Youth and Transition or Spiritual Support can be referred to for pieces of work to be carried out and our therapy services also can be offered for therapeutic intervention. Caseload classification, which all members of the family support team now do, means that the families have regular re-assessment of their need. The classification ranges from red – in crisis with multiple need areas – to blue – keep in touch – which is done through a Keep in Touch (KiT) volunteer.

The HNA can also recommend symptom management, hospice at home or EoL care. These services are usually arranged through an urgent panel taking place after the weekly regional MDT meeting.

Planning is underway for all existing BCYP and families to have a HNA carried out during 2025.

# Quality Account 2024/2025

## Service Improvements - 2024/2025 (continued)

### Specialist Well-being Practitioner

We have recently recruited a Children's Palliative Care Well-Being Practitioner who will support the development of skills to ensure the well-being of all staff within the specialist palliative care team so that they can continuously deliver high-quality care to BCYP and their families.

This was in response:

- To national information and the 2017 report by the office for national statistics (ONS) on suicide, analysed by occupational data, which identified female health care workers as having a risk of suicide 24% higher than the female national average.
- Recognition of the impact of compassionate fatigue and burnout in healthcare professionals that work within environments that are highly emotive and stressful such as children's palliative care.
- The remote working challenges of the specialist palliative care team members.

The Specialist Well-Being practitioner will promote well-being and use a variety of preventative and reactive strategies to foster well-being within the specialist palliative care team such as: 6 steps - positive response to challenges, peer Supervision and support Huddles, PETER Model of well-being at work and the Wellness Recovery Action Plan (WRAP), the key principle of this model is personal responsibility.

The outcomes of the above strategies will include wellness that enables passion and joy within work, a feeling of containment due to being supported and protected. This individual support will then ensure the teams' resilience increases and supports individuals' emotional and social intelligence.

### Single Point of Contact (SPOC)

SPOC was a pilot project hosted by Rainbows in 2024 and will continue in 2025 funded by Rainbows. The pilot service was a recommendation arising from the NHSE Midlands 24/7 Children's Palliative Care Exemplar project. Funded by the East Midlands CYP PEOLC Network, the pilot tested the proof of concept that having an East Midlands wide 24/7 SPOC service would help address the inequity in choice across the region, improving the quality of experience during the last months of life for BCYP and families across the East Midlands.

Having access to 24/7 specialist advice is a core palliative care standard and is essential to support family choices for their child to be cared for effectively and safely at home or in a hospice or hospital setting.

Unless a BCYP is on the Rainbows children's hospice caseload, access to specialist advice 24/7 is a postcode lottery. There is only one ICB that provides access to specialist advice 24/7. In addition, access to 24/7 community nursing is fragmented, with services not always able to initiate a 24/7 response when needed, or they are constrained by how many BCYP can be supported at any one time. There is no Paediatric Palliative Medicine Consultant in the East Midlands.



### Alfie's Story

When Alfie was five days old his family were told to say their goodbyes. But Alfie proved medics wrong and is now one year old.

Alfie suffered a traumatic birth, which meant he needed immediate resuscitation. "It was an incredibly traumatic time," said Tom. "Doctors managed to revive Alfie after a prolonged period, but he was found to have significant issues affecting his brain, heart, lung, kidney and liver."

Alfie was diagnosed with Severe Hypoxic Brain Injury. He was unable to breathe on his own and he suffered seizures. He was transferred from Kettering General Hospital to Leicester Royal Infirmary.

"After five days of tests, an MRI scan confirmed significant brain damage and the medical team recommended taking him off life support," said Tom. "Myself and Alfie's mummy, Charlotte, prepared ourselves, and his two sisters – Sofia, (who was four at the time) and Alicia (who was two at the time) – to say goodbye."

It was there, in Leicester, Alfie's family were introduced to Gemma Lewis, a Rainbows Clinical Nurse Specialist. Working alongside the NHS team and other colleagues at Rainbows, Gemma was able to support the family, and help them make treasured memories, by providing the skills and services of Rainbows within the hospital setting.

"We were very grateful that Gemma was there to help us, especially with memory making," said Tom. "Doctors advised Alfie could survive for several days, but with his presentation, we were told to expect minutes maybe hours. His breathing apparatus was removed, and we were "ready" to cuddle him for the last time.

"But as we held him close, he continued to breathe. We reached five minutes, then 30 minutes, then two hours and he carried on. As the hours rolled past, Alfie continued to hold on.

"Eight hours went by and the medical team linked up a drip to provide nourishment and fluids to maintain comfort. Then eight hours became 12, and then 24 and still he carried on."



***"Myself and Alfie's mummy, Charlotte, prepared ourselves, and his two sisters – Sofia and Alicia to say goodbye."***  
Alfie's Dad



### Alfie's Story (continued)

Slowly Alfie began to get stronger. His seizures receded, his heart rate normalised, his breathing strengthened, and his blood pressure improved. But due to the significant trauma already experienced, Alfie was still considered end-of-life care.

After four days, Alfie was transferred back to Kettering General Hospital and his family were supported by Karen Parsons, a Rainbows Paediatric Clinical Nurse Specialist for Northamptonshire.

Karen helped Tom and Charlotte to liaise with the Community Children Nursing (CCN) team and helped with Alfie's advance care planning, symptom management and medication. Visits from the Rainbows' Hospice at Home team, which included Music Therapy to record a heartbeat keepsake, were also put in place.

Two days later, Alfie was able to go home. Over the following few weeks Alfie stabilised, and he moved from end-of-life care to palliative care.

Alfie's parents continue to be supported by the Rainbows' Family Support specialists in many ways, with Sofia soon to benefit from the Sibling Support services.

"While he is still considered Palliative, Alfie remains with us, fighting on," said Tom. "He has started to grow and put on weight, with small improvements being noticed as the weeks progress. There is no timescale on how long he will survive, but doctors are now talking months, not hours and days.

"Rainbows has been an incredible support to us and continues to be so. No-one ever expects to have such difficult conversations, and the continued support provided by the Rainbows' Nurses throughout has helped enormously. Whether it is arranging for memories to be made - such as taking Alfie for a walk in the pram whilst in ITU, casting hand and footprints or attending medical appointments, or taking notes and helping to interpret the jargon. The team around us have always been on hand to provide advice, guidance and act on our behalf.

"From the initial news to now ongoing palliative care, the team at Rainbows have supported us every step of the way, and we will be forever thankful for their help in enabling the quality time we have enjoyed as a family."

***"We will be forever thankful for their help in enabling the quality time we have enjoyed as a family."***

*Alfie's Dad*





## Part Three

### Priorities for improvement 2025/2026

#### Future Planning – Patient Safety

##### Priority 1: Development of a morbidity and mortality review process

The development of a Mortality and Morbidity (M&M) review process for BCYP who die within Rainbows is a crucial step in fostering a culture of safety, learning, and continuous improvement. This approach not only helps ensure that safe and high-quality practice is maintained throughout the entire care process, from transfer and treatment to post-bereavement, but also provides a structured framework for learning from each case.

By focusing on both identifying areas for improvement and acknowledging good practice, the M&M review process creates an environment where clinical teams can reflect on their work, celebrate successes, and address potential gaps in care. It is particularly important in palliative and end-of-life care, where complex and emotionally charged situations require the highest levels of professionalism and sensitivity.

The educational and learning platform that this process offers will enhance clinical care by equipping staff with insights that can be applied to future cases.





### Future Planning – Clinical Effectiveness

#### Priority 2: Develop an integrated clinical data dashboard

Rainbows services are growing and developing. In order to understand our opportunities for improvement, we need to know how we are doing and be able to provide evidence based real life, consistent, reliable and improved data management and reporting capability to enable easy access to information and insights into Hospice operations in order to demonstrate clinical effectiveness. Several clinical / nursing metrics dashboards are already in use and embedded in practice. Along with a review of the technology used to create them, these will also be reviewed to ensure quality of data and to avoid duplication as more service dashboards are developed.

### Future Planning – Patient Experience

#### Priority 3: Develop evaluation and feedback tools for all clinical services including community and outreach

Going forward, we are keen to evaluate all our Rainbows clinical services and receive feedback about experience from families to ensure we are meeting their needs and goals. Our sibling support and counselling services have created evaluation forms that will be sent to users of the service including age-appropriate ones for the siblings to ask about their experience and if they have achieved what they wanted to during their allocated sessions. During the pilot phase of the community hubs the feedback received from families attending has enabled us to tailor future hubs and ensure we are providing what the families need and where they need it. Receiving feedback and evaluating the services is also likely to show us where the services are, or can be, working together more to provide better care such as 'Hospice at Home' and our Clinical Nurse Specialists.





### 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. A team of Advanced Clinical Practitioners and Clinical Nurse Specialists are available 24/7 to support the Hospice and wider services across the East Midlands. We are supported by a GP who provides scheduled visits twice/week to Rainbows. We have a Specialist Palliative Medicine Consultant available for advice and support remotely when needed.

During 2024/2025 Rainbows provided the following services to Health and Social Care:

- Hospice services - short breaks, symptom management and end-of-life care
- Psycho-social family support services
- Specialist palliative care advice and support
- Therapies
- Palliative Care Clinical Nurse Specialists in Hospitals across the East Midlands
- Hospice at Home services
- 24/7 Single Point of Contact for Specialist Palliative Care advice
- Support to the NHS, including step down services

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 and safety of the 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 grants from NHS England (NHSE) and Integrated Care Boards (ICBs). Where NHS and Social Care funding is secured, this only partly contributes to the costs of the 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.

The focus of our work in 2025/2026 will be to further develop our relationships with ICBs and to increase Clinical Commissioning funding from the NHS, particularly in relation to provision of specialist palliative care support for symptom management and end of life care. We will also continue to expand our community services including Hospice at Home and Community Hubs.

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In 2025 we will be embarking on our new strategy for the next three years. The strategy will focus on ensuring that the services we offer are continually evolving, improving, innovating and adapting, particularly in response to the external environment and changing needs of BCYP and their families. We will aim for excellence in service delivery in order that we can provide the best for our families. What we are currently doing is good, however there is room to improve, and we want to be excellent.

Our ambition is to be a Centre for Excellence in Research and Training. However, that is not an end in itself and is linked to our aim to be excellent in our delivery of services. We need to understand what excellent end of life care looks like and how we will achieve it. We then need to ensure that we share that externally by becoming an affiliated teaching hospice and delivering education to the workforce across the East Midlands. In addition, we are aiming to increase our research activity by working in collaboration with the University of Leicester Research Department. We want our BCYP to receive the best palliative and end of life care – whoever is providing it and wherever they are.

### Financial Considerations

The Income provided by the NHSE grants and Statutory funding in 2024/2025 was £1,741,911.

The remainder (84%) of the funds needed to run Rainbows is generated through donations, legacies, fundraising events, retail shops and lottery.

### Information Governance

Rainbows needs to collect and use certain types of information about Data Subjects who come into contact with the organisation in order to carry out its work. Personal information must be collected and dealt with appropriately – whether on paper, electronically, or recorded on other material – and there are safeguards to ensure this under the Data Protection Act 2018 and General Data Protection Regulation (GDPR).

Rainbows places huge importance on Information Governance and the key strands of the Rainbows Information Governance policy are openness, legal compliance, information security and quality assurance. Rainbows continues to actively manage personal data in line with all appropriate legal, ethical and quality standards.

### Clinical Coding Error Rate

Rainbows was not eligible to submit data to the Summary Hospital-level Mortality Indicator (SHMI) during the period 2024/2025. Rainbows are not subject to the Payment by Results clinical coding audit during 2024/2025 by the Audit Commission.

### Data Quality

In 2024/2025, 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 ICBs
- Quarterly Quality report to ICBs
- Annual data to Together for Short Lives and Hospice UK
- Baby and child death data to Child Death Overview Panel
- Data for the Safeguarding Audit Tool
- External Supporter reports (including Trusts and Grants)
- Quarterly occurrence reports to the Local Intelligence Network (Controlled Drugs)
- Medicines incident data to Medicines Management Committee for learning and improvement.

### Participation in National Audits

In 2024/2025 there were no audits or enquiries relating specifically to specialist children's palliative care that we were eligible for. Rainbows are not eligible to take part in National Clinical Audits.

### Local Clinical Audits

Audit and Continuous Quality Improvement programmes are reviewed at the Good Clinical Governance meeting bi-monthly driving clinical improvement. In 2024/2025 there were several audit and QI projects including:

- Improving nutrition and hydration care plans, auditing of practice and mealtime observations
- Developing a Hospice Paediatric Early Warning Score
- Safety warning stickers in clinical practice to flag dual feeding ports
- Introduction of After Action Review learning events

Preceptorship quality improvement projects: Both preceptees who started in 2023/2024 successfully completed their preceptorship programmes. There were no new preceptees who started in 2024. We are expecting two newly qualified nurses to join the team in 2025.

We have solved 14 “pebbles” in 2024/2025. “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 and effectiveness and which will, 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 charts, nutrition and hydration and record keeping. We use national audit tools specifically developed / amended for hospices. The audit tools have been peer reviewed, and quality assessed. This allows us to monitor the quality of care Rainbows provides in a systematic way and creates a framework by which we can review our compliance to the standards and make improvements.

The Clinical Quality Assurance Committee and Finance, Audit and Risk (FAR) 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 the most recent audit in February 2025 was good with no further action required. This is the fifth year running where audit compliance has been 100%.

The Continuous Quality Improvement plan provides a framework to ensure that 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.

Improvement projects this year have included: development of learning resources for racism awareness and dying matters week, the introduction of an amended and extended pain assessment tool for non-verbal babies, children and young people and the development of a Paediatric Early Warning Score specifically for Hospices.



### Infection Prevention and Control (IPC)

Infection Prevention and Control and risk-based approach ensures that everyone using and working at Rainbows remains safe. This includes robust IPC policies and procedures and monthly audit (see appendix 2). There have been no Hospice Acquired Infections (HAI's) among children, young people and their families in 2024, including Covid-19

We have continued to be supported remotely with advice and training by our Partner IPC lead at University Hospitals of Leicester - the last physical audit took place in March 2020 - which showed 91% compliance. Due to external pressures beyond our control the audit has not been able to be repeated yet. However, UHL have prioritised the induction and training of a new IPC link worker at Rainbows who is supporting with continued internal monthly IPC, PPE and hand hygiene audits with high compliance (95% and above) for 2024/2025.

### 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 and shared as required. Compliance to actions taken is reported to the MHRA and Central Alerting System team and logged internally.



### Research

Rainbows is recognised nationally as a research active hospice, and we continue to develop our research activity and profile. The NIHR East Midlands Regional Research Delivery Network continue to support research delivery at Rainbows by funding one day a week of research nurse time and half a day a week of research management time. This funds some national collaborative work around research readiness and support in paediatric palliative care organisations.

Rainbows have participated in five research studies over the past year, one of which was our own Memories in Heartbeats study which has now been completed and is in analysis / write up stage. The Memories in Heartbeats study results will be presented at the Together for Short Lives conference in May this year and we will also be aiming for publication in a national journal in due course.

Our research manager chairs the Research in Children's Hospices (RiCH) group, a national group focussed on supporting research delivery and staff within Children's hospices across the UK and will be presenting a poster at the Together for Short Lives conference in May this year. She also delivered a presentation at the Association for Paediatric Palliative Medicine annual conference in London in November 2024.

In our ambition to work towards a Centre for Excellence for Research and Education, we have made several contacts with a view to forming future collaborative working relationships.

- An eminent Professor of child health has agreed to work with us as a strategic advisor for research development at Rainbows. She will help to develop our research strategy and will be our research lead, working to support us towards our goals.
- University of Leicester has met with us to discuss a potential collaborative academic partnership in working together towards a Centre for Excellence. We have discussed some potential research themes. It was agreed that a James Lindt Alliance Priority Setting Partnership (JLA / PSP) would be a gold standard exercise to undertake.

- LOROS Hospice are keen to explore furthering a closer working relationship going forward, especially around equality, diversity and inclusion which is one of our areas of interest as a research theme.
- A local Trust has expressed an interest in funding some research at Rainbows and is keen that we collaborate with other organisations that it has funded, hence our contacts with The University of Leicester (including the Centre for Empathic Health) and LOROS.

We have submitted a funding application, jointly with the University of Leicester, to a local Trust to fund a JLA / PSP. This would be a 2-year project and is a large body of work incorporating precise methodology which would identify areas of priority for research in paediatric palliative care and areas where research would make the most difference.

The future looks exciting for research at Rainbows, we recognise that this is a unique opportunity for Rainbows to work collaboratively with, and be supported by, an academic institution such as the University of Leicester, however we will be working hard to ensure that Rainbows is leading the way and maintaining our unique individuality, building on our established reputation for excellence.



**The future  
looks exciting  
for research at  
Rainbows.**



### Transition and Youth Work

Over the last year the Transition service has supported approximately 190 young people. Transition support begins at 13 with an introduction to what Transition is and the support that the team at Rainbows can offer. Specific support is offered at key ages to consider changes in the law, benefits and services. Last year saw the introduction of Transition Webinars as an alternate way to provide information to as many young people and their families as possible. The Webinars provided are 'An Introduction to Transition', 'Decision Making in Transition' and 'Transition the Next Steps', six sessions were held in total.

Young People and Family Days were also introduced last year to engage Young People and their families with Rainbows Transition Service in a fun and innovative way. The days were themed and provided several activities for families to take part in, as well as providing an opportunity to receive information and discuss transition needs. Days were held for 13 to 17 year-olds and 18 to 24 year-olds to address specific issues.

Work with adult hospices in the region continues, to develop appropriate support for young people in adult palliative care.

Joint training regarding transition continues to be delivered in conjunction with LOROS adult hospice and last year saw the introduction of a new session entitled 'Children's Conditions and Symptoms Being Seen in Adult Palliative Care'. This session has been delivered twice and there are plans to deliver further sessions.

Leavers' well-being days were also introduced for young people and their families to be able to have a sense of closure before being discharged from the service.

The Transition team is now locality based, and this has seen the introduction of a new 3-day per week post to cover the North of the region.

This year will see further Webinars, Young People and Family Days and leavers events, as well as targeted support for specific issues. Webinars for professionals are also planned this year. The Transition team will also be hosting workshops at locality-based hubs. In addition, we will be presenting at the Together for Short Lives conference this year after having two abstracts accepted.

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, signpost and to build confidence as well as offering different types of support depending on their needs. This could include one to one support, group work sessions, fun activities, learning and developing new skills, memory making and realising and achieving their aspirations.

Often the one-to-one work includes discussions around managing their condition, dealing with it and looking at developing coping strategies to build resilience. There are 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.

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

Some quotes from young people on their view of youth work at Rainbows:

**"We never want to mope around and be miserable because of our disability, the youth workers encourage and provide opportunities to get out and have fun"**

Young person, 19

**"It's good not only to collaborate in the future of advocacy, but lead, which means we, as the next generation, are in the driving seat"**

Young person, 23



## Quality Account 2024/2025

### Youth work achievements in 2024/2025

Working with SEND Music project to deliver music development, production and creative space to learn new skills and record and produce tracks with support from experts.



Supporting with the Hub Outreach sessions.

Making a Difference Group – Youth Forum.

Monthly Youth Club Sessions

Youth workers attended annual Health Based Youth Workers Conference, a great opportunity to network with other health-based youth workers and develop learning and working partnerships particularly with those also working in Hospices.

Youth Workers are part of the Health Based Youth Workers Network meeting regularly to share resources, good practice, training opportunities and other resources.

Monthly Gaming Club – in the planning stages.

Working with the Fundraising team to attend events and support young people in speaking at these events.



Organised activities and trips for the young people based on their feedback, example includes Comic Con.

Delivering talks on the Youth Service to other departments within Rainbows to help their understanding of the role we have in supporting the young people.

### Part Five

#### What Others Say About Us

From the **Deputy Director of Public Health and Chair of the Child Death Overview Panel** following a recently reviewed case where the panel discussed the excellent care provided to the family.

“The panel praised the excellent collaborative working between the hospital teams (obstetric and neonatal teams) and the team at Rainbows Hospice to formalise a special ‘Baby Plan’ prior to the birth. The panel noted effort to conduct face to face meetings with the key people from all areas being present to talk and discuss options with parents, as well as the regular reviews of the plan and updates when circumstances changed. Furthermore, while the baby never made it to the hospice, the panel recognised the excellent preparation including arranging a parental visit and time given to help them prepare for this option in advance.

Chairing and taking part in Child Death Overview Panel is never an easy job and one that is full of sadness. However, examples of care such as this help remind us all of the excellent work you and others do to ensure families do not face such difficult circumstances alone. Thank you.”

Feedback from Great Ormand Street following a transfer of a young person from there to Rainbows for End of Life Care.

“There have been many barriers preventing the young person from getting home, and GOSH were grateful for the support shown by the Specialist Palliative Care Team at Rainbows. It demonstrates the collaborative working that occurred to facilitate this transfer.”

#### 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 Care Act (2022) 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 in 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 2024/2025.

The CQC inspection process is currently undergoing a complete review, and a new inspection regime is expected to be implemented later this year.

No concerns have been raised to or by the CQC throughout 2024/2025

A mock quality standards inspection was carried out in February 2024, which did not identify any significant concerns. An improvement plan was created from the recommendations and observation with all actions completed and implemented.





## Quality Account 2024/2025

### Commissioner Quality Assurance Visits:

Quality reports continue to be submitted quarterly to all ICB Quality Leads. Monitoring meetings with ICBs are carried out following the quarterly report, as required. No concerns raised during 2025.

Nottingham and Nottinghamshire ICB undertook a quality visit in 2024 led by their Head of Nursing for Children and young people. The report highlighted our strengths and successes as well as some recommendations to support further improvement:

“The team at Rainbows has a focus on safety around medicines management. There is a positive culture around the reporting of incidents and learning from them to balance the governance requirements and the involvement of parents and carers in managing the care of the children and young people. There are bi-monthly medicines management meetings and regular huddles where learning is identified and shared.

Integration with the East Midlands ICBs and Rainbows has grown and is well embedded, fostering relationships where open and honest conversations are held, including inviting ICB colleagues to complete a quality visit.

The Rainbows team is always striving to improve and there is the potential for development opportunities in the use of Champions or people, outside of the leadership team, with an interest in a particular area of work. This includes, medicines management or infection prevention and control, to identify areas for improvement or good practice to model and promote excellence amongst colleagues and peers.”

### Areas for Further improvement

As part of Rainbows commitment to continuous improvement, Rainbows has adopted the NHS England endorsed structured learning tool After Action Review. This approach uses a 4-question structured approach to reviewing events and incidents where there is learning. This may be when things have gone well or where they have not gone as well as we would have liked. The focus is on learning and improvement and seeks to understand what was expected to happen, what actually happened, what the difference is, what has gone well and what can we improve upon. Rainbows has held 6 AARs in 2024/2025 that included using it as part of the evaluation of new services as well learning following an adverse incident.





### Children, Young People and Carer's Feedback:

Family feedback surveys have focused on specific events and services such as our new community hubs, family fun days and remembering events. Here is a selection of the feedback from our events

#### Community Hubs

Fifty-three family member beneficiaries, including twenty-two children, participated in five Community Hubs provided by the Rainbows Family Support Team between June - December 2024.

At the start of the hub events parent / carer participants described a variety of fun and social supportive activities with peers and Rainbows members of staff that they hoped to achieve by taking part:

- “To meet other families in similar situations”
- “To speak to staff for support if needed”
- “For my child he wants some good friends”
- “Learn something new”
- “Gain support”.

ALL families achieved what they had hoped to achieve for their BCYP. One respondent reported: “I didn’t really know what to expect. Would have been nice to have met more people / families”.

Another parent suggested that “an activity to create a memory of the day” would have made their experience better.

Others wanted to receive “acceptance for myself and my actions”, “meet a psychologist for myself to share my thoughts and feelings” as well as meet others for “possible friendships” and to “know I’m not alone”.

Most participants attended a morning session (n=10) with two thirds of these attending between 1-2 hours. There was participation in all activities offered with n=18 reporting taking part in “coffee, cake and chat”.

There was positive description about the creative activities at the Hubs being “inclusive”, “enjoyable”, “intriguing”, “superb” and “brilliant” with one respondent suggesting “it might be nice to do an activity as a group”.

There was a minority of comments about creative activities not being age appropriate or suitable e.g. “arts and crafts not suitable for my child, they are too young to colour” and it would have been good if “there were more adult or older teen activities”.

Conversely, there was feedback that “it was good to chat about transitions to adulthood / University”. On this occasion a Rainbows Transition Worker participated in the event.

Collectively, all venues were rated highly (4.9/5 average) by parents. When asked about what sort of facilities or ideas would be useful for a future Community Hub participants suggested “To advertise better”, “Let people know! Such an amazing facility to use!” and “Offer in school holidays perhaps”.

#### Family Fun Day

Centred around the Olympics and Paralympics the family support team received feedback from 18 families following the summer family fun day. Here is a selection of the feedback:

- “What a day! Thank you! It’s been great chatting and interacting with others. Thank you for all you have done to make today so accessible and fun. We have never seen our son so engaged!”
- “Thank you for a lovely day out where we can do things altogether as a family”
- “Nice to meet other families and share experiences in a fun and relaxing environment”
- “Great to see (brother) enjoying himself and joining in with all activities”
- Fun activities and super friendly and cheerful staff!”

## Quality Account 2024/2025

We also received 13 feedback forms in 2024/2025. 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.

### You Said:

“Please can staff go back to wearing polo shirts as uniform so it doesn’t feel as clinical especially when we go out”

### We Did:

“Staff will continue to wear scrubs in the hospice to comply with infection prevention and moving and handling regulations, however they will wear their own clothes when out on trips”

### You Said:

“Please can we have better highchairs in the dining room to support babies in an upright seated position”

### We Did:

“We have purchased new highchairs which will be available for your next stay. Thanks for the suggestion!”

### You Said:

“The staff ID sign on doors feels negative and not very welcoming”

### We Did:

“Thanks for letting us know about this. The sign has been changed, and we hope it is now more welcoming”

### You Said:

“I was in the young person’s lounge and was asked to leave because someone else had booked the room. I felt angry as I was playing a game and couldn’t continue with it until later”

### We did:

“I am sorry that this happened to you during your game. We have now made it clearer in the diary and with signs, when the room is booked out so that staff will know when this is and can support you to use somewhere else, so you are not interrupted when you are in the middle of your game”



### Complaints, Concerns and Compliments

Complaints	2
Concerns	4
Compliments	81

The complaints were related to issues related to a short break stay and another around communication following an escalation of care to hospital outside of child's care plan. Policy, procedure, care planning, training and monitoring have all been reviewed and changes made to manage this better in the future. This includes the introduction of assessment tools a specifically designed Paediatric Early Warning Score for use in Hospice care to effectively identify & manage deteriorating babies, children and young people (see Part 2 Clinical Effectiveness). The Lead Nurse for Clinical Operations thoroughly investigated all the concerns and worked with the families to improve care for future stays.

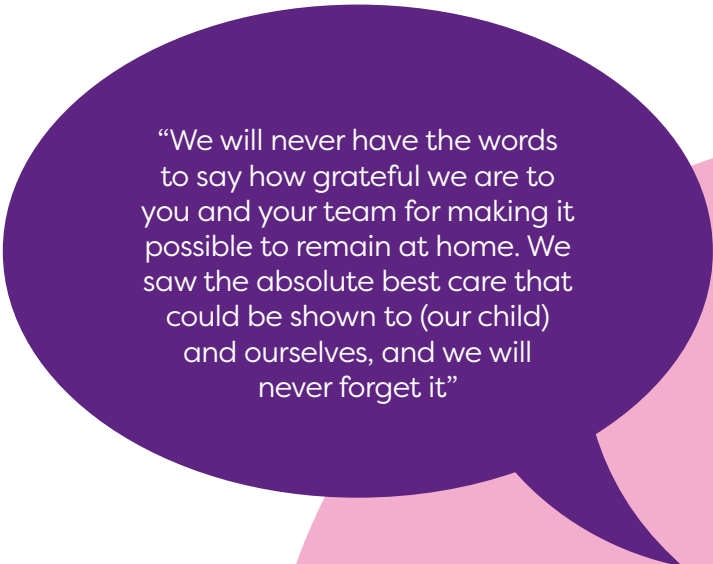
One Informal complaint / concern was related to miscommunication around the use of the buzzers which caused upset. The Lead Nurse for Clinical Operations thoroughly investigated and apologised for any distress caused. We are sorry this happened and individual learning and reflection has taken place around clearly communicating expectations.

Another was related to how lengthy and stressful a family found the admission process. The Lead Nurse and admissions nurse have worked with the family by offering a home visit prior to the next stay, to ensure all the information is collected. This will take place at least a week prior to the planned stay to ensure all paperwork can be collated. We have also explored admissions times and reducing paperwork which can be reviewed from previous stay rather than completing fresh every stay.

There have been 81 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.



"I wanted to say thank you again for the remembrance service. It was lovely to be able to walk round the gardens....We did some crafts this time and we were given some things to bring home for the children to do too. We felt very well looked after."



"We will never have the words to say how grateful we are to you and your team for making it possible to remain at home. We saw the absolute best care that could be shown to (our child) and ourselves, and we will never forget it"

## Part Six

### Review of Quality Performance

#### Quality Schedule

#### Hospice Safety Indicators

Hospice Safety Indicator	2024/ 2025	2023/ 2024
Number of patient safety related incidents/accidents, including medication errors (April 2021 – March 2022)	Total incidents = 106* Clinical incidents = 51 Near Misses = 6 Medication errors (including CDs) = 59 Controlled Medication errors = 8	Total incidents = 76* Clinical incidents = 27 Near Misses = 13 Medication errors (including CDs) = 49 Controlled Medication errors = 12
Number of patients who developed category 3 and 4 pressure ulcers in our care	0	0
Infection Prevention and Control rates:	0	0
Total number of children admitted with known infection. This includes:	0	0
• Number of C-Dif	0	0
• Number of MRSA	0	0
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 2024 – March 2025)

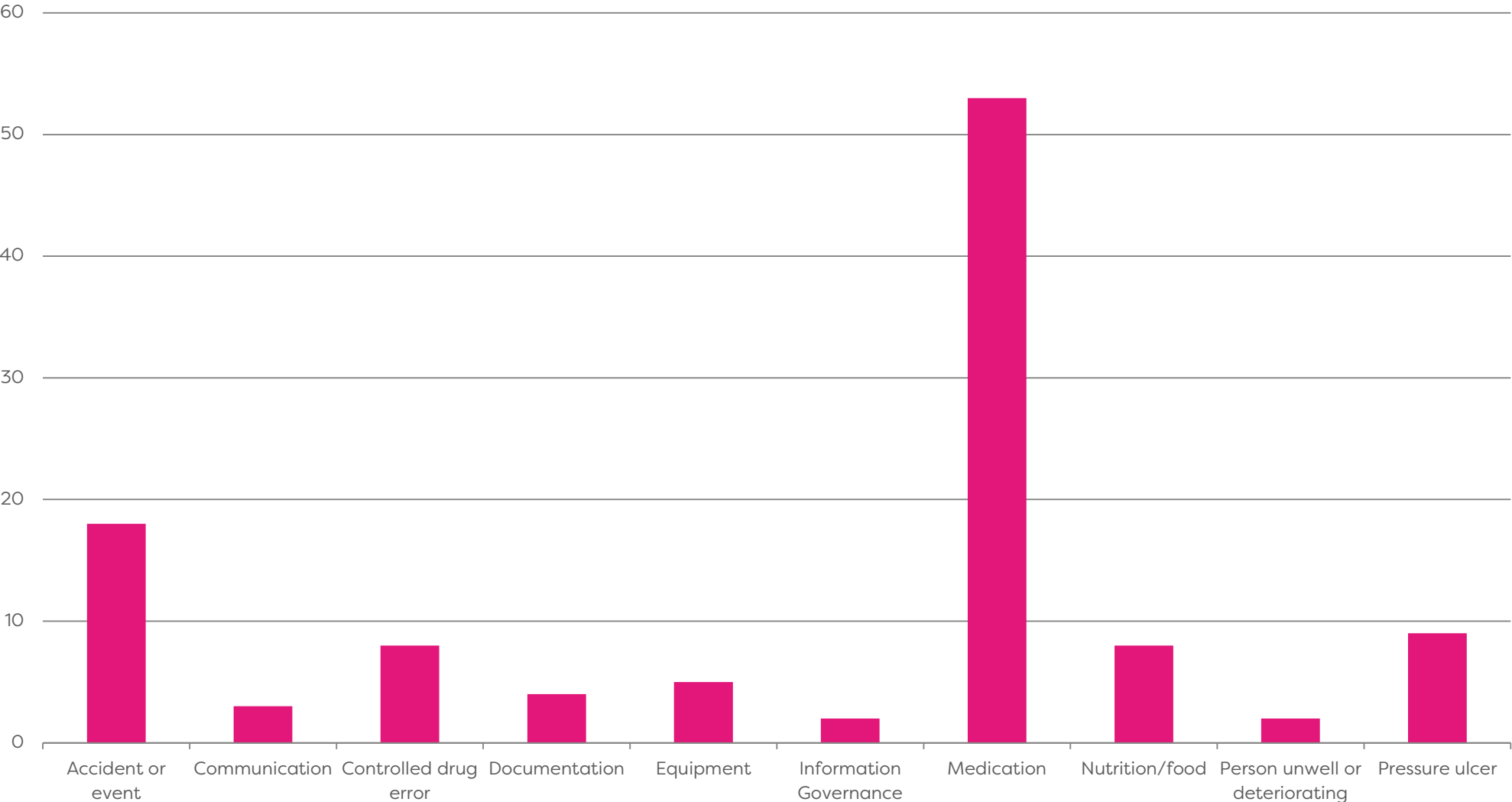
The increase in incidents from last year reflects the maturity of our just culture framework for medicines management, our commitment to continuous learning and improvement following every error, by the nurses involved, the medicines management meeting, as well as our excellent reporting culture. It also reflects the increase in the acuity and complexity of the medicine's regimes that babies, children and young people received. The following chart shows that our highest single area of incidents is medication, which is to be expected, as administration of medication is our highest risk, of frequency and complex intervention. Reporting of other clinical incidents, such as accidents and events, the second highest area of incidents recorded (n19), again reflects our reporting culture and includes a change in the patient demographic; increase in providing care for babies and toddlers who may be prone to slips, trips and falls when they are playing and learning to walk, for example. Reporting has meant that incidents can be addressed quickly and safely to minimise recurrences in the future.

Rainbows nurses administer in excess of 61,152 medication doses every year. The pie chart below drills down to the categories of medication errors to focus the areas for improvement in administration of medications, storage and transcribing of the charts. Errors during administration of medication includes all stages of the medicines process (nine rights). Overall medication errors have increased slightly from the previous year, although the proportion of the errors that are administration errors have remained largely consistent and reflect the volume of administrations. 56 of the total medication errors, including eight involving controlled drugs, were no harm minor errors. Three incidents were categorised as moderate as further observation or treatment was advised for safety reasons but where no further harm was reported following this. Although relatively low numbers of errors, all errors are fully investigated, and analysis includes thematic analysis which allows quick identification of any trends, meaning systems changes can be made if required and learning put into practice to minimise the same errors occurring again. Learning is shared via email, 10@10 briefings, feedback forms from medicines management meetings, "incident on a page" flyers, Team Meetings and The Good Clinical Governance Meeting.



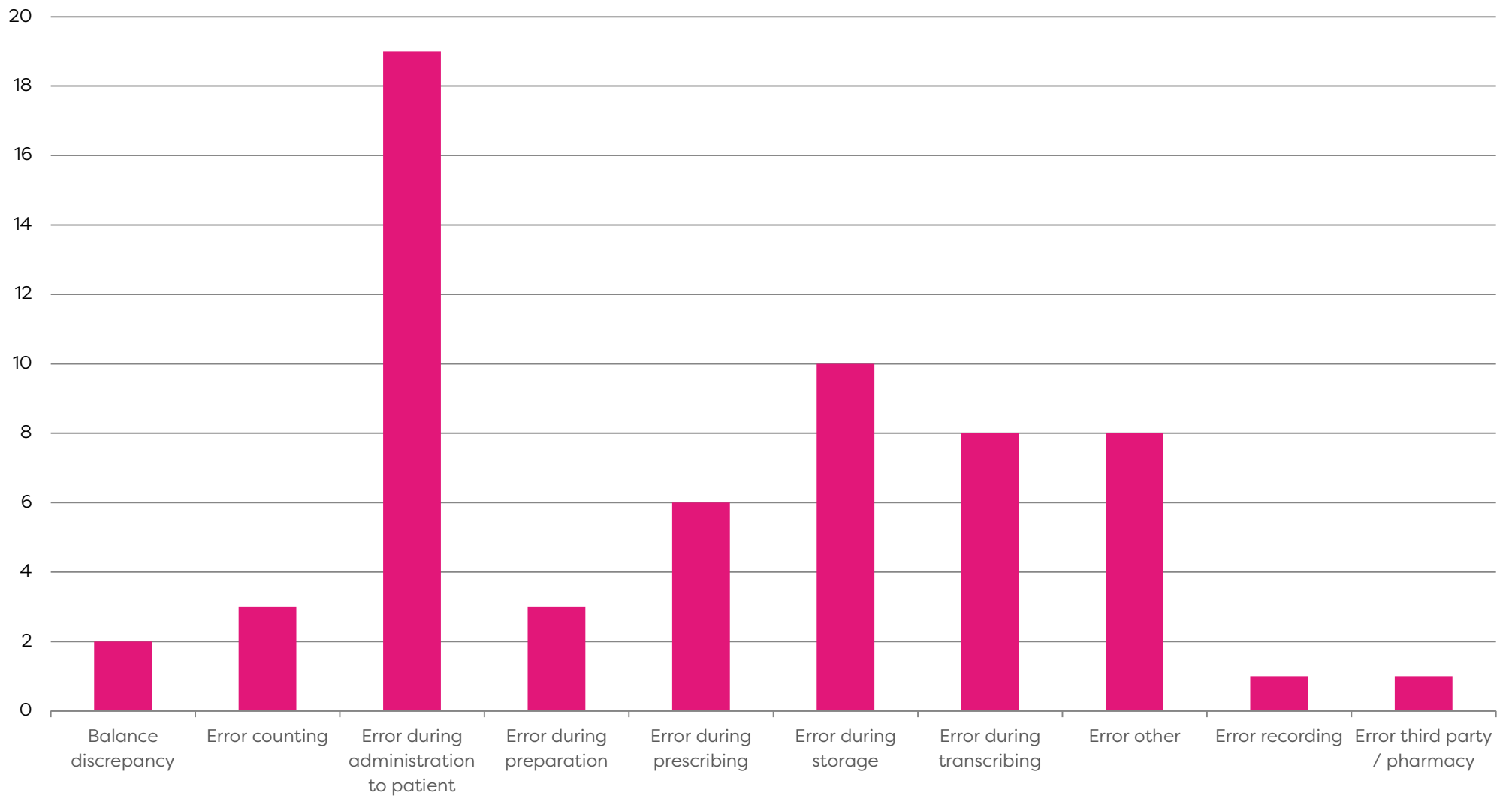
Quality Account 2024/2025

All Clinical Incidents including Medication by Category (April 2024 - March 2025)



## Quality Account 2024/2025

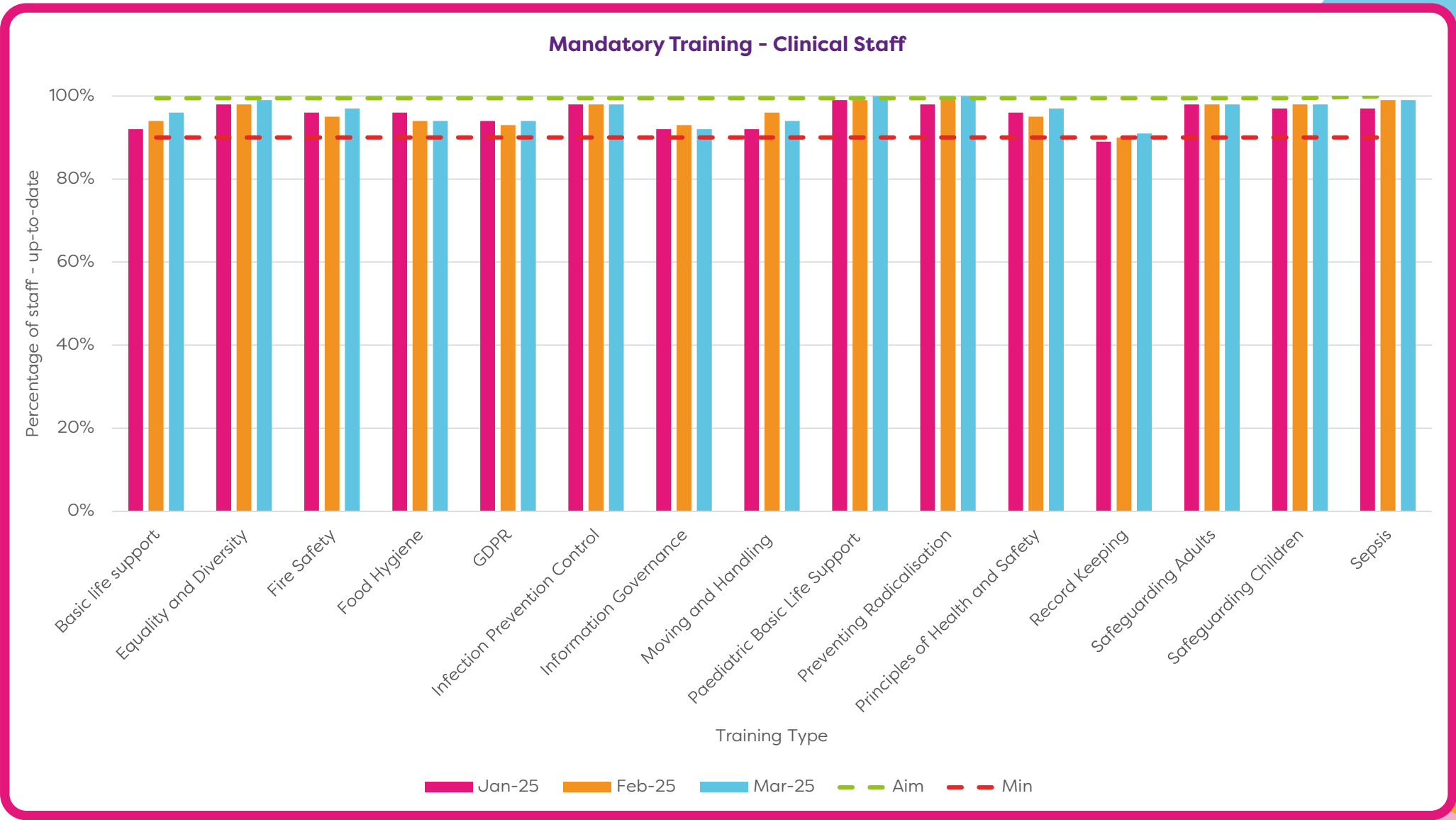
Medicines Incidents by Stage at which it occurred (April 2023 - March 2024)





Workforce

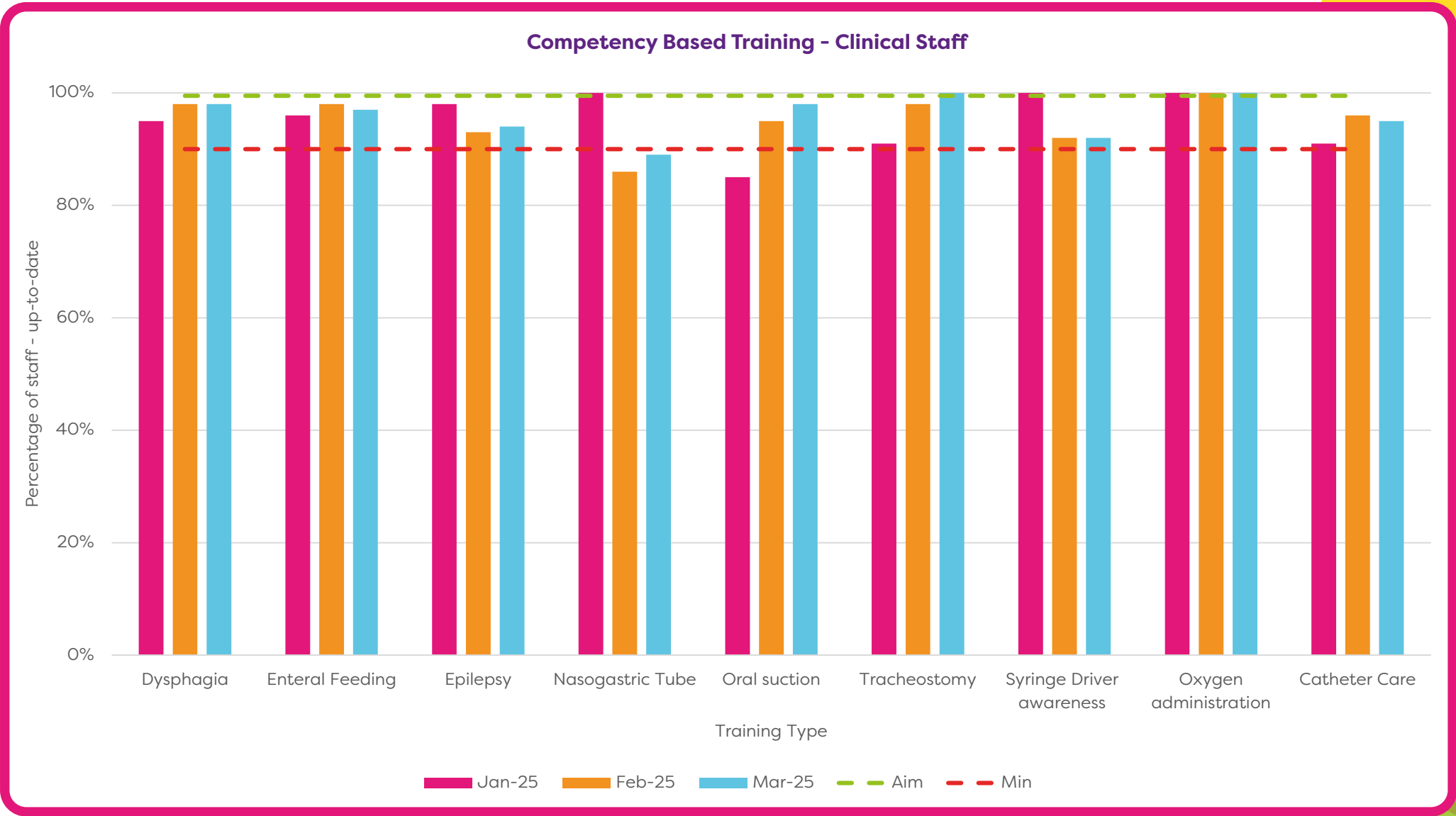
Mandatory Training:



Quality Account 2024/2025

Workforce

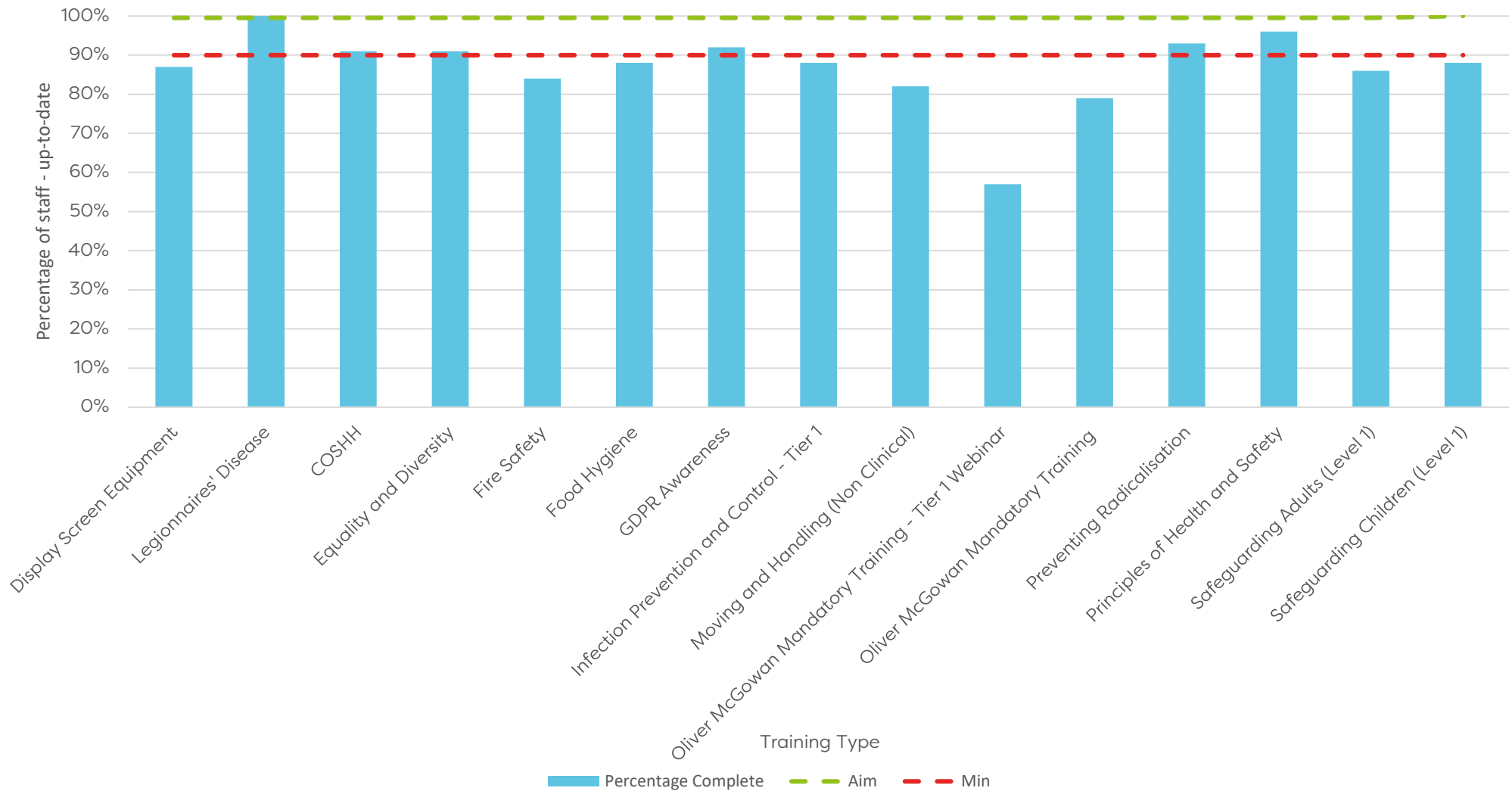
Competency Based Training:



## Quality Account 2024/2025

### Mandatory Training:

Mandatory Training - Non-Clinical Staff



**Note:** Oliver McGowan - Tier 1 Webinar Mandatory Training compliance has been addressed and is now above 90%



## Quality Account 2024/2025

### Equality, Diversity and Inclusion (EDI) Strategy

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. Inclusion 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 several 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. Our vision is to collaborate, celebrate our differences, and make a lasting impact.

We are delighted to have revised our values in the last 12 months, of which inclusion plays a central role. Our values of One Team, People Centred, Aim High and Own It provide the foundation for our Inclusion Strategy. We have forged partnerships with external experts to ensure that our Inclusion strategy touches every part of the organisation, and we are thrilled to have formed a Values, Culture and Inclusion Champion Group which will officially launch in April 2025.

All managers at every level of the organisation will be undertaking psychological safety training and we will be rolling out a programme of inclusion workshops across the year for all staff to access. In addition to this, from April 2025, we will publish an internal bi-monthly newsletter around matters of well-being, inclusion and values which will provide information and signposting around relevant and topical issues.

Inclusion is a continual process and there is always more to learn, and we will continually review and monitor our progress in this area.

### Freedom to Speak Up (FTSU)

Work in Confidence continue to provide the service of a FTSU guardian as well as an anonymous online platform accessible to all staff who wish to raise concerns, queries or ideas for improvement.

Engagement from our FTSU guardian has been much improved with a proactive approach and awareness sessions with our Board of Trustees, new staff members and our VCI Champions. We will continue to invest in the area over the coming 12 months, continually reviewing its efficacy across the organisation.



### Safeguarding

In 2024/2025 Rainbows successfully retained the highest level of safeguarding assurance, 'Good with Innovation' awarded by Leicester, Leicestershire & Rutland ICB. The ICB made the comment that, "the response was exemplary and comprehensive" identifying the following areas which lead to their decision:

- Safeguarding Lead is now full time demonstrating that the organisation is responsive to need.
- Safeguarding Lead has worked with LHS SystmOne Administrator to fully integrate mental capacity assessments and best interest documentation onto SystmOne. Training has been provided to all staff regarding practically assessing capacity for every care decision to be made. Every young person who is unable to consent to all or some of their care and treatment has an MCA and best interest document aligned to each care plan. Rainbows Care Team are now confident to take ownership of the process and Rainbows are 100% compliant with the Mental Capacity Act (2005)
- Monthly safeguarding theme with accompanying leaflet and featured in Rainbows twice monthly Round-Up magazine.
- Safeguarding Supervision: weekly offer for both the Care and Family Support Teams.
- Joint level 3 Safeguarding Training with LOROS, facilitated by Rainbows.
- Police Prevent Team – quarterly presentations to Rainbows staff.
- Monthly, 'Let's Talk Ethics' forum to discuss cases and contemporary ethical subject areas E.g. The Assisted Dying Bill.
- On-going work with Ben Troke, lawyer, in updating the My Adult Still My Child website resource
- Safeguarding assurance sessions provided to the Board of Trustees.

Rainbows remains 100% compliant with the Mental Capacity Act (2005) and Deprivation of Liberty Safeguards (2009). Case note audits are completed twice monthly and continue to demonstrate that all young people over the age of 18 who are unable to consent to their care and treatment have the relevant mental capacity assessments recoded in their clinical records.

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

Safeguarding at Rainbows is organisational wide. The Safeguarding Lead offers support, supervision and training across all departments. Rainbows shops have a safeguarding visit every 6 months or as and when required. Safeguarding meetings are held monthly with the Head of Volunteering. There are a number of people who hold key safeguarding responsibilities including a Trustee Lead, Executive Lead, Safeguarding Lead and 2 Safeguarding Link Workers.

### Duty of Candour

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



## Quality Account 2024/2025

### 2024/2025 Activity Report

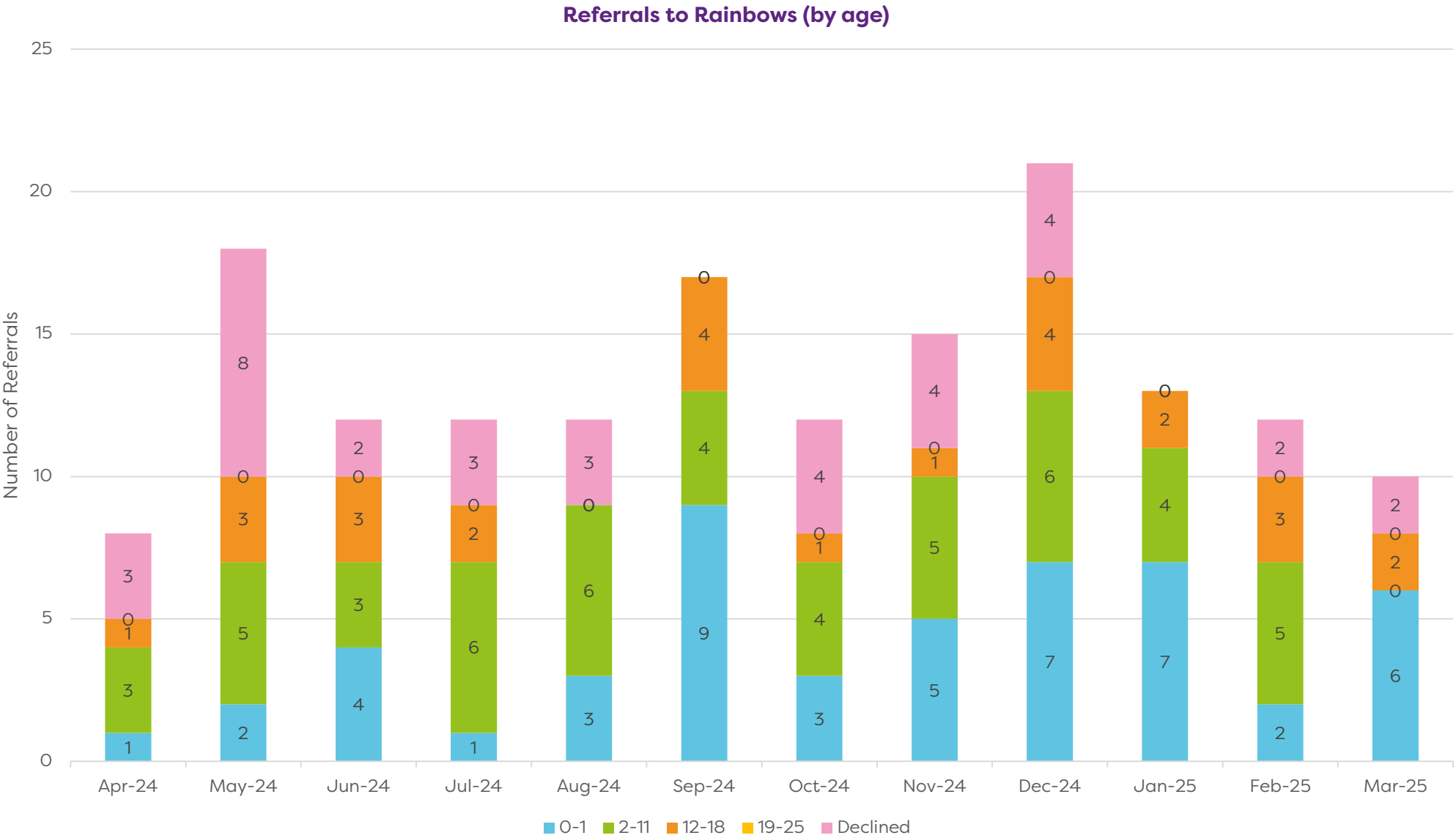




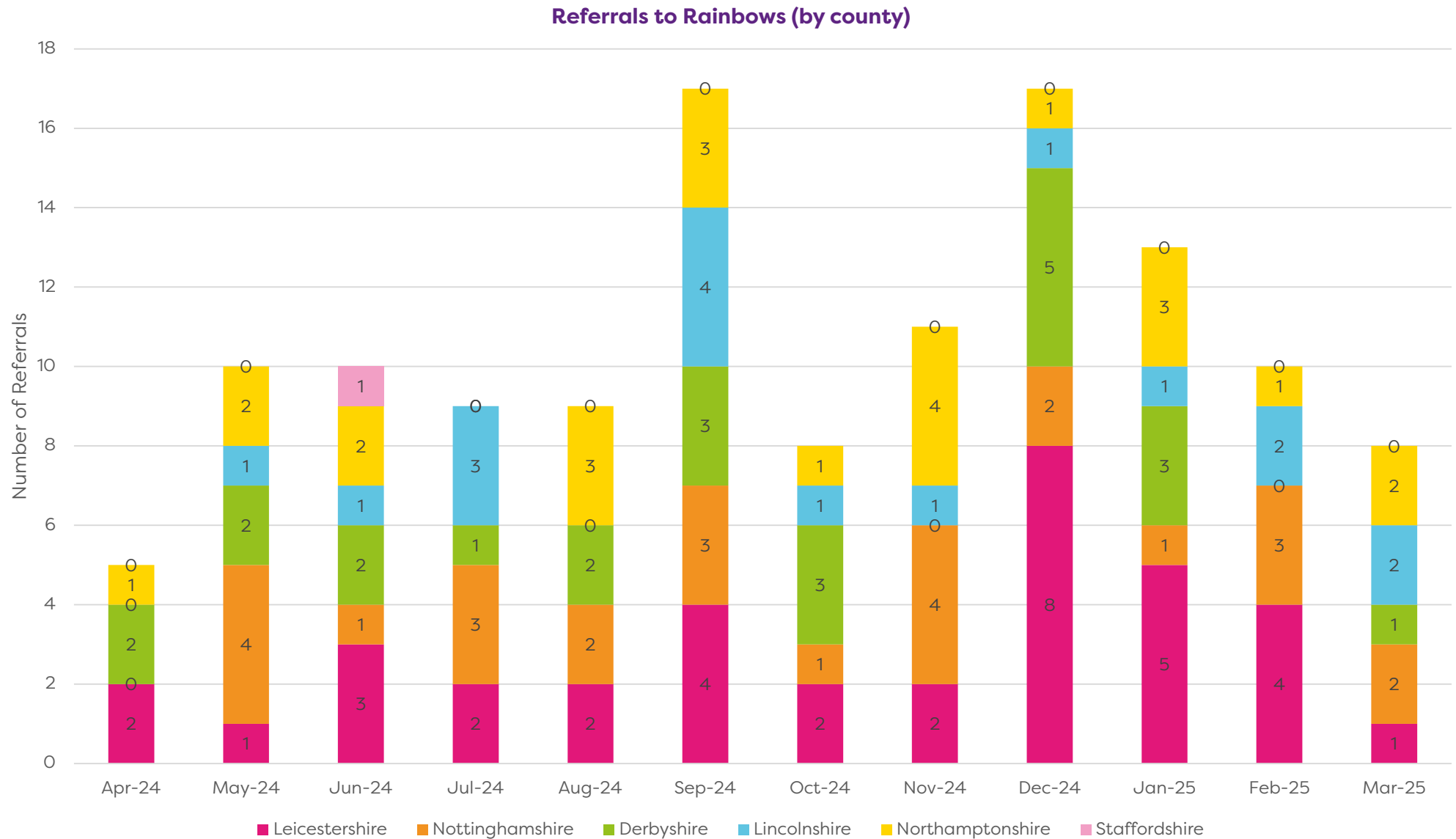
## Quality Account 2024/2025



Quality Account 2024/2025



## Quality Account 2024/2025





### Part Seven

#### 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 to achieve our vision and aims. Rainbows has an established governance structure, which was externally reviewed in 2022 and internally in 2024. A Clinical Trustee chairs the Clinical Quality Assurance Committee, with other Clinical Trustees as members.

Rainbows has increased its number of Clinical Trustees over the past year to ensure clinical knowledge and experience is represented on the Board.

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. Rainbows has a comprehensive digital Risk Register which is monitored by the governance committees who regularly update the Board in relation to areas of high risk. Further work is being carried out in this area with a plan to implement a comprehensive Board Assurance Framework in 2025 to support the Trustees in monitoring Strategic Risks to the organisation.

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 the recently updated 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 assured 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 Eight

#### Responses to Rainbows Quality Account

##### NHS Leicester, Leicestershire and Rutland Integrated Care Board

The NHS Leicester, Leicestershire and Rutland Integrated Care Board works closely with Rainbows Hospice for Children and Young People ensuring we have the best services we can have for our end of life care. The Hospice integrates well with its partners in Leicester, Leicestershire and Rutland. Rainbows are responsive to needs of our children and other end of life services in Leicester, Leicestershire and Rutland. The Hospice is very proactive in the community and keen to work collectively to improve care. The Children and Young People Team always feel welcome and included in the hospice planning process.

##### NHS Nottingham and Nottinghamshire Integrated Care Board

Rainbows Hospice for Children and Young People and the Nottingham and Nottinghamshire Integrated Care Board have and continue to work together in partnership to deliver quality palliative care for babies, children and young people within Nottinghamshire locality. The Hospice keenly works alongside and in partnership with other locality providers. Rainbows Hospice for Children and Young People and our Children and Young People Team have built a good working relationship and are supportive in developing the future direction of travel. Rainbows are always striving to continue to develop and improve both service and facility provision, and worked very hard to ensure there was no impact to patients and families or service delivery during recent building works.

Well done.



## Appendix 1

### Audit Calendar 2024/2025

Month	Clinical		Corporate		Health and Safety (H and S)	
	Audit	Quality Improvement	Audit	Quality Improvement	Audit	Quality Improvement
April	External Placement Audits External Controlled Drugs Audit	15 Step Challenge	Data Protection External Audit		Fire Service Audit Solar Panel Audit	
May					Water Risk Assessment Pool Service Annual Audit	
June			Annual Accounts External Audit		Electrical Kitchen Equipment Audit	
July		15 Step Challenge	New Shops Finance Audit Profit Protection Audit		Kitchen Food Safety Audit (EHO) Review of COSHH	
August					Kitchen HACCAP First Aid Box Checks	
September	Mattress Audit				Shops - Health and Safety Audit	
October		15 Step Challenge			Fire Safety Audit EICR Electrical Safety Audit	Compliance with Environmental Policy



## Appendix 1

### Audit Calendar 2024/2025 (continued)

Month	Clinical		Corporate		Health and Safety (H and S)	
	Audit	Quality Improvement	Audit	Quality Improvement	Audit	Quality Improvement
November	External Controlled Drugs Audit External Medication Storage Audit		New Shops Finance Audit		Extraction Fan Cleaning (Kitchen and Laundry) Fire Dampers Security (External CHUBB)	
December	Uniform Audit				Risk Management policy	
January	Mixed Sex Accommodation	15 Step Challenge	Profit Protection Shops Audit		AIR Handling and AC units First Aid Box Checks	
February					LOLER (mini-bus tail lift)	
March	External Infection Prevention Control Audit				PAT testing (TR19 inspection compliance)	

## Appendix 2

Clinical Audit	Outcome
Placement Audits	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 and University of Lincoln.
External Medicines Storage Audit	An audit was carried out in February 2025 by an external Pharmacy Assistant from University Hospitals of Leicester (UHL). The audit findings were exemplary, and no further action was required / no recommendations made. Of note was the labelling and organisation of the cupboard and monthly internal stock audit. This is the fifth 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 using the Rainbows audit tool. An action plan is developed with any actions required. The stock medication list was reviewed and updated in January 2025 to reflect changes in acuity and medicines usage. The annual update of nurses' signatures for purposes of ordering medicines from UHL was updated in January 2025.
Leicester, Leicestershire and Rutland Safeguarding Collaborative Assurance Template	<p>This template outlines assurance against key safeguarding requirements for adults and children and to identify areas for development or where additional assurance is required. The template was submitted on 18/11/24.</p> <p>Rainbows demonstrated compliance with the NHS Standard Contract, Children Act 2004 and the Health and Care Act (2022). Rainbows was rated as Good and includes innovation which provides a very high level of confidence of the skills, expertise and understanding of the requirements with no omissions or concerns. Safeguarding training compliance is above 90%</p> <p>Safeguarding at Rainbows is managed safely and effectively. Our Safeguarding Lead provides reports to our Good clinical governance committee, Clinical Quality Assurance Committee and Board of Trustees. Innovations include "let's talk Ethics" forum, monthly safeguarding theme with accompanying leaflet and featured in organisation wide twice monthly Round-Up magazine, weekly safeguarding supervision offer and On-line webinars for parents on the Mental Capacity Act and decision-making.</p>
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.

## Quality Account 2024/2025

Clinical Audit	Outcome
Drug Chart Audit	Weekly audit of Medicines Administration Records (Drug charts) is carried out to monitor standards on a continuous cycle and ensure continuous improvement in practice. Themes where compliance is being monitored and improvements made include transcribing of as required medicines to include frequency, and when given, efficacy recorded in the BCYP electronic care record.
External Controlled Drugs Audit	<p>Audit carried out in January 2025 by an external Pharmacy Assistant from University Hospitals of Leicester (UHL).</p> <p>The audit noted great recording of CD administration with registers clear and concise. The audit found our practice to be good with minor best practice recording points noted for improvement such as the consistent recording of wastage. No further action required. This is the fifth year in a row that our compliance has been 100% for CD storage.</p> <p>Monthly CD spot checks by the Controlled Drugs Accountable Officer continue and now include a supportive check of transcribing and prescribing of controlled drugs onto the medicines administration records.</p>
Nutrition and Hydration Audit	<p>New for 2024 this audit checks our compliance with the NICE guidance and clinical guidelines as well as Regulation 14 of the health and care act (2014. Reg 14) around nutrition and hydration for children and adults. It also incorporates mealtime observations, which was written in consultation with Children and young people, who told us what was important to them at mealtimes – such as being included in conversations and the social aspect of mealtimes and that softer or puree diets are presented in an appetising way and include variety.</p> <p>A wider piece of work was commenced following the pilot audit to update our care plan templates, up-skill our catering staff around textured diets and update our enteral feeding policies, which is now complete.</p>
Infection Prevention Audit	<p>Infection Prevention and Control audits have continued to be carried out with Hand hygiene audits and PPE audits being carried out monthly, increased as necessary during any infection outbreak. Hand Hygiene and PPE compliance remained at 100% during 2024. 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 96% to 100% throughout the year. Partnership working with UHL has continued including email, visits and access to training.</p>



Clinical Audit	Outcome
Mattress Audit	<p>A full mattress audit by an external assessor took place in 2023 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. Monthly mattresses checks are done by the housekeeping team as per manufacturers guidance and replacements made as necessary.</p>
Record Keeping Audit	<p>Rainbows continued to carry out weekly monitoring using a recognised clinical records audit template against NHS and Health care professional body standards and criteria. This was reviewed and updated in 2024. Following the introduction of SystmOne electronic records (in February 2022) audit results have improved particularly around tissue viability and mouth care assessments. The annual Record Keeping Audit record keeping competency has been updated to include electronic record keeping and cascaded to staff to complete. With SystmOne fully embedded this is an annual refresher of the principles of good record keeping. 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.</p> <p>The weekly record keeping audit is broken down into sections for compliance monitoring, paper documentation, SystmOne documentation and care plans/assessments.</p> <p>The weekly record keeping audit is completed by nurses and HCAs to support team learning and improvement.</p>
Mixed Sex Accommodation	<p>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. 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 several processes that support the sensitive management of males and females whose bedrooms are located in the same area of the Hospice. Young people have historically reported the importance of being accommodated by age rather than gender.</p>



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



**[rainbows.co.uk](http://rainbows.co.uk)**

Rainbows is registered as Cope Children's Trust in England and Wales. Registered Charity No. 1014051.  
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