



Rainbows Hospice for Children and Young People
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Registration Company in England and Wales Number: 2743297

Registered Charity Number: 1014051

Care Quality Commission Provide ID: 1-101728495

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

Rainbows Quality Account
2017-2018

“Rainbows is an amazing place, not just for the twins, but for all the family. Every day is different but I know the challenges which lie ahead and I will take it as it comes. I have great family support and I have Rainbows. I have hope for the future.”

(Parent)



“I really love my brother and when he first came home from hospital it made me very happy. Now he goes to Rainbows and it is a great place for children who aren't very well and are struggling to get better.”

(Sibling)

“Rainbows may be a hospice but it isn't a place to die, it's about living and in those 16 nights a year respite we receive they both do a lot of living.”

(Parent)



Our Vision, Mission and Values:

Our Vision: Every baby, child and young person with a life-limiting illness to receive the help they need to experience a quality of life before a dignified death, with families supported through every stage of their journey.

Our Mission: In our Hospice and across the East Midlands we:

- Create memories for families to treasure
- Relieve the pain and symptoms of life-limiting conditions
- Provide comfort and compassion at the time of death
- Support families before and after bereavement

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

- Welcoming
- Excellent
- Co-operative
- Accepting
- Responsive
- Energetic

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Part 1

Statement of Quality from Interim Chief Executive

Welcome to our 6th annual Quality Account, a summary of our performance against selected quality measures for 2017/18 and our initiatives and priorities for 2018/19.

Rainbows is an independent regional charity. Babies, children and young people with life-limiting and life-threatening conditions come to the hospice for specialist respite stays, symptom management, palliative and end of life care. Their families are also supported and helped by Rainbows on their difficult journey.

The aim of this report is to give clear information about the quality of our services, to demonstrate that our children, young people and their families can feel safe and well cared for and that all of our services are of a very high standard. We could not provide such high standards of care without the hard work of our staff and over 350 volunteers and, together with the Board of Trustees, I would like to thank them all for their support.

Our focus is, and always will be, our children, young people and their families. We actively continue to seek the views of all who access our services and respond to this feedback in a proactive way in order to ensure we maintain the highest standards of quality.

Rainbows Board is supported by a Clinical Quality Assurance Committee and a Corporate Governance Committee. The Clinical Quality Assurance Committee has a particular remit to ensure that the hospice has a culture of continuous improvement.

The vast majority of our funding comes from supporters in our communities, so the opinion of the general public is greatly valued by us all here at Rainbows. We thank all of the people across the East Midlands who raise the funding required to maintain our services. Their contribution is vital to the ongoing care for babies, children, young people and their families.

Rainbows' Director of Care is responsible for the preparation of this report and its content. To the best of my knowledge the information in the Quality Account is accurate and a fair representation of the quality of care provided by Rainbows Hospice for Children and Young People.

David Strudley

Interim Chief Executive Officer



Part 2

Priorities for Improvement and Statements of Assurance from the Board

In line with Rainbows' Strategic Plan, the following improvement priorities have been identified for 2018-2019.

The hospice works with staff and board members to create a strategic plan. This provides guidance based on the needs of the babies, children and young people we support. Through listening to feedback we gain a real sense of what is important and this drives our priorities for the future.

Future Planning (Patient Safety):

Priority 1: To implement Datix

We aim to implement Datix to electronically record all incidents, accidents and near misses. To ensure our electronic information is data rich, viewed thematically and shared across the organisation. To be able to close the loop on individual incidents, increasing the breadth of our generated reports and reviewing themes across the organisation.

Priority 2: Information Technology Improvements

Rainbows will be launching a new database system which will ensure all client records are electronically based and staff working in the community have remote access to client records. Development of a robust IT infrastructure will support existing and future services. It is expected that there will be improved sharing of data and information for staff working in the hospice and community.

Future Planning (Patient Experience):

Priority 1: Reorganisation of the Care Team

Phase one of the care review introduced a new senior structure and these posts have now been recruited into. The aim is for there to be improved clinical leadership. Looking ahead for 2018/19 we need to ensure we have got the structure right and ensure we maximise senior experience cover directly providing care, embedding knowledge and providing development and career progression to the teams.

Phase two of the reorganisation will be the development of some new Band 6 Nurse roles. The aim of these roles is for there to be a positive impact at the front of care delivery ensuring clinical leadership and introducing development opportunities for staff. We intend to evaluate the success of the new structure.

Priority 2: Reorganisation of the Care Team

Within Rainbows there are some examples of excellent leadership, however there is a need to promote and improve consistency across the whole workforce. Leadership development is crucial across all healthcare economies and we are committed to ensuring that effective leadership is embedded at all levels. In conjunction with this programme of development, we will also focus on the importance of effective followership, to ensure that Rainbows values and behaviours are explicit and rooted in everything we do.



Future Planning (Clinical Effectiveness):

Priority 1: Increase Levels and Variety of Feedback Received

We aim to increase the levels and variety of feedback we receive from children, young people and families and strengthen the links to measuring success and influencing service developments.

We will utilize a variety of methods to gather feedback, to improve how this information is collated and thematically reviewed and to capture the voice of the child and young person in measuring effectiveness.

Priority 2 : Ensure Sustainable and Affordable Care Services

At Rainbows, as in other similar organisations, we are facing challenging times as the demand for our services and complexity of treatment grows and resources become ever more squeezed. It is essential that we ensure the services we provide are affordable, continue to add value for our children/young people and families and represent good use of our resources.

Care and support staff are uniquely placed to lead positive change based interventions that can add value to our families and do less of the things that create unnecessary process driven work. In the coming 2 years year we will undertake a clinical led review of our services to ensure we have a sustainable and affordable care service that continues to support and care for our families.

This will include mapping our focus of care with the Senior Care Leadership Team, reviewing service provision, identification of service changes which balance affordability and quality impact and exploring how we deliver education and training.

Progress against the improvement priorities identified for 2017-2018

Progress against the quality improvement priorities identified for 2017 – 2018 is outlined below:

Progress made against Priority 1(Patient Safety):

Development of a Clinical Governance Group with a Focus on Patient Safety

What we did: Clinical governance meetings have been taking place alternate weeks since April 2017. These meetings are attended by all senior nurses and the hospice Safeguarding Lead, with other care and support staff contributing to relevant parts of the meeting. The quality of care and patient safety are scrutinised with discussion about incidents and complaints, safeguarding, staff training and leadership.

What the outcome has been: Response to the clinical issues raised in national/local reports, patient/family surveys, complaints or feedback and any serious untoward incidents has improved with the introduction of these meetings. The need for further training or guidance and changes needed to policies or procedures has been highlighted through the open discussions which take place in these meetings. This group has ensured that patient safety is a priority and that anything which may affect this is dealt with in a timely and structured way providing feedback and assurance to the Senior Management Team and the Clinical Quality Assurance Committee.

Clinical systems and processes are reviewed to ensure Rainbows meets its statutory and regulatory standards, particularly in relation to the Care Quality Commission's Essential Standards. The profile of operational governance has been raised through the regularity of these meetings, which have a focus on safety and quality and the importance of leadership embedded into the team.



Progress made against Priority 2 (Patient Experience):

Focus on Transition

What we did : Rainbows is working with LOROS (adult hospice in Leicester) to develop a pathway to ensure that young people who transition from Rainbows at the age of 30 years can have their palliative care and complex needs met. LOROS are committed to this project and the work is progressing well with excellent attendance and engagement at joint, quarterly meetings. We hope to use this pathway to work with adult hospices in Nottinghamshire, Lincolnshire, Derbyshire and Northamptonshire in the future.

What the outcome has been: There are now plans in place, with an evolving pathway, which will enable young people who transition from Rainbows to continue to have their palliative care needs met and for families to feel supported through the process of transition. We will now consider whether we need to reduce our upper age limit to 25 years whilst we continue to develop and sustain partnerships with those organisations who will support young people as they transition from children's services to an adult one. Rainbows has hosted the launch of the East Midlands Transition Network in April 2018 and there was an excellent turnout from Employers, education, housing health and social care.

There were presenters from all aspects of this pentagon of support and the Directors of Care of Rainbows and LOROS completed the picture with a report on progress in working together for young adults with cognitive impairments, This work is on-going but has had a positive impact by engaging adult and children's services and engaging the parents in the future care of their young person and to be part of the planning for this care and support.

Priority 3 (Clinical Effectiveness):

Develop Services that are Responsive and Add Value

What we did: In April 2017 Rainbows provided the first episode of end of life sitting in a child's home. Staff who provide this care have received bespoke training at the hospice which includes professional boundaries and communication.

What the outcome has been: For those families who have received this care and support in the past 12 months, being able to be at home, their place of choice, with their family around them has been an extremely positive experience for them. We are now able to respond to a family's wish to remain at home when their child enters the end of life phase and to support them and care for them and be flexible to their needs. This has helped to extend our reach by offering a service which can be delivered in the home.



Statements of Assurance from the Board

There is a legal requirement to report on the following, these statements identify our position as set in the Quality Account Regulations.

Review of Services (mandatory statement):

Rainbows is a nurse led hospice providing care and support for children and young people with life-limiting conditions from birth to 30 years of age, and their families. Medical care is provided through a 24/7 on-call service from a team of 4 GPs with training and expertise in palliative care. The Lead GP and Medical Director is at the hospice on one day per week.

During 2017/18 the hospice provided the following services to the NHS:

- In-patient services
- Day care services
- Psycho-social family support services
- Specialist palliative care advice and support

The hospice has reviewed all the data available to us on the quality of care in these services.

Rainbows' Clinical Quality Assurance Committee receives bi-monthly reports, which enable them to review the quantity of care provided by all clinical services. A report on all clinical incidents is also provided, and regular clinical audits are carried out. The Clinical Quality Assurance Committee submits a quarterly report to the Board of Trustees.

All services delivered by the Hospice are funded through a combination of fundraising activity and contracts with NHS and Social Care Commissioners. The NHS contracts mean that all services delivered by the hospice are part funded by the NHS. Where NHS and Social Care funding is secured this only partly contributes to the costs of clinical care of children and young people. The cost of provision of a holistic family focused service are borne by the charity through fundraising activity, for example, family support, sibling support, cultural link work, spiritual support, play and recreational services, music therapy; complementary therapy, family accommodation, hospitality and bereavement support. On-going supplies and provisions, costs of maintaining the hospice buildings and gardens are all reliant upon fundraising/charitable income.

A focus of our work in 2018/19 will be to further develop our relationships with commissioners and to increase Clinical Commissioning Funding from the NHS. Rainbows are also working with other hospices to secure a commitment on a Department of Health grant.



Participation in National Audits:

During 2017/18 Rainbows was ineligible to participate in the national clinical audit and national confidential enquiries. This was because there were no audits or enquiries relating specifically to specialist palliative care in 2017/18.

Research:

Our Medical Director, Dr. Sat Jassal, has agreed to be a part of an advisory panel for a research project being undertaken in Leicestershire and Nottinghamshire looking at medical treatments in advanced illness. This research, being led by LOROS adult hospice, will explore barriers and enablers in end of life care planning with patients and families from Black, Asian and minority ethnic backgrounds. Preparatory work is underway and is at the stage where funding is being sought for this research.

Quality Improvement and Innovation Goals Agreed with Our Commissioners:

A proportion of hospice income in 2017/18 was conditional on achieving quality improvement and innovation goals (CQUIN) agreed between the hospice and any person or body they entered into a contract, agreement or arrangement with for the provision of NHS services, through Commissioning for Quality and Innovation payment framework.

No goals or indicators were identified by the CQUIN for the hospice.

What Others Say About Us (the provider):

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

- Treatment of disease, disorder or injury

The hospice is required to register with the Care Quality Commission (CQC) and its current registration status is unconditional. The CQC did not take any enforcement action against the hospice during 2017/18.

The hospice did not participate in any special reviews or investigations by the CQC during 2017/18.

The hospice is subject to periodic reviews by the CQC and the last review and unannounced on-site inspection took place on 31st May, 1st and 2nd June 2016. The hospice was fully compliant and rated as low risk. The overall rating for the hospice was Outstanding.



Data Quality:

The hospice did not submit records during 2017/18 to the Secondary Users Service for inclusion in the hospital episode statistics which are included in the latest published data. This is because the hospice is not eligible to participate in this scheme.

In 2017/18 Rainbows collected and submitted the following data:

- Internal activity/performance data to Clinical Quality Assurance, Corporate Governance and the Board of Trustees
- Patient specific data to CCG's
- Annual data to Together for Short Lives
- Child death data to Child Death Overview Panel

Information Governance Toolkit:

Rainbows commissioned an independent review of compliance with the requirements for information governance management, confidentiality and data protection assurance, information security assurance and clinical information assurance identified in the Information Governance Toolkit for Voluntary Sector Organisation.

The hospice has always been committed to a culture of Information Governance and a large amount of work has been undertaken by the hospice. Work is currently progressing on the Information Governance Toolkit and this is being coordinated by an external expert together with our Director of Business Resources (who is the hospice SIRO) and Director of Care (who is Caldicott Guardian). A framework, data mapping template and business continuity plan are all part of this work, along with training needs analysis, improvement plan and audits.

Clinical Coding Error Rate:

The hospice was not subject to the Payment by Results clinical coding audit during 2017/18 by the Audit Commission.



Duty of Candour:

The Francis Report and the investigation at Morecambe Bay Hospitals NHS Foundation Trust in 2015 both highlighted staff's fear of speaking out as contributory factors in poor care and patient safety. As a result, the Department of Health has published a report called 'Learning not Blaming' which includes a recommendation that there should be a Freedom to Speak Up (FTSU) Guardian in every NHS Trust and NHS Foundation Trust by 2017. As Rainbows provides some NHS funded care we have appointed an independent FTSU Guardian for the hospice who took up post in April 2017.

The FTSU Guardian role has been created so that staff can 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.

Our FTSU Guardian has led an organisation wide training session to explain her role. She also talks to new staff on induction days about her role. As an independent FTSU Guardian, she works alongside Rainbows' Senior Management Team and Board Members to ensure that the hospice is an open and transparent place to work, where all staff are actively encouraged and enabled to speak up safely, feel confident that their concerns are acted upon and receive timely and ongoing feedback about the issue they have raised. In April 2018 the Hospice identified two FTSU Champions who are based within different departments operating across the Hospice.

The FTSU Champions are designated officers for whistle blowing at Rainbows and will take any grievances forward on behalf of staff.

The hospice Public Interest Disclosure (Whistle Blowing) Policy has been changed to include the roles and has been implemented across the hospice.



Part 3

Review of Quality Performance

Total number of children and young people served during the year	494
Number of new referrals received – % accepted, % declined, % other*	49% accepted 16% declined 35% other
Number of children/young people aged 0 – 17 years	343
Number of adults aged 18 – 30 years	151
Number of bed nights used	2,576
Number discharged from service during the year	2
Number of day care episodes	1,044
Total number of deaths during the year Number of deaths that occurred at the hospice	26 7
% of total deaths in patients with diagnosed palliative condition % of deaths at the hospice in patients with diagnosed palliative condition	100% 100%
Number of parental complaints	9
Number of parental concerns	5

*There are a number of reasons why children may not attend Rainbows following a referral. This includes (but not exclusively) family decisions, awaiting assessment, admission to hospital, etc.

The majority of children and young people who visit Rainbows have on-going therapy needs, including respiratory conditions, positioning, feeding and posture needs. The hospice has two Physiotherapists and a Therapy Assistant to support named young people with specific therapy interventions.

In 2017/18, Rainbows supported a total of 43 children and young people receiving long term ventilation. This included 14 with level 2/3 (life sustaining) needs and 29 with level 1 (overnight ventilation) needs. We provided 127 nights of 1:1 care overnight and 2:1 care during the day for level 2/3 ventilation, 30 nights at level 2 ventilation (without 1:1 care overnight but requiring close monitoring) and 355 nights at level 1 overnight ventilation.



Local Quality Measures

Rainbows has chosen to measure performance against its peers using the Together for Short Lives Core Care Pathway.

The following measures reflect our performance:

Referrals:

There has been a 20% increase in referrals on the previous year. This year we have seen a considerable increase in neonatal referrals following the employment of a Neonatal Link Nurse and associated activities to raise the profile of Rainbows with neonatal professionals and units across the East Midlands. We have reviewed our referral and review processes to make this more robust. We are reaching significantly more families in need.

Our Participation in Clinical Audits:

To ensure that the hospice is providing a consistently high quality service, we undertake our own clinical audits, using national audit tools, where available, developed specifically for hospices, which have been peer reviewed and quality assessed. This allows us to monitor the quality of care being provided in a systematic way and creates a framework by which we can review this information and make improvements where needed.

Each year the Clinical Quality Assurance Committee approves the audit schedule for the coming year. Priorities are selected in accordance with what is required by our regulators and any areas where a formal audit would inform the risk management processes within the hospice.

Through the Clinical Quality Assurance Committee report, the Board of Trustees is kept fully informed about the audit results and any identified shortfalls. Through this process, the Board has received an assurance of the quality of the services provided.

The following audits were completed at the hospice between 1st April 2017 and 31st March 2018:

Clinical Audit	Outcome
Placement Audits	<p>Annual audits are carried out by the University of Nottingham, University of Leicester and De Montfort University and, new for 2018, Derby University.</p> <p>All standards are met to an exceptionally high standard, with Rainbows being selected by the University of Leicester as a top leadership placement for the new four year nursing degree in adult, mental health and leadership (the first of its kind in the country) due to the strong leadership at Rainbows.</p>
Mattress Audit	<p>A mattress re-audit was carried out in September 2017 against multiple criteria to ensure mattresses remain safe, robust and meet IPC standards. One mattress was condemned and disposed of. No mattresses required replacement covers.</p>

	<p>The Hospice's housekeepers continue to monitor via monthly checks using the Rainbows monitoring form and escalate any concerns.</p>
Medicines Storage Audit	<p>Audit carried out in November 2017 by external Pharmacy Assistant from University Hospitals of Leicester (UHL). The audit recommended that the audit trail of FP10 prescriptions should be more fully implemented, all pharmacy fridge temperatures to be recorded in a temperature recording book and a room thermometer was also recommended.</p> <p>An audit trial of the FP10's is now in place and was rolled out via the '10 @ 10' sessions and this process is included in our medicines management policies. Pharmacy fridge temperatures continue to be monitored.</p>
Children and Adults Health Safeguarding 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 hospice demonstrates compliance with the Children Act 2004 and the Care Act 2015.</p> <p>Safeguarding at Rainbows is managed safely and effectively.</p> <p>The hospice Safeguarding Committee meets bi-monthly and reports are presented to the hospice Clinical Quality Assurance Committee and Board of Trustees.</p>
Drug Storage Audit	<p>Regular audit carried out every three months. Tool devised to carry out audits and action plan produced following each audit if appropriate.</p>
Record Keeping Audit	<p>Following the full record keeping audit of the clinical care plans that was carried out in November 2016, an action plan was developed to improve compliance with the standards.</p> <p>Part of the action plan was to form a working party to review and redesign the care plan templates to ensure efficient completion and therefore high compliance with the standards.</p> <p>Weekly monitoring using a recognised clinical records audit template against NHS standard and criteria since November 2017 following a number of actions and the introduction of new care plan template has seen audit compliance results of 75-100%.</p> <p>Ongoing work continues including development of electronic record systems.</p>
Controlled Drugs Audit	<p>Audit carried out in November 2017 by external Pharmacy Assistant from University Hospitals of Leicester (UHL). Issues</p>

	<p>regarding crossing out in the CDR noted, CD register left out on work surface and a list of signatures authorised to order CD's required updating.</p> <p>As a result of the audit, the signatures list has been updated and the CDR is now stored and locked in the CD cupboard. A '10 @ 10' (10 minutes at 10am) session was carried out with nurses with the updated/changes to practice along with reminders around the Standard Operating Procedure and good practice.</p>
<p>Infection Prevention Audit</p>	<p>An infection prevention audit was carried out by an external infection prevention lead from UHL using the recognised NHS template.</p> <p>A number of issues were noted and an action plan developed. The main issues requiring extensive remedial work was the redesign and refurbishment of the sluice which is underway, a highchair has been removed as the straps are not removable for effective washing and some reorganisation of store rooms to remove items being stored on the floor, which make cleaning more difficult.</p>
<p>Mixed Sex Accommodation</p>	<p>Re-audit carried out in January 2018 in accordance with the Mixed Sex Accommodation policy. This is an annual audit which seeks to ensure compliance against all standards set by the Department of Health who 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'.</p> <p>Rainbows is committed to maintaining the privacy and dignity for males and females staying at the hospice. Rainbows has 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.</p> <p>The audit demonstrated compliance with these processes.</p>

Quality Metrics/Quality Markers We Have Chosen to Measure Patient Safety:

Number of patient safety related incidents/accidents, including medication errors	162 incidents* (of which 39 were near misses) 22 drug errors**
Number of reportable (to local safeguarding services) safeguarding incidents occurring in the organisation	5 ***
Infection Prevention and Control rates:	
Total number of children admitted with known infection This includes	33
• Number of C-Dif	3
• Number of MRSA	5
Total number of children who developed symptoms whilst staying at the hospice This includes	1
• Number of C-Dif	0
• Number of MRSA	0

* The majority of incidents were 'no' or 'low harm' and none were serious

** These were all assessed against the National Patient Safety Agency (NPSA) definitions of harm (2011) and found to be 'no' or 'low harm'

*** There have been 5 official safeguarding referrals made during this period (with another 4 enquiries/informal referrals made but not requiring a full process – they were handed over to the worker involved or closed down as specified).

Additional Information:

Safeguarding of vulnerable children is paramount and all staff and volunteers are trained to recognize and report any forms of abuse. The hospice has a good relationship with the local safeguarding children's board and will discuss any potential abuse and assist in investigating and supporting the outcome of any abuse cases.

Clinical Effectiveness:

Please see section above on local audits.

Patient Experience:

An annual Family Feedback Survey is undertaken to secure feedback on the quality and range of services provided by the hospice. In 2017/18 the response rate was 23% which is lower than last year – this will be considered in the design for next year. An action plan is currently being developed.

Below is some of the feedback received from families through the survey:

'We like that Rainbows totally get all of our needs with support and help of getting through our every day.'

'The only difficulty we experience when our son is at Rainbows is the internet/skype/ mobile connection!'

'Rainbows has been our lifeline during difficult times.'

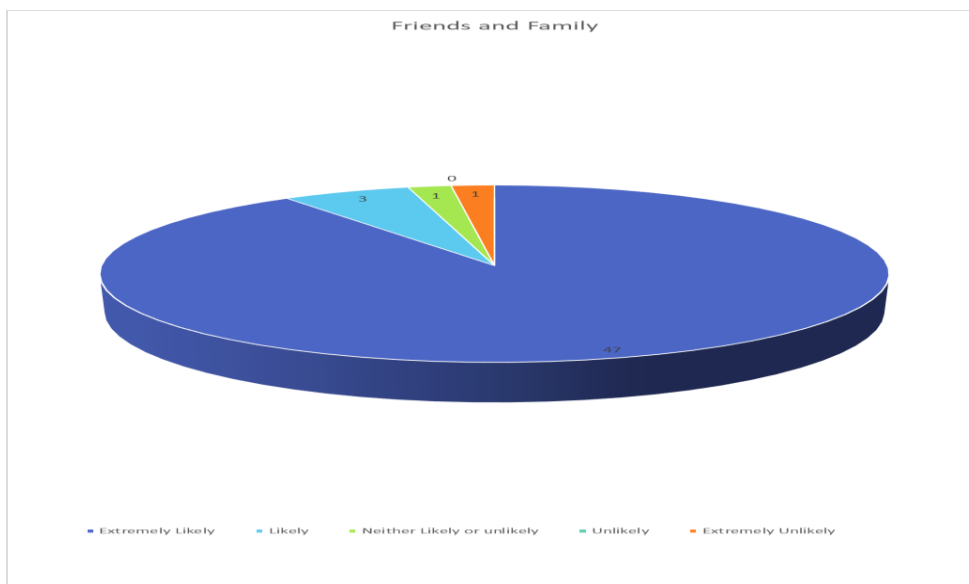
'Can you please make the swimming pool more accessible? It has been out of order on various occasions.'

'Just so lovely, clean and colourful. A nice feel to the place. Feel safe when we leave our child there. No worries as he is in special hands.'

'Your service saved us! It has given us hope and perspective to learn to look through a positive lens and to acknowledge that everyone can have quality of life. Your generous and welcoming hearts have blessed us immensely.'

The 'Friends and Family Test' was also included within the survey, the results are demonstrated below:

How likely are you to recommend Rainbows to Friends and Family if they needed similar care?



During the year we have been asking the children to feedback about their activities in the arts and crafts room – they use various communication techniques to achieve this, their comments include:

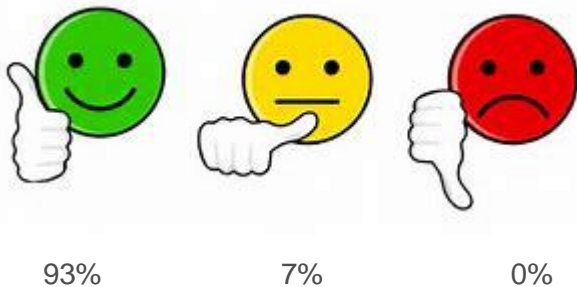
'I am very, very happy making puppets in the arts and crafts room'

'I was very sad because I could not find any people to play with in the doll's house' (We made sure that there are now some dolls)

'I smiled throughout the tactile story'

'I chose the smiley face because I enjoy arts and crafts. I was very relaxed and settled.'

We also asked the children their thoughts on our gardens and outside spaces. We asked how does the garden make you feel?



Staff Satisfaction:

We have carried out an internal designed and managed staff satisfaction survey from 2007 to January 2017. This year we have decided to participate in the Hospice UK 2018 Staff Survey, this will replace the in-house process we have followed for many years.

Owing to the scheduling this will take place later than our traditional January time. The timing of data collection will be during June/July 2018 and results will be reported by the end of August.

This route will include the results being benchmarked against both the Charity Pulse (other charities) and Hospice Survey (other hospices) benchmarks.

We are committed to the wellbeing of our staff and the results of the survey will help us identify where we need to provide support.

The Board of Trustees Commitment to Quality

The Board is fully committed to provide the best service for our children/young people in order to achieve our aims. The hospice has an established governance structure, with members of the Board sitting on both clinical and corporate governance committees. The board has an active role in ensuring that Rainbows provides a high quality service in accordance with its Statement of Purpose which is updated regularly and displayed in hard copy format at the hospice.

The Board of Trustees regularly reviews the structure of meetings across the organisation to ensure the appropriate committees and groups are in place with clear lines of accountability and input from members of the Board as required. In addition, the hospice has a comprehensive Risk Register which is monitored by the governance committees who regularly update the Board in relation to areas of high risk.

The Board is confident that the treatment and care provided by Rainbows is of a very high quality and is cost effective.

Statements from Local Involvement Networks (LINKs)

This is the sixth year that Rainbows has been required to submit a Quality Account. The hospice has engaged with West Leicestershire Clinical Commissioning Group which has the responsibility for the largest number of persons to whom we provide relevant services. The Quality Account will be shared with all three Clinical Commissioning Groups in Leicestershire (West Leicestershire, Leicester City and East Leicestershire & Rutland) and their comments will be included here when received.



Comment on Rainbows Quality Account 2017/18

Statement prepared by Leicester, Leicestershire and Rutland Clinical Commissioning Groups (CCG)

Once again we would like to thank Rainbows for the opportunity to review and comment on the 2017 / 18 Quality Account. This is a wide ranging document and covers the key elements required within a quality account. It acknowledges a number of areas of achievement and good practice and in particular CCG commissioners would like to note:

- Rainbows continue to maintain clear governance structures and Board commitment, which supports the hospice to address the quality of clinical care and the quality of the user and carer experience. We note that Rainbows will look to focus on developing relationships with commissioners during the forthcoming year, which is positive.
- The Quality Account states clearly the organisation's improvement priorities for 2018-19 and that these align with the Rainbows' Strategic Plan. Progress with the previous years' priorities was stated, which was useful, as this gives commissioners assurance of progress with these.
- The hospice plan to implement DATIX to electronically record incidents, accidents and near misses. We view this as a positive move as this will encourage sharing and learning across the organisation.
- Rainbows are looking to strengthen clinical leadership, following the reorganisation of their Care Team and the development of some new Band 6 Nurse roles. We are encouraged to hear that this will support clinical care and development of staff.
- As with all healthcare providers, the hospice faces challenges around resources, patient complexity and demand. Commissioners are pleased to hear that there are plans for a clinical led review of services to ensure sustainability and efficiency that continue to support patients and their families.
- There has been proactive work with LOROS (adult hospice) to develop a transitional pathway so that young people can have their palliative and complex care needs met. Rainbows also hosted the launch of the East Midlands Transition Network in April, which demonstrates commitment to this area of work.
- It was seen that Rainbows provided the first episode of end of life sitting in a child's home. Staff who provide this care received bespoke training to enable this, and commissioners are pleased to read that the hospice can support a family's wish to remain at home when the end of life phase is approaching.
- We are pleased to note that the function of the Freedom to Speak Up Guardian is embedded within Rainbows, and that there are now 2 FTSU Champions to support this. Commissioners feel that this demonstrates continued pledge to improvements with patient safety and quality care. The organisation's Whistle Blowing policy has also been updated to reflect this.
- An audit programme is well established at Rainbows, with the results informing quality improvements within the organisation. Commissioners were delighted to read that the hospice has been selected by the University of Leicester as a top leadership placement for the new 4 year nursing degree in adult, mental health and leadership – which is the first of its kind in the country. This is a marvellous achievement, and we look forward to receiving feedback from you on this.



- We also recognise that the hospice remains an active member of the regional Clinical Network and the wider NHS England Palliative Care and Local Leadership group to improve quality in relation to specialist palliative care locally, regionally and nationally.
- Patient Experience and family feedback remains vital to Rainbows, and it is encouraging to see the positive comments received from families, children and young people. However, the response rate for this had declined from the previous year, and the hospice is developing an action plan to address this, which is reassuring. However, the Quality Account stated that there were 9 complaints made by parents; it would be useful to see narrative on particular themes that may have been identified from review of these, as well potential learning for the hospice.
- Rainbows actively measure against patient safety metrics such as incidents/accidents and reportable safeguarding incidents. Commissioners would find it useful for this to include number of 'never events'. It was noted that all the reported incidents were assessed as 'no harm' or low harm', which again is assuring.
- Rainbows have decided to participate in the national Hospice UK 2018 Staff survey, which will replace the current in-house process used for a number of years. This means that data collection for this will take place over the summer, and measured against other national charities and hospice survey benchmarks. Commissioners welcome this opportunity to see how Rainbows measures against other hospices.

We remain committed to a positive working relationship with the provider, as well as providing continued support for the improvement ambitions identified within this Quality Account.

