Richard House Trust
Quality Account
2017/18

Richard House
London's first children's hospice

262 children on the open caseload

2,745 hours of respite care

15 student nurses completed their placements

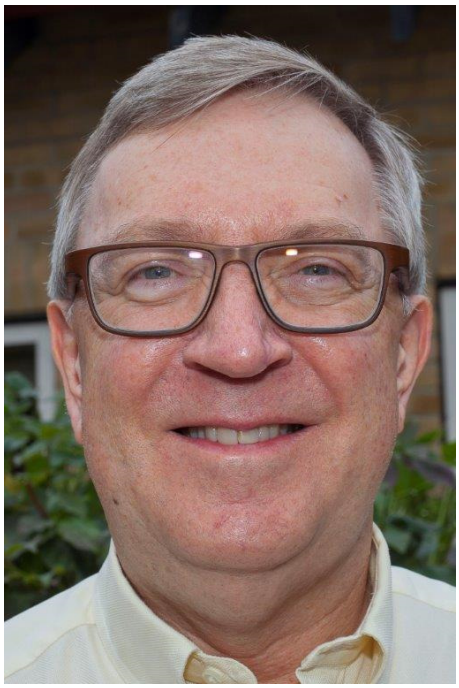
86 events for children and families

328 people volunteered their time

786 hours of step down care

Richard House Trust is a registered charity (1059029) and a company limited by guarantee (3232837 - England & Wales). Its registered office is Richard House Children's Hospice, Richard House Drive, London E16 3RG.

Statement from the Chief Executive - Chris Baker



I am very pleased to present Richard House's Quality Account for the year 2017/18 on behalf of the Senior Leadership Team and Board of Trustees. Richard House Children's Hospice is a charity that provides care and support to children and young people with life-limiting or life-threatening conditions and their families. The hospice is based in Newham, East London, but serves the greater London area.

As always my thanks go out to everyone who have supported us this year; be it through fundraising for the hospice, as one of our vital volunteers, or as part of the dedicated team who work in the hospice.

Meeting the 2016-19 strategic goals

2017/18 proved to be a year of dynamic growth and change after the restructure of the previous year. We met our financial targets by carefully reviewing the charity's spending and generating more income through a combination of targeted fundraising campaigns and statutory funding. This allowed us to begin building up services that families had told us that they valued, especially those which had to be temporarily reduced in the previous year. We also continued to work towards achieving the goals set out in the 2016/19 Strategic Plan. In summary, these goals were to:

- Create a network of support services to help people enjoy family life and manage challenges when they arise. *For example, the legal advice provided by Law Works and the therapy services provided by the Social, Therapeutic and Resource (STaR) team.*
- Provide care to children and young people with very complex health needs at the point that they need it most. *This includes providing step down care to help children get home from hospital and developing the highly skilled nursing team necessary to care for children with tracheostomies and those who are dependent on ventilatory support, or those who require parental nutrition.*

This Quality Account reviews how well we achieved these goals in 2017/18 and describes our planned approach for the year ahead under four improvement priorities:

- Provide care
- Community engagement and involvement
- Organisational competence
- Sustainability

The following document also describes how the team refined plans for 17/18 and redefined the plans for 18/19 in order to still achieve those goals with fewer resources. For example, partnership working with other charities, hospices, community groups, NHS and Social Care organisations is key to our ability to improve the quality of our services and the experience of families.

The plans for 2019/20 and beyond

The Senior Leadership Team are currently working on the finer detail of the strategy for 2019/20 and beyond. The Director of Care has lead the scoping work around each care service area, with input of heads of service, family feedback, national guidelines and examples of successful service provision by colleagues elsewhere in the country, and national best practice guidelines. We are excited to discuss these ideas further with families, clinical colleagues and commissioners, who have all been supportive of plans so far. Their involvement is essential when developing the way Richard House will care for and support families in the future.

We expect an inspection from the Care Quality Commission (CQC) during 18/19 against the new framework designed specifically for children's hospices. We were last inspected in June 2016 and were awarded the overall rating of 'Good'. See section 6, p16 for a detailed breakdown of feedback.

This report is an accurate and honest appraisal of our services as delivered in 2017/18.

"Richard House has given us stability. I know that it's a safe place where I can leave my son and not worry. It's great to know that he is surrounded by staff who love and care for him. All the members of the team are dedicated and hardworking. They provide a happy, fun and caring environment away from home." Parent

1. Summary of services

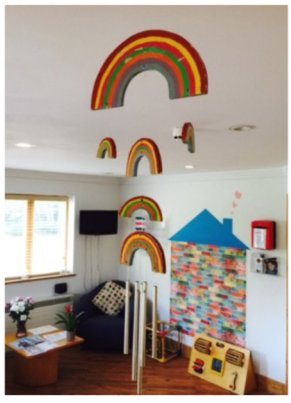
Richard House provides a family centred, needs led, and outcome based service to ensure that all psychological, physical, emotional, social and spiritual needs of our children, young people and families are met.

Step down care – we teach, support and reassure care givers so that when a child's condition is stable, they are able to be transferred from an acute hospital environment to a home-like setting such as a hospice. This care ensures a staged support into full family responsibility.

"I stayed at the hospice for five nights and during that time the nurses taught me everything I needed to know so that we would be confident and able to care for her at home, like what medications to give her and when to give them to her. They even came to my home and helped set it up for her arrival."

Respite care - We offer short breaks whereby our dedicated care team will look after children and young people at the hospice while their families take a break and recharge their batteries, whether for a few hours or a few days.

"Even all I give her sometimes doesn't feel enough, so to have a respite break where Hope goes to stay with the lovely nurses at Richard House and is fussed over and loved, gives me that little break to regain the strength needed for me to be able to give my most to Hope. Richard House is a precious place."



End of life care and bereavement support - Our qualified practitioners and volunteers offer emotional support to young people, their families, carers and loved ones from the onset of diagnosis through and after their death. We work with each family to help make a child's last days as comfortable as possible and we provide support to help families move through this very difficult time of saying goodbye. We have a special area called the Rainbow Suite, which contains a peaceful bedroom that is chilled and a small lounge area to spend time privately with extended family or guests.

"We gave him a bath and dressed him. After he died he was moved to the 'Rainbow Suite', a peaceful private space where we, and our family and friends, could take our time saying goodbye to our beautiful angel. We will never forget their kindness."

Music therapy - offers families the chance to communicate their feelings without the need for words. Our music therapist (who is state registered with the Health and Care Professions Council) works with individuals and groups to help them express themselves. These can be sessions which run not only for the child or young adult, but for the family as a whole, or for siblings. She also runs pain management and relaxation music sessions for children who are experiencing pain and anxiety in their illnesses.

"Here was a child who physically couldn't say anything, but music therapy really worked for him and now he can say a few words."

Group support - Our support groups offer an opportunity to meet with other people in similar circumstances and talk about your thoughts and feelings in a supportive, non-judgemental environment. We encourage members to express their thoughts and feelings as well as listen to and support one another, and take part in social activities together. We also help them to build a supportive network outside of the hospice so that support is ongoing.

"Our mum's group is a much needed break from the usual routine and is a great chance to meet up with other families, share our experiences and learn from each other."

Family activities - We offer a wide range of activities ranging from themed fun days at Richard House and exploring new places, to challenging activities like go-karting, or trips to the sea; which will be the only opportunity for many families.

“We haven’t gone to the seaside since we last were lucky enough to go with Richard House four years ago. It means we can spend time together as a family and relax without stress. It’s great to see the kids all having fun!”

Young adults transition - We use our nursing, social work and youth work expertise to help young people, their families and professionals to navigate the incredibly complex education, health and social care systems when using and moving on from children’s hospice facilities to adult services.

"I love life and there's stuff I have achieved and I will achieve with help, support and people who understand."

2. Improvement Priorities for 2018/19

2.1. Provide care

- *To be a leading provider, taking up the role as a hospice hub for children's palliative care, providing high impact, sustainable and cost effective services.*

- *To collaborate with others to increase our reach to more children, young people and their families.*

Our main goal will always be to continue to provide the best possible care and support to children and young people with life-limiting or life-threatening conditions and their families. Our Director of Care and Head of STaR services, who were both appointed during 2017, spent time researching best practice before drawing up plans for development. These were based on a combination of national guidelines (for example, the most recent End of Life guidelines published by NICE in 2017), their experience working in other health and social care settings and the examples of excellent practice that they observed when visiting other hospice services. In addition to our existing services, Richard House aims implement the following service improvements.

"Richard House lets kids really live. They get to be kids, and do what kids do, and it gives them some time away from hospitals and invasive procedures." Parent

The Social, Therapeutic and Resources (STaR) Team are Richard House's support services which were relaunched with additional therapies, a wider range of activities and events for families in 2017. The further development of the **STaR services in 2018/19** will include:

- The roll out of the holistic star assessment to the whole caseload
- The further development of Richard House provided therapy services
- A continued focus on providing the activities and events that children, young people and families find the most rewarding and fun
- Research, plan and implementation of a new Transition service, with joint activities with St Francis Hospice, local schools and other charities who also support the young people who access the service

"I am always well supported at Richard House, every one there always makes me feel at home." Parent

Hospice at Home – This will incorporate three different services, for which we have identified a local need. We did this by consulting with local colleagues in healthcare, children's hospice care and the families who use this service.

There is a three year implementation plan, focussing on the area of greatest need first:

1. End of life care in the home – delivered by specialist palliative care nurses
2. Short day respite periods in the home – trained carers allow parents to leave the home environment in the knowledge that their child is safely cared for
3. Help at home – practical help in the home provided by volunteers

"Richard House has been a blessing to us all. I just wish we were able to come here more often." Parent

To support the provision of **more step-down care and other complex care** we intend to:

- Continue the investment in training our staff to a high level so that they have the clinical competency to care for children with very complex needs and care regimes
- The conversion of one of the two very large bathrooms in the residential unit to a 5th bedroom. At peak times there is sometimes not enough space to accommodate children booked in for regular respite and requests for step-down care. This additional room could be designed to be used for step-down, or urgent stays, so that regular respite would not need to be re-arranged to facilitate this care.

"They gave us advice, nurses have really good experience, gave little tips that are very useful, nurses know our son really well now, they are a bit like your family, not just carers who just do their job – you can trust people there." Parent

Transport fund – Transport was one of the key reasons that families gave in the family survey for why their children could sometimes not attend Richard House, particularly during term time. We knew that this was a problem from feedback from commissioners and parents because school transport, although funded for our caseload, does not go out of borough and therefore children outside of Newham find it hard to stay at Richard House during the week. We have secured Trust funding through our Fundraising Team to resolve this access issue, so parents can still get their children to the hospice when statutory transport funding is not available.

2.2. Community engagement and involvement

We will continue with the approach described in 3.2 in 18/19, which involved all staff taking a joint and planned approach to engaging with their peers in the community. For example:

- Hospital
- Community nursing teams
- Social care

- Education
- Charities
- Community groups
- Networks:
    - Professional – Palliative Care Networks
    - CHaL – London hospice network
    - Together for Short Lives – national umbrella body for children's hospice

"We have supported Richard House for many years now and love coming here. Seeing everyone having so much fun, singing and laughing is just what an East End gathering should be. Great to be part of something that means so much too so many children and families who use the marvelous services here." Doreen Golding BEM Pearly Queen of Old Kent Road and Bow Bells and Freeman of the City of London

We will also continue to engage with the families who use Richard House, to make sure that the service remains based around their needs. As well as informal conversations in the hospice families communicate with us through the annual survey, mum's, dad's and siblings' groups, service user feedback forms after each stay/activity and the quarterly parent forum, introduced in 2018. There is also a quarterly newsletter to parents to keep them informed and the messages that we share through social media.

"What I like most are the real connections with families and the moments when you feel you have really reached someone and met their needs. I also like the staff at Richard House and the feeling that everyone cares about the service we provide."

Nurse

Richard House will also update the leaflets about the service for 18/19, aimed at difference audiences, e.g. parents or professionals. This is a resource which can be left with key organisations, such as hospitals, children's community nursing teams, or social work teams, who are our main referrers because they come into contact with families who could benefit from accessing Richard House services and could provide that initial introduction.

2.3. Organisational competence

The two main aspects to this priority are:

- To maintain and improve our culture of high performing teams to continually improve our organisational competence.

- To maintain and grow a culture of continuous learning and improvement.

As part of our commitment to continue building and maintaining high performing teams we have a rolling recruitment drive for nurses, with a strong emphasis on investment in training to encourage staff to join Richard House and stay for longer. This saves us money on our ongoing recruitment costs and allows us to provide the kind of personal service that families appreciate with genuine continuity of care.

"I think that I have grown a great deal in my time here so far and feel like the hospice is my second home. I work within a marvelous team, who work very well together and are always there to offer support to each other, which is vital for us for as nurses to continue to deliver quality care to the children." Nurse

Student placements have been organised with City University, London Southbank University (nursing) and the University of East London (social work) and Goldsmiths (therapies). This is to encourage people young in their career to consider children's palliative care as a focus for their career. 15 nursing students had placements at Richard House in 2017/18 and we will continue this programme in 2018/19.

Richard House now have formal Education Strategy for 18/19 to define the investment in training and ongoing development that all our team members can expect. In order to continue to provide complex care we need to maintain and develop the clinical competence of the care team.

I`ve always been struck by the friendliness of the care staff and the atmosphere of positivity the place has always had from my very first shift. I enjoyed the hub of activity that was always around Richard House. The homely feeling with all the added services provided made it a place I wanted to be a part of and six years after my first shift…here I am." Nurse

Other options that are being considered for 18/19 and future years include shared nursing posts across a couple of hospices, rotational posts working directly with the hospitals and joint working with the local children's community team to create more consistent 24/7 end of life and complex care services in the home.

2.4. Sustainability

The two main aims for this priority are:

- To raise sufficient income to enable Richard House to achieve its vision and mission and ensure an efficient cost base.

- To develop and maintain the financial viability of the work of Richard House.

Richard House will have a clear income generation plan, which sets out how we will fund each element of service, including new service developments. The income targets are ambitious, but realistic as they are based on expectations of activity and planned campaigns.

"It is a privilege to help Richard House Children's Hospice provide life-changing support to vulnerable children and their families in one of London's most impoverished boroughs. As Churchill said, 'we make a living by what we get, but we make a life by what we give." John, Ex-Chief Executive Officer, Barclays Corporate Bank

Making operational and financial goals understood by the entire organisation is part of the organisational strategy for ensuring that all teams within the hospice are working well together and to shared goals. Our 2017/18 staff survey results demonstrate that the staff are invested in the successful future of the hospice and want to know how they can best contribute to this. Regular team and all staff meetings allow the full hospice staff to communicate directly with the Senior Leadership Team about plans for hospice. Staff now all understand the impact of funding and spending levels and the importance of working to realistic budgets.

"I feel honoured to work here. To come in every day and know what difference staff make is inspiring. We all pull together as a team, a Richard House family, to give the best service possible." Staff

There is also a longer term goal to make the hospice building more energy efficient, which will be less expensive to maintain and reduce our impact on the environment.

3. Review of our improvement priorities for 2017-18

Below you will find a review of our achievements in 2017/18 against each of the objectives.

3.1. Review of improvement 1: Provide care

We rebuilt and invested in family support services, resulting in the formations of the new STaR (Social, Therapeutic and Resources) Team, as a response to families feeding back how much they valued activities, therapies and events.

To coincide with the STaR team re-launch, we introduced the star outcome-based assessment tool. This holistic health and social care assessment is now given to all families who are new to Richard House. It provides a clear understanding of each family's individual circumstances and needs. This assessment will also be rolled out to all families on the existing caseload who use Richard House services during 2018/19. A better understanding of a family's needs helps us to provide truly bespoke care packages. Families are re-reviewed at three months and then annually, so that we can monitor that they are receiving the best support for them at that moment.

A parent told us in the 2017/18 Family Survey that Richard House was:

"Very helpful in times of need when struggling to look after my son you are there to take him and give him a great place to stay away from home. Richard House is a shoulder to cry and lean on." Parent

During 2017/18 we received more complex healthcare referrals from boroughs who previously haven't used our services, illustrating that the hospice is recognised as being a provider of complex care. Providing care to the most seriously ill children, whilst supporting other families to stay well supported in the community is the main aim of the 16-19 strategy. For example, we are continuing to work closely with hospitals, children's community nursing teams and social care professionals to help get children out of hospital and into their home, through step down care.

"Richard House is just the most amazing place. They are such very lovely people and great care providers." Parent

3.2. Review of improvement 2: Community engagement and involvement

In 2017 Richard House reviewed the way we approach community engagement and realised that successful engagement required a whole organisation approach. Instead of making connection and awareness of children's palliative care the responsibility of one

person, the focus changed to providing protected time for key team members to build stronger relationships with a range of professionals and community groups. Our teams interact with different elements of the community on a daily basis and engagement has become an integrated and prioritised part of everyone's work.

"I am passionate about the wellbeing of the people I serve and Richard House is a great example of people from the differing faiths and cultures which make up this community and beyond, coming together to look after the whole family when they need it. I am delighted to be here and share the celebration of life and the warmth shown here today." - The Rt Hon Stephen Timms, Member of Parliament for East Ham

Creating greater support for the family in their everyday lives

Helping families resolve practical issues in their lives can help reduce some of the sources of stress for that family, such as not having enough money, support for their child or somewhere to live. Our partnership with Law Works (through Together for Short Lives) has become increasingly popular and a result has become the main focus of our Family Matters Clinics. This legal advice service helps families navigate the complicated legal issues that can arise when at least one of their children have complex health care needs. This can include negotiating a personal health budget, care packages, suitable accommodation and advice on visa issues.

In our 2017/18 Family Survey a parent told us that ***'Richard House Children Hospice help me in gaining confidence, lots of skills and meeting new people.'***

This year we have focussed on finding out what our families want and need from the Richard House and shaping our plans for the hospice around them. We did this through the annual family survey and listening to all the comments of families about what they had enjoyed. The feedback that we received from families this year was that they really missed the services that had been scaled back during the restructure and the staff members who were no longer part of the team. Family support services became a key priority to rebuild, a process which began in 2017 with the formation of the STaR team. The relaunched range of services have a strong focus on therapies and wellbeing, but most importantly fun for all the family.

Parents also told us through the Family Survey that Richard House:

'.....***Help my kids feel happy and us doing activities together.'*** and

'I am always well supported at Richard House, everyone there always makes me feel at home.'

Building stronger links with existing local services

As well as providing therapies our team refer on to other services such as the Child and Adolescent Mental Health Services (CAMHS) where this has been identified as a need. Forming stronger links with existing services across health, social care and other charity services is part of our engagement strategy.

Libby Basson, the Director of Care, has led the programme of engagement with all local schools, particularly John F Kennedy Special School (JFK) in Newham and Stephen Hawking School in Tower Hamlets, as many of our caseload attend these schools. Together we hope to share each other's resources to provide the children with the best possible opportunities for fun and learning, for example JFK now use our sensory room to provide interactive storytelling sessions to groups of children.

By collaborating with local arts charity Together 2012 we have developed the Living Films Club further. It is now available to more children and young people, who gain skills and qualifications in film and media from taking part in the group. This was as a result of direct feedback from families who wanted better access to this activity. It is both a great opportunity to learn about film-making and a way to explore any issues affecting them in their lives.

Richard House attend and contribute to Dying Matters events at the Royal London Hospital. We have a strong relationship with this hospital as it is our closest Paediatric Intensive Care Unit and we often work together to help get children home from hospital through planned step-down care.

3.3. Review of improvement 3: Organisational competence

The 2017/18 staff survey revealed that 97% of staff and volunteers liked the people they work with, which is positive indicator that morale is good within the organisation. The same survey revealed that 97% of staff and volunteers believed in the aims of Richard House, which demonstrates a committed and cohesive team.

"I like working here at Richard House because I know what it means to the families who come here." Staff

We consulted with staff and redefined the Richard House values to capture what they thought were the essential elements of the service and how they felt about working for the organisation. The re-defined values are based on the central idea that 'We take **PRIDE** in what we do'.

We create a happy and **P**OSITIVE environment for all

We are **R**ESPECTFUL and welcome people from all our diverse communities and treat them with care and respect

We value openness and **I**NTEGRITY in all our dealings

Our **D**EDICATED staff and volunteers put children, young people and families at the centre of our work

We are passionate about achieving **E**XCELLENCE in all we do.

In 2017/18 we focussed on finding out what we were valued for as an organisation and improving on those elements of service. By concentrating on these elements we could be sure that we were meeting an actual need within the community. For example, increasingly complex referrals from a wider area demonstrates a developing reputation for caring for complex children. We therefore prioritised maintaining our capability to provide complex care not provided elsewhere in the community.

Feedback from families also told us that the support services were very much valued, as were the relationships that they built with other families and the staff at Richard House. This was the evidence we needed to re-invest in the support services, therapies and activities.

"He came home from hospital traumatised and very sensitive to touch. His first trip to Richard House was for sessions to help him recover from this. These sessions really helped and he went on to have music therapy, which helped him connect with his voice and experience sounds in different ways.

Here was a child who physically couldn't say anything, but music therapy really worked for him and now he can say a few words.

He has barely stopped smiling, and I couldn't be more proud of him." Parent

3.4. Review of improvement 4: Sustainability

During 2017/18 Richard House built on the restructure of the previous year to create a stronger, more resilient organisation, which is able to reach the long term goals set out in the strategy. Through this planned approach of greater efficiency and a renewed focus on income generation Richard House achieved financial stability and moved from a deficit of £500K to a small surplus.

There was a clear plan implemented by the Senior Leadership Team to bring financial security in both the short and long-term for the charity. Income generation plans for fundraising, statutory and retail teams include realistic but challenging financial goals, to allow Richard House the ability to grow as a provider of children's palliative care. These goals and plans were set with budget holders and explained to the operational teams delivering the service

so that we could all be working to the same goals. Greater transparency and accountability around expenditure and the processes required to meet income generation targets has also helped with this goal.

An example of the changes made was the introduction of an additional statutory funding complex care tariff for children with the highest healthcare needs. This was in recognition of the fact that our caseload is growing increasingly more complex (in line with our strategy) and these children require more nurses or higher trained nurses to care for them whilst at the hospice.

Anayah suffers from a condition that causes severe muscle weakness throughout her body, including her respiratory system. As a result she can't breathe on her own and is connected to a ventilator 24 hours a day.

Anayah now comes to Richard House regularly for planned respite. This allows her parents to spend some time together with her two brothers and to have some rest and recuperate.

Mum, Naureen says: "Respite is so important as it gives me the chance to have a little break and spend time with my two sons and my mother who is ill. All of the nurses are so good with Anayah, they are amazing; they help in every way you could imagine. If I have a problem they will sort it out then and there. It's fantastic here, Anayah loves it here and so do I."

Statements of assurance from the board

4. Review of audits statement

During 2016/17, Richard House has strengthened its clinical governance by developing a new audit framework. This framework includes is a new traffic light system which facilitates managing the risks inherent to providing children's hospice service.

The external audits to which Richard House contribute include:

- *Newham Safeguarding Risk Matrix* – Richard House contributes to Newham's risk matrix. This tool highlights the strengths and areas for improvement in Richard House's processes. This is an addition to our previous audit schedule.
- *Pharmacy audit* by Guy's and St Thomas' NHS Foundation Trust (GSTT) – Richard House's medication use is audited by GSTT.
- *Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) caseload review* – GOSH regularly reviews the treatment plans for all the children on our shared caseload.
- *NHS England Controlled Drug Audit* – Richard House report on controlled drug use quarterly to NHS England
- *Care Quality Commission (CQC)* – Richard House Children's Hospice underwent an inspection in 2016 based on the framework of Adult Social Care Services and in the future will prepare for a full inspection under the Framework for NHS Hospitals: Children and Young People's Services. Richard House was awarded an overall rating of 'Good' for its services (see p 16 for more information).

4.1. Review of National Audits

Richard House participates in national audits as part of the national umbrella children's hospice and palliative care charity, Together for Short Lives.

The Director of Family and Care Services receives minutes from the NHS National Advisory Group on Clinical Audit and Enquiries (NAGCAE).

Richard House is not directly involved in National Clinical Audit and Patient Outcomes Programmes (NCAPOP) but at times may be asked to contribute on relevant programmes such as the Clinical Outcome Review Programmes including the Maternal, Newborn and Infant Programme. We continue to keep abreast of national and local Child Health priorities.

4.2. Review of Local Audits

4.2.1. Clinical and community engagement committee

The Clinical and Community Engagement Committee is a sub-committee of the board and meets quarterly to ensure that excellent and appropriate governance and communications systems and controls are in place, ensuring effective and efficient use of resources.

During 2017/18 this group was comprised of:

- Nicola Ukiah - Chair/Trustee Director
- Libby Basson - Director of Family & Care Services
- Katrina McNamara - Trustee Director
- Mizan Abdulrouf - Trustee Director
- Steve Wanklyn - Pharmacist (Palliative Care)
- James Joly - Trustee Director
- Dr Meng Tan - Trustee Director
- Tania Siriwimala - Pharmacist (Palliative Care)
- Chris Baker - Chief Executive

4.2.2. Review of clinical audits

We continue to develop our audit programmes to improve the quality of our services. Audits that have been part of our annual schedule during 17/18:

- Medication management
- Accidents and Incidents
- Infection control such as hand washing and equipment
- Emergency trolley
- Fridge Temperatures
- Clinical Record Audits
- Body maps
- CD Audit
- Personal Emergency Evacuation Plan (PEEP) Audit
- Bathing Temperature Audit
- The Director of Family and Care Services attends the Controlled Drugs Local Intelligence Network [LIN]
- Safeguarding section 11 safeguarding risk matrix
- Policies review
- Complaints management

4.2.3. Improvements as a result of clinical audit

Improvements in 2017/18

Clinical audit helps Richard House to continually improve the quality and safety of the service.

The Pharmacist conducted a Medication Management audit at Richard House. As a result of this review a working group was formed, the Medicine Improvement and Safety Group, in order to make continuous improvements throughout the year. The first task of this group was to review the Standard Operating Procedures and associated policies, with the aim of increased safety in medication management. Charge nurse PDN and pharmacist specifically reviewed all Medication Management Policies and related SOPs mapped them against current practice.

The PDN then undertook audits to identify other areas where process could either be improved, or more consistently applied. In some cases it identified where the best practice guidance could be clarified through the addition of a specific policy. An example of this

was the Body Map audit, from which the following changes were implemented:

- Pressure Ulcer Prevention Management and Skin Integrity Policy was written
- A recognised assessment tool was adapted for local use
- An action chart was devised
- New Body Map document devised post getting feedback from staff
- The feedback from staff was that they would appreciate more training and understanding on how to audit. Audit training was carried out for all staff involved in audits on 3rd May

The Internal Clinical Governance and Quality Group was introduced as a working group in October 2017. This group meets twice a month and reports into the Clinical Governance and Quality Board Committee. This group consists of the Director of Care, Head of Care, Charge Nurse, Practice Development Nurse, Quality Lead and Head of STaR services and other colleagues as required depending on the agenda. The rolling agenda covers:

- Monitoring and Evaluation
- Accidents, Incidents and complaints
- CQC
- GDPR
- Progress against audit schedule
- Policies and procedures
- Training

A new Education Strategy was introduced in 2018 and this includes a section on clinical audit training, which identifies the importance of a robust approach to quality improvement.

Improvements planned/implemented in 18/19

The audit training planned for May 2018 will allow for wider staff involvement in undertaking audit, so it's not just down to a small number of the senior nurse management team. This provides the clinical team with more knowledge and skill to effectively audit, assess and make necessary changes to improve the quality of our service delivery.

A revised clinical audit schedule for 18/19 will include the following in addition to the existing schedule:

- Hand Hygiene
- Long term Ventilation
- Staffing vs. Acuity (skill mix) for LTV patients
- Infection Control - use of PPE
- Medication reconciliation
- New audits will be added to throughout the year where the need for improvement is identified in relation to reported incident action plans

4.3. Clinical research

Richard House has a policy that we do not undertake research at this time. This policy is reviewed regularly, mindful that we may need to take up a research role as we continue to consider the impact of our work.

5. Patient safety

5.1. Incident and complaint reporting in 17/18

The management of all incidents and complaints are overseen by the Director of Care, managed through the Internal Clinical Governance and Quality Group and then reported to the Board through the Clinical and Community Engagement Committee as part of our Clinical Governance process. Commissioners of children's palliative care are also informed as part of our performance reporting.

Measure	Q1	Q2	Q3	Q4
Healthcare associated infections (MRSA and Clostridium difficile cases)	0	0	0	0
Complaints about issues relating to care: *The Director of Care managed all complaints relating to care and spoke with families on the telephone, or had a face to face meeting to discuss their concerns. Processes were updated and additional training given whenever the investigation found this to be the appropriate response.*	4	3	2	2
Incidents and Serious Incidents: *All but one of the incidents were 'low' or 'very low risk' and policy and processes were followed. The moderate risk' incident was discussed with the CCG, local authority and hospital involved.*	12	5	5	7
Medication Incidents: *All medication incidents recorded as 'low' or 'very low risk'. Policy and processes were followed and discussed with external pharmacy support. Pharmacist support will be increased in 18/19 to improve medicines management and further reduce incidents*	3	4	2	8
Pressure ulcers (grades 1-4)	0	0	0	0
Urinary tract infections in patients with a catheter	0	0	0	0
Venous thrombo-embolism (VTE).	0	0	0	0
Notification and subsequent reporting of CQC inspections and recommendations	0	0	0	0

5.2. Safeguarding

The Director of Care is the designated safeguarding lead, deputized by the Head of STaR Services and the Head of Care in her absence to ensure that children, young people and families always have a named lead that they can contact.

We have a safeguarding policy and a safeguarding statement, which defines our approach to safeguarding as follows: Safeguarding and protecting our patients and visitors from harm is a very high priority for staff at Richard House and plays a large part in everything we do. We take our safeguarding responsibilities very seriously - it is everybody's business.

We embrace the Essential Standards of Quality and Safety from the Care Quality Commission and in doing so are committed to working in partnership with local agencies and authorities to ensure that all who visit us or, are admitted into our care, are protected from harm.

Child protection is the process of protecting individual children identified as either suffering, or likely to suffer, significant harm as a result of abuse.

We respect and promote the dignity, rights and welfare of children, young people and young adults who visit us and accept our duty to:

- Protect children from maltreatment
- Prevent impairment of children's health or development
- Ensure children grow up in circumstances consistent with provision of safe and effective care.
- Take action to enable all children to have the best outcomes.

The responsibilities for the safeguarding of children and young people are identified by The Children Act (1989), Every Child Matters Green Paper (2003), The Children Act (2004) and, the No Secrets Review (2009). These documents and publications provide the legislative framework for the protection of children, young people and vulnerable adults. All are supported by statutory and supplementary guidance in Working Together to Safeguard Children (2013).

We ensure our commitment to our safeguarding responsibility by undertaking a range of measures:

- We ensure that statutory requirements around Disclosure and Barring Service checks are undertaken for all staff and visitors
- Child protection policies and systems are up-to-date and robust to ensure that accurate records with regard to actions and decisions are made promptly
- Safeguarding training is in place with systems to monitor compliance. Supplementary training is provided and reflective Processes are in place to learn from events
- We have identified roles and responsibilities for named professionals and they have a key role in promoting good professional practice within the hospice and provide advice and expertise for fellow professionals, staff and volunteers
- The Chair of the Board of Trustees receive regular reports on safeguarding arrangements and evidence of best practice within the hospice and supporting a culture that enables safeguarding issues and promotion of children's welfare to be addressed.

6. Care Quality Commission (CQC)

In 18/19 the CQC will introduce a new framework specifically for children's hospice care, which has been developed in conjunction with Together for Short Lives and a selection of children's hospices from across the country. Richard House began the preparations to meet this new standard as soon as the draft framework was released for comment. This includes shaping our new residential service feedback forms (for children and parent/carers) around the key lines of enquiry within the standard. This way we have a better understanding throughout the year if we are providing a high quality service to all service users.

6.1. Care Quality Commission registration status

Richard House Children's Hospice is regulated by, and registered with, the CQC in the following way:

Elizabeth-Anne Basson - Registered Manager
Christopher John Baker - Nominated individual

Overview of the service: Richard House provides care and support for children and young people with life-limiting / life threatening and complex healthcare conditions, and their families, in North East and North Central London. The services include specialist nursing and medical care, short breaks and respite care, end of life care, and family support before or after death.

Type of service - Hospice services
Regulated activities - Diagnostic and screening procedures, treatment of disease, disorder or injury

6.2. What the Care Quality Commission says about us

Independent health and social services regulator, the Care Quality Commission (CQC), made an unannounced visit on 1st, 2nd, 8th and 21st June 2016 Richard House was assessed as meeting the standard of 'good' overall. There were a few areas where Richard House required better evidence of following safe processes and procedures. These recording issues have now been addressed.

Richard House Trust

Richard House Childrens Hospice

Inspection report

Richard House Drive
Beckton
London
E16 3RG

Tel: 02075110222
Website: www.richardhouse.org.uk

Date of inspection visit:
01 June 2016
02 June 2016
08 June 2016
21 June 2016

Date of publication:
06 September 2016

Ratings

Overall rating for this service	Good

Is the service safe?	Requires Improvement
Is the service effective?	Good
Is the service caring?	Good
Is the service responsive?	Good
Is the service well-led?	Good

The full CQC report can be viewed here:

www.cqc.org.uk/location/1-112020930/inspection-summary

Key information from the report can be seen below.

Is the service safe?

Our findings Families were confident their child was safe using the services provided by Richard House. This included both the residential unit and sessional activities. One relative told us, "I don't feel worried when [my child] is there." Another said, "[My child] is happy when there and I feel comfortable leaving them. They know how to treat them."

Areas for improvement:

However, records showed that night time fire drills had not been held, there was not a record of which staff had been present for a fire drill and there were not any personal emergency evacuation plans for individuals. We discussed this with the provider and they carried out a night time drill and started a record of staff that had been present. They also spoke to the local fire service and arranged for a fire safety inspection which took place before our inspection was completed. Action had been taken as a result of the visit based on the advice given. We also found that hot water temperatures were not checked to ensure they were within a safe range and that although the registered manager told us that staff checked water temperatures by hand they did not measure hot water temperatures before bathing or showering children and young people. This placed children and young people at risk of scalding if a water temperature control valve was faulty.

Action subsequently taken by Richard House to address the areas highlighted by inspection:

- The appropriate number of night time fire drills have been scheduled across the year and record keeping improved
- Personal emergency evacuation plans (PEEPs) have been introduced and the risk assessments related to fire are now carried out on an individual, rather than group, basis
- A scoop thermometer is now used when staff run a bath for a child or young person and they then makes a record of the temperature. This provides a fail-safe for the electronic thermostat within the bath that automatically provides water of an appropriate temperature and a record that safe practice is being followed.

Is the service effective?

Our findings Families told us that they were very happy with the care provided and felt that staff were skilled and competent. One relative told us that their child had very complex needs and that this had meant that they had always stayed with their child as although the nurses were very well trained they had not able to carry out all of the necessary tasks. However, nurses had now received specialised training and in future would be able to meet all the child's complex needs. This relative added that they had confidence in the nurses and in future would not stay with their child

Is the service caring?

Our findings Families all said that staff at Richard House were very caring. One relative told us, "Very, very good. They're brilliant with people like me and my son. I'm just glad there's something like that for children with complex needs, there's not many places that are as good." When asked if they thought staff were caring another commented, "Definitely. 110%. Very dedicated and passionate about what they do." One young person told us, "Staff are caring" and in a video about the service we saw that another young person had said, "Staff are very nice and do care about you the same way as your parents would."

Is the service well-led?

When asked about the registered manager one relative told us, "She's lovely. She's dedicated, very open and honest." Can phone up any time; don't need an appointment if you want to speak to her." Another said, "The registered manager is good. She is good at approaching families."

Is the service responsive?

Our findings Children and young people received an individualised person-centred centred service based on their specific needs, choices and preferences. Support for families was also based on need and preference. The service responded as flexibly as possible to ongoing and changing needs. For example, some people used the service for residential stays, others for day care, music therapy or perhaps just a weekly bath. A nurse told us, "Personalised care is care given to an individual based on individual needs. It's about the person being in the centre of the care and about it being holistic."

7. Data management and handling

7.1. Data protection and confidentiality

Richard House handles a great deal of very sensitive and highly confidential personal information on a daily basis and therefore we take information governance very seriously. We recognise the importance of upholding confidentiality and strictly adhere to:

- *The Common Law Duty of Confidentiality*: this means that information given in confidence must not be disclosed without a person's consent unless there is a valid justifiable reason such as a requirement of a statute of law or it is judged that there is an overriding public interest to do so.
- *The Data Protection Act (1998)*: this is covered by our policy on Data Protection.
- *The Caldicott Report*; a review undertaken by the Caldicott Commission which made a number of recommendations on the use and disclosure of patient identifiable information. Our Caldicott guardian is the Director of Family and Care Services.
- *Professional Codes of Practice*: all health professionals must adhere to their professional codes of practice which include significant sections on patient confidentiality.
- *General Data Protection Regulation (from 21 May 2018):* This new European-wide law is to improve the 'Regulation on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (Data Protection Directive)'. It supersedes the other regulations described above.

We maintain hard copy and database information for the children using our service. All children and young people have a care record, which is held securely in filing cabinets, in a locked office, with access granted only to relevant staff.

7.2. Following best practice in data management and handling

In 2017/18, Richard House continued to follow the latest statutory requirements and best practice guidelines to provide services that are safe and put patients and families first; including Information Governance and Duty of Candour. We also prepared for the introduction of GDPR in May 2018 with refined data management and handling processes, particularly in the Fundraising Department in relation to the way that supporters are

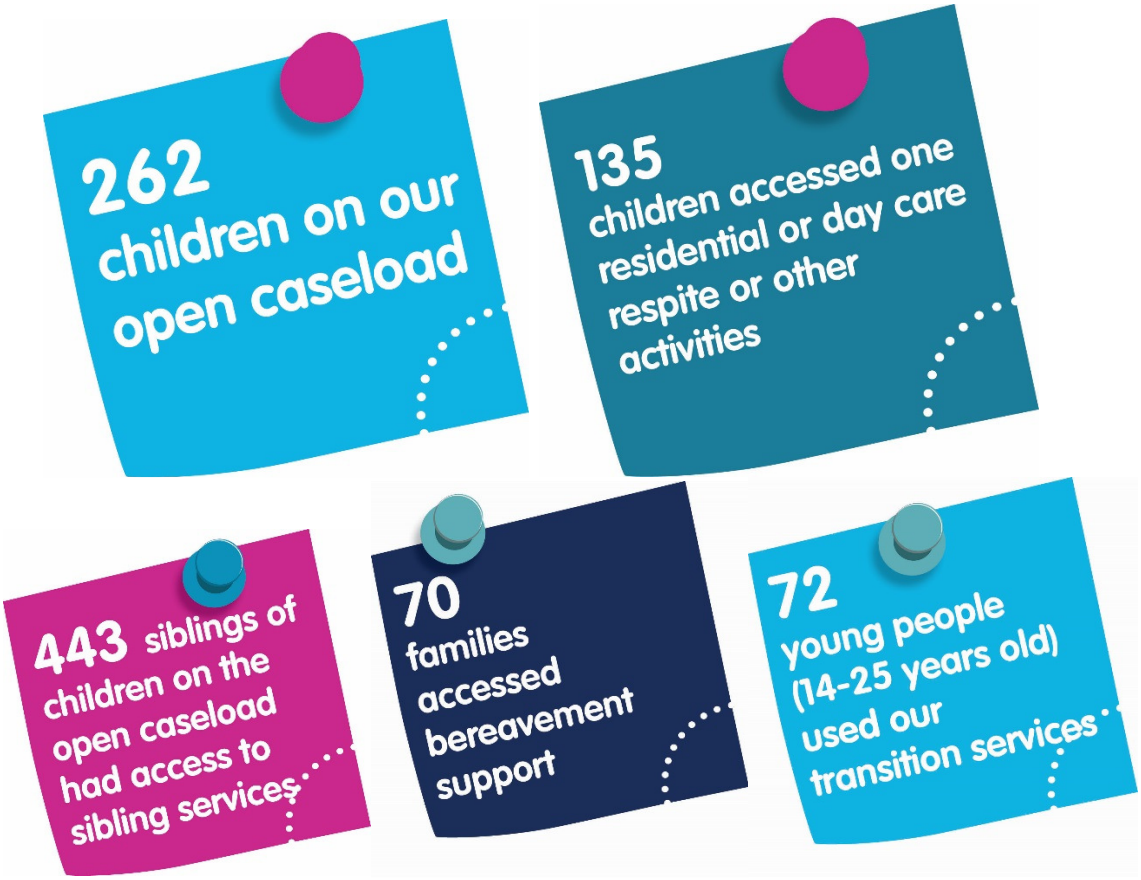
contacted. Our processes regarding data sharing for service users already met the standard, due to the highly confidential nature of the data involved.

Richard House complies with the duty of candour and provides to the families and carers all necessary information if a reportable patient safety incident occurs, regardless of whether a complaint has been made or a question asked about it. A reportable patient safety incident is one which could have or did result in moderate or severe harm or death.

8. Richard House in numbers

8.1. Using data to understand Richard House

We use data to monitor and improve the way that the **306** families registered make use of our services. At the end of March 2018, there were:



As part of our active eligibility review process, Richard House periodically reviews and closes those on the caseload who have been inactive for a significant period of time. Richard House works closely with families before any closure is finalised to ensure the family can discuss their current needs and be referred on to more appropriate services.

8.2. Monitoring referrals

Richard House received 53 new referrals during 2017/18 and table 1 below provides a breakdown of the outcome of these referrals.

Table 1: Referrals in 2017/18

Referral source	Referrals
Children who have subsequently closed	***26***
Accepted	**7**
Children's Community Nurse	1
Family Liaison Sister	1
Health Visitor	1
Nurse	1
Paediatric palliative medicine	1
Senior Nurse	1
Specialist SLT Complex Needs	1
Declined	**17**
ANP Metabolic Medicine	1
Children's Community Nurse	2
Family	7
Health Visitor	1
PAMIS Grampian Family Support Director	1
School Nurse	1
Senior Practitioner	1
Senior Sister Diana Team	1
Social Worker	2
Not reviewed	**2**
Consultant- Palliative Care	1
Senior Practitioner	1
Enquiry stage	***1***
Not reviewed	**1**
Social Worker	1
Open on the caseload	***25***
Accepted	**25**
Children's Community Nurse	5
Clinical Lead	1

Clinical Psychologist	1
CNS for Children with Intestinal Failure	2
Consultant Paediatrician	1
Consultant Paediatrician, Child Health	1
Continuing care nurse specialist	1
Long Term Ventilation Clinical Nurse Specialist	1
Metabolic Nurse Specialist	1
Neonatal Outreach Nurse	1
Nurse	3
Paediatric Respiratory Nurse Specialist	1
Senior Nurse	1
Senior Sister Diana Team	3
Specialist Paediatric Nurse and Team Lead	1
Team Leader	1
Post Bereavement	***1***
Accepted	**1**
Paediatric palliative medicine	1
Grand Total	**53**

We analyse the source of referrals to ensure that we are maintaining the necessary working relationships in order to be an integral part of the local health and social care provision.

8.3. Reducing barriers

We monitor the age and gender of service users to ensure that our caseload is representative of our local communities. If children of a certain age, or gender, were under-represented in the caseload we would investigate to see if there is an access barrier that we could resolve. The higher percentage of male referrals is expected because certain life-limiting genetic conditions are carried through the female line but only expressed in male children.

Table 2: Referrals and open caseload by gender and age in 2017/18

	Male – referrals accepted	Male – Children and young people supported	Female – referrals accepted	Female – children and young people supported
Newborn to 28 days	0	0	1	1
28 days – 4 years	14	22	13	27
5 years – 11 years	1	59	2	39
12 years – 15 years	2	39	1	9
16 years – 18 years	2	17	0	18
19 years – 21 years	0	16	0	5
22 years – 25 years	0	0	0	6

8.4. Ensuring equity of access

Ethnicity is recorded to ensure that the children who access Richard House are representative of the local demographic. Should we identify that a particular ethnic group is attending the service less, it would suggest that there are barriers to access within that community that need to be addressed. We can then use our community engagement strategy to find out why this is and how we can make our services more accessible for all.

Table 3: Referrals and open caseload by ethnicity in 2017/18

Ethnic Origin	Children supported during 2017/18	Percentage 2017/18
Any other ethnic group	12	4.58
Arab	1	0.38
Asian or Asian British	1	0.38
Asian or Asian British - Any other	7	2.67
Asian or Asian British - Bangladeshi	47	17.94
Asian or Asian British - Indian	19	7.25
Asian or Asian British - Not Stated	5	1.91
Asian or Asian British - Pakistani	42	16.03
Black or Black British - African	42	16.03
Black or Black British - Caribbean	13	4.96
Black or Black British - Not Stated	1	0.38
Black or Black British - Other Black	8	3.05
Mixed - Any Other	4	1.53
Mixed - White and Asian	3	1.15
Mixed - White and Black African	1	0.38
Mixed - White and Black Caribbean	6	2.29
Not stated/unknown	4	1.53
White	1	0.38
White - any other	8	3.05
White - British	17	6.49
White - English	18	6.87
White - Irish	1	0.38
White: Turkish Cypriot	1	0.38
Grand Total	**262**	**100.00**

8.5. Using data to understand local needs

Information on diagnostic categories is maintained to assist the service in providing the correct level of support to children and young adults requiring specialist palliative care and to understand the needs of the communities we serve.

Table 4: Caseload by diagnostic category in 2017/18

Diagnostic Category	Total Children Supported
Acquired - Other	9
Circulatory	1
Congenital - Other	21
Genetic - Neurological	11
Genetic - Other	64
Metabolic	17
Neurological - Acquired	34
Neurological - Congenital	70
Neurology	9
Oncology	6
Organ Failure - Acquired	6
Organ Failure - Congenital	12
Other	1
Perinatal	1
Respiratory	3
Undiagnosed	1
Not recorded*	6

*This information shall be updated on the system as a result of this process.

8.6. Using data to monitor end of life care planning

Hospice care sets out to plan the most positive experience of life possible for each child or young person and that includes planning for death. If a family would like their child to be allowed to die at home or in the hospice, instead of in hospital, we will work with the hospital and community teams to ensure that this is part of their advance care plan. We then monitor if the child or young person was able to die in the place of their choice. If

they did not, we will try to find out why this happened to see if there is any way that the circumstance could be avoided in the future.

Table 5: Place of death in 2017/18

Place of Death	Numbers
Hospital	9
Not recorded	2

One family whose child died in hospital chose to use Richard House's post-bereavement room (the Rainbow Suite), which is a purpose built bedroom with a cool bed where a child can stay after death, instead of a funeral home. The family were able to remain on-site in a family flat and we worked with a local funeral home so that the child could be taken directly from the hospice to their funeral. Bereavement counselling was offered to this family.

The majority of children's hospice care is about helping the child, or young person and their family have the best possible experience of life. End of life care, referring to an individual's last weeks and days, is a comparatively small part of children's hospice care, as we can see reflected in the figures below. However, we are working with the local hospitals and community nursing teams to make sure that families are informed earlier about the option of hospice care. Sometimes families are only told about Richard House when their child is days or hours from death, at which point they are less likely to want to be in a new environment. In order for hospice care to be a genuine choice for families they need to know about it as early as possible so that they can get the most out of the service for their child and become comfortable with the surroundings.

Table 6: Numbers of deaths by age band in 2017/18

Age Band	Number of deaths
Newborn to 28 days	0
28 days – 4 years	7
5 years – 11 years	2
12 years – 15 years	1
16 years – 18 years	0
19 years – 21 years	0
22 years – 25 years	1

8.7. Errors and coding

Instead of the ICD10 codes, Richard House uses the Together for Short Lives (previously ACT) eligibility criteria to aid in the referrals process. The criteria are grouped into four categories, which are defined as follows:

Table 7: Together for Short Lives Categories

Category	Description
Group 1	Life-threatening conditions for which curative treatment many be feasible but can fail. Where access to palliative care services may be necessary where treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services. *Examples: Cancer and irreversible organ failure*.
Group 2	Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities. *Examples: Cystic fibrosis and muscular dystrophy.*
Group 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. *Examples: Batten's disease and mucopolysaccharidosis.*
Group 4	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. Additional criteria apply to this group. *Example: Severe multiple disabilities such as following brain or spinal cord injuries including some children with severe cerebral palsy and complex health care needs with a high risk of an unpredictable life threatening event or episode.*

Our caseload has been categorised as follows:

Table 8: Caseload by category in 2017/18

Category	Number of children in category
None set	4*
1	28
2	22
3	57
4	161

* A number of these children are still at 'enquiry' stage and full details will be gathered prior to full acceptance onto the caseload. Any errors in recording are pro-actively identified and highlighted in weekly and monthly reviews of the case files and then corrected.

9. Our wider partnership networks

In addition to submitting this document to NHS England, the Quality Account will be made available on our website, in order to reach our wider network of partners, including:

- *Families* – our most important partners
- *Health, social care and education colleagues* – the hospitals, community teams, social care and schools who work with our care team to provide the best possible care and support to the children and families on our caseload
- *Clinical Commissioning Groups (CCGs)* – responsible for health commissioning
- *Local Authorities* – responsible for social care commissioning
- *Local schools* – both mainstream and special schools
- *Together for Short Lives and other hospice colleagues* – as part of our working together to improve children's palliative care
- *HealthWatch* – responsible for acting as the voice of the community
- *Health & Wellbeing Boards* – responsible for Health and Wellbeing Strategy for each borough
- *Children's Disability Council (CDC)* – for national best practice and shared learning
- *Local clinical panels designed to plan children's care across a number of agencies, such as Hackney's Joint Children's Commissioning Panel (JCCP) and Newham's Complex Health Needs Tracking Meeting*
- *Children's Hospices across London (CHaL)* – to maximise children's hospices shared

resources and fundraising potential across the London area

- *Rainbow Trust* – We work closely with this charity particularly in the area of sibling support
- *Together2012* – This charity works with Richard House to provide the Living Films Club. This CIC runs a free year-round programme of creative workshops for disabled people and their companions, and free disabled-led exhibitions, events, performances and screenings for everyone

We will encourage feedback and any questions generated by this document as part of our commitment to transparency, accountability and engagement with the wider community.

If you would like to provide feedback on the quality account or asking any questions please contact Libby Basson, the Director of Care, by email at libbyb@richardhouse.org.uk, or by telephone on 020 7540 0238.

10. Summary

The core purpose of Richard House remains to 'accompany families with children and young people with life-limiting / life-threatening and complex healthcare conditions during the child's or young person's journey through life and through death, creating positive experiences along the way which become good memories for the future'.

In 2017/18 we met our aim to achieve financial stability and begin the process of planning and building the services that meet the needs of families, based on what they have told us. We can see that we are making progress towards our strategic goals of providing care to the most seriously ill children, whilst supporting other families to stay well supported in the community.

We recognise that we can only achieve all the ambitions for improving the lives of children and their families in our strategy by working with other the other organisations who are also striving to achieve similar outcomes. We hope to improve the quality of care that families receive by sharing resources, experience and skills with these colleagues. By working together we can better support families in their everyday lives, when their child needs more clinical support, provide more options for end of life care and support family members after bereavement.


Thank you