Noah's Ark - The Children's Hospice

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Inspection report

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This report describes our judgement of the quality of care at this service. It is based on a combination of what we found when we inspected, information from our ongoing monitoring of data about services and information given to us from the provider, patients, the public and other organisations.

Ratings

Overall rating for this location	Outstanding	☆
Are services safe?	Good	●
Are services effective?	Good	●
Are services caring?	Outstanding	☆
Are services responsive to people's needs?	Outstanding	☆
Are services well-led?	Good	●

Summary of findings

Overall summary

Our rating of this location improved. We rated it as outstanding because:

- Staff had training in key skills, understood how to protect children and young people from abuse, and managed safety well. The service controlled infection risk well. Staff assessed risks to children and young people and kept good care records. They managed medicines well. The service managed safety incidents well and learned lessons from them.
- Staff provided good care and treatment, gave children and young people enough to eat and drink. Managers made sure staff were competent. Staff worked well together for the benefit of children and young people, advised them and their families on how to lead healthier lives, supported them to make decisions about their care, and had access to good information. Key services were available seven days a week.
- Staff always treated children and young people with compassion and kindness, respected their privacy and dignity, took account of their individual needs, and helped them understand their conditions. They provided emotional support to children and young people, families and carers.
- The service planned care to meet the needs of local people, took account of children and young people's individual needs, and made it easy for people to give feedback. People could access the service when they needed it.
- Leaders ran services well using reliable information systems and supported staff to develop their skills. Staff understood the service's vision and values, and how to apply them in their work. Staff felt respected, supported and valued. They were focused on the needs of children and young people receiving care. Staff were clear about their roles and accountabilities. The service engaged well with children, young people and the community to plan and manage services and all staff were committed to improving services continually.

However:

- The service did not measure the effectiveness of pain medicines, given when required using pain assessment tools as per policy
- The staff did not clearly state in the policy or staffing tool how to measure the level of support required for children and young people at the ark during the night.
- Staff told us electronic patient records were difficult to use. There was a possibility that staff may not access information in a timely manner.
- The service did not have a formal agreement with the local children's hospital for the provision of clinical services from paediatric consultants at the Ark.

Summary of findings

Our judgements about each of the main services

Service	Rating		Summary of each main service
Hospice services for children	Outstanding	☆	Our rating of this service improved. We rated it as outstanding. See the summary above for details.

Summary of findings

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Background to Noah's Ark - The Children's Hospice

Noah's Ark Children's Hospice is a nurse led service which provides clinical and holistic support for 350 babies, children and young persons and their families in North Central and North West London. Clinical services include end of life care services, step down care, symptom management, planned and emergency care, and post death care whilst also providing a range of holistic services including family link support, family activities, home support volunteering, bereavement services, transition support, specialist play and a range of therapies.

This support is both inpatient and community based and is provided by a range of staff including paediatric nurses, specialist carers, family link workers and social workers. They support children's family members through support groups such as sibling groups and parent groups.

The purpose built building was opened in February 2020 for children and their families to receive on site care.

The service was registered for the treatment of disease, disorder or injury and had a registered manager in place.

We last inspected the service in December 2016 where it received a rating of 'good'.

How we carried out this inspection

During our inspection we spoke to the families of children, staff members and reviewed records. We inspected the Ark where inpatient services were provided and inspected community services.

You can find information about how we carry out our inspections on our website: https://www.cqc.org.uk/what-we-do/how-we-do-our-job/what-we-do-inspection.

Outstanding practice

We found the following outstanding practice:

- The service had commissioned a project to investigate the perceptions of children's hospice care from local healthcare practitioners. The project evidenced changes in attitudes and perceptions of the healthcare practitioners and received national news. The projects results were recognised by the Minister of State of Care and Mental Health. The service has organised open events and delivered training to healthcare professionals to continue to promote the services that the Ark has to offer.
- Care delivered by the service was consistently holistic and highly personalised to the babies, children and young people with support that extended to the wider family. The service worked across multiple sectors and continually went above and beyond to meet the needs of the babies, children and young people and their families.

Summary of this inspection

Areas for improvement

Action the service MUST take is necessary to comply with its legal obligations. Action a trust SHOULD take is because it was not doing something required by a regulation, but it would be disproportionate to find a breach of the regulation overall, to prevent it failing to comply with legal requirements in future, or to improve services.

Action the service SHOULD take to improve:

- The service should ensure that staffing policies and tools clearly state levels of staffing required for managing children and young people at night.
- The service should continue to recruit to vacant nursing staff posts and monitor the staffing establishment to ensure they are able to meet patient’s needs.
- The service should ensure that pain levels are documented and then assessed using pain assessment tools after the administration of when required pain medication.

Our findings

Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
Hospice services for children	Good	Good	☆ Outstanding	☆ Outstanding	Good	☆ Outstanding
Overall	Good	Good	☆ Outstanding	☆ Outstanding	Good	☆ Outstanding

Outstanding ☆

Hospice services for children

Safe	Good ●
Effective	Good ●
Caring	Outstanding ☆
Responsive	Outstanding ☆
Well-led	Good ●

Is the service safe?

Good ●

Our rating of safe stayed the same. We rated it as good.

Mandatory training

The service provided mandatory training in key skills to all staff and made sure everyone completed it.

Staff including nurses, specialist carers and volunteers received and kept up-to-date with their mandatory training. The service undertook quarterly audits to ensure training was up to date. The mandatory training completion rate was 100% at the time of inspection.

The mandatory training was comprehensive and met the needs of babies, children, young people and staff. Training covered 31 topics and included, but was not limited to, safeguarding children, consent, conflict resolution and mental health awareness. Staff told us they felt supported to complete mandatory training and were given time to complete it, especially on induction. The mandatory training learning materials were provided under an agreement from a local NHS trust.

Managers monitored mandatory training and alerted staff when they needed to update their training. We saw the training compliance matrix that clearly detailed when staff where next due refreshers on the training subjects.

Safeguarding

Staff understood how to protect babies, children, young people and their families from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse and they knew how to apply it.

Staff received training specific for their role on how to recognise and report abuse. All staff who worked with children received level 3 safeguarding training whilst board members all had minimum level 1 safeguarding training. This was in line with national guidelines for safeguarding. All staff were up to date with safeguarding training. Any staff, including bank staff, who were not up to date with safeguarding training were not allowed to provide care until it was completed.

Staff could give examples of how to protect babies, children, young people and their families from harassment and discrimination. Staff knew how to identify adults and children at risk of, or suffering, significant harm and worked with other agencies to protect them. Staff were trained to identify safeguarding issues and could describe the pathway to make a safeguarding referral. The service had a designated safeguarding team who worked with local authorities to help care for children and families who needed safeguarding support.

The service had up-to-date DBS checks for all staff in the service including nurses, carers, family link workers, volunteers and the leadership team. They kept up to date logs of staff's professional registrations.

The service completed an annual 'blind spot' audit with out of sight areas of risk identified and actions taken to reduce the risk of children being left alone with adults.

Staff received training on lone working and knew how to respond in emergencies. Staff had access to devices when in the community that could be activated to contact local emergency services if required.

The service had completed a safeguarding audit commissioned by their local safeguarding authority in which they scored highly. Actions that were identified were in the process of being completed.

The service was active in local safeguarding groups and we saw evidence of staff attending meetings and sharing learning.

Cleanliness, infection control and hygiene

The service controlled infection risk well. Staff used equipment and control measures to protect babies, children, young people, their families, themselves and others from infection. They kept equipment and the premises visibly clean.

Clinical and therapy areas were clean and had suitable furnishings which were clean and well maintained.

Cleaning records were up-to-date and demonstrated that all areas were cleaned regularly. We saw complete cleaning records of clinical areas. Staff cleaned equipment after patient contact and used green labels to show when it was last cleaned.

We observed staff following infection control principles including the use of personal protective equipment.

The service had suitable access to hand washing facilities. Staff working in the community had access to hand washing facilities in patients' homes. We observed staff washing their hands before and after patient contact. The service measured the temperature of all visitors on signing in.

The service performed quarterly infection prevention control audits on the effectiveness of cleaning processes including hand washing technique. The service scored 100% in their latest cleaning audit and 100% in an external cleanliness audit completed by an NHS provider in November 2022.

Environment and equipment

The design, maintenance and use of facilities, premises and equipment kept people safe. Staff were trained to use them. Staff managed clinical waste well.

Children, young people and their families could reach call bells and we saw staff responded quickly when called. Accessible bathrooms had emergency cords available hanging at a reachable height.

Staff received training in fire safety and the service had designated fire marshals.

The service had security card swipe access to each area of the Ark and was able to control access to different areas of the service to protect families and staff.

Clinical rooms were spacious and had equipment to meet the needs of the users.

Families were encouraged to bring their own medical equipment specific for the child to the service for visits. The service could access equipment if needed through agreements with the local hospital.

Staff carried out daily safety checks of specialist equipment including hoists. We saw completed quarterly audits to ensure checks were being done.

The service had enough suitable equipment to help them to safely care for babies, children and young people. Staff received training in the use of specialist equipment that was appropriate to their role. For example, competency assessments for the use of infusion pumps for delivering pain relief in end of life care were developed in collaboration with specialists from the local specialist children's hospital.

Staff disposed of clinical waste safely. Waste bins were clearly labelled and there was information displayed in each room about the waste procedure. The service had contracts with external providers for the removal of domestic and clinical waste.

Assessing and responding to patient risk

Staff completed and updated risk assessments for each baby, child and young person and removed or minimised risks by following care plans. Staff identified and quickly acted upon children and young people at risk of deterioration.

Staff used a nationally recognised tool to identify babies, children or young people at risk of deterioration and escalated them appropriately. Staff were able to describe what they would do if a child were to deteriorate. They had non-emergency access to medical advice via an agreement with the local hospital or could access the children's GP in hours. In case of emergency, staff would dial 999.

Staff completed risk assessments in babies, children and young people's care plans. Care plans detailed how to manage risks including what to do in an emergency including the management of epileptic seizures and anaphylaxis. The service requested up to date information from children's families and their doctors before taking responsibility of care. We reviewed 7 care plans, and all had up to date risk assessments.

All staff were trained, and up to date, in basic life support and had access to 2 'grab bags' which contained equipment for the basic life support where contents were reviewed weekly. Specialist carers carried emergency medications on their person and were trained in the administration of them. They were able to administer these if required when visiting children in the community or on social visits outside the service. Nurses received additional specialist paediatric life support.

Staff shared key information to keep babies, children, young people and their families safe when handing over their care to others. We saw evidence of up to date records in children's notes from their care teams outside the service. Staff told us they would contact the children's doctor in more urgent interventions.

Shift changes and handovers included key information to keep babies, children and young people safe. We observed part of a daily huddle where staff discussed staffing requirements for the days ahead to meet the needs of the children staying at the Ark. We did not observe discussion around physiological needs of the children. The service was introducing a handover proforma which documented the discussions required at the huddles.

Nurse staffing

The service had enough nursing staff with the right qualifications, skills, training and experience to keep babies, children, young people and their families safe from avoidable harm and to provide the right care. Managers regularly reviewed and adjusted staffing levels and skill mix, and gave bank and agency staff a full induction.

The service used a flexible staffing model to ensure that there was always enough staff to safely care for patients. If there was not enough staff for scheduled care due to sickness or prioritisation of end of life care, visits or respite stays were rearranged with the family. This model was agreed by families on referral to the service. Families we spoke to understood the need for the flexibility due to constantly shifting complex needs of each child and family.

Managers calculated and reviewed the number and grade of nurses and specialist carers needed for each shift. However, it was unclear if this was in accordance with national guidance. The number of staff required to manage each baby, child and young person in the Ark was determined by a multidisciplinary team made up of a medical director, nurse and social worker using a medical dependency tool on referral to the service and reviewed on each admission to the Ark. The number of nurses and supporting staff matched the planned number on the day of inspection. We reviewed nurse staffing levels from the previous month for the service and saw nursing and supporting staff levels matched the required number during the day. However, it was unclear if staff matched the required number during the night as the service did not have a policy or guidance to assess staffing levels during the night. For example we saw on the 20th and 21st January 2023 that there were only 3 staff members on the night shift against a requirement of 4. We were told by the service that this was because there was flexibility in staffing at night due to decreased workload. However, we did not see this mentioned in staffing tools or policies.

The service held daily huddles with nurses and carers to discuss staffing levels and requirements for the care of children at the Ark.

A senior nurse was on call during out of hours for advice and support, such as reviewing unexpected end of life referrals. The rota was shared between all senior nurses.

The service leaders could adjust staffing levels daily according to the needs of babies, children and young people. The service had access to bank and agency staff when required for staff sickness and urgent referrals. However, the service relied on the use of agency nurses to provide care in the service. Agency nurses had covered 32% of shifts and bank staff covered 4% of shifts in September. We saw agency use decreased to 15% in January 2023 and was consistently higher than bank usage throughout the last 12 months.

Service leaders requested bank and agency nursing staff that were familiar to the service and made sure they had a full induction and understood the service.

The service had a high turnover rate, due to changing careers and maternity leave, for specialist carers with 6 staff members leaving 6 posts over the past 12 months. These positions had been refilled over the course of the year. The service was working to improve staff retention with review of pay, training opportunities and increased support.

The service had high but reducing vacancy and turnover rates of nursing staff partly due to an increase in establishment. Nursing staff numbers had increased from 7 positions filled in January 2022 to 13 positions filled in January 2023. The service had an active recruitment campaign to further expand the service including a band 7 nursing position and a hospice midwife to work across local midwifery and neonatal units. The service had recently increased their budget for nursing staff and so had higher vacancy rates.

The service had a low sickness rate for nursing staff.

Medical staffing

The service could access medical staff with the right qualifications, skills, training and experience to keep babies, children, young people and their families safe from avoidable harm and to provide the right care and treatment.

The service had 24/7 access to medical advice when required. The service could access advice through contacting the child’s GP or could liaise with paediatricians and their teams through an agreement with a local NHS trust. Staff could also access advice through the medical directors employed by the service.

Records

Staff kept detailed records of babies, children and young people's care and treatment. Electronic records were up-to-date and paper records stored securely. However, staff told us the electronic records were not always easily accessible.

Patient notes were comprehensive, and staff could access them. The service kept a paper version and electronic version of care plans that were taken to children’s houses on community visits. Staff also had access to the electronic records with laptops issued by the service where staff could update notes and records in the community. However, care records were sometimes difficult to navigate, and staff told us it was ‘clunky' and it had been noted in some incidents as a possible contributory factor. The service offered additional training of the electronic care system for staff who requested it.

Records of administering medicines and nutrition as per care plans were recorded on paper and kept with the care plans. After visits, these papers copies were scanned into the electronic records.

We reviewed 7 care plans, and all were detailed with all the information on children’s individual needs required to provide care. Examples included, but were not limited to, resuscitation status, allergies, details of equipment needed, monitoring requirements and emergency plans.

Paper records were stored securely onsite or in the family’s home. Each child had a unique ID number on the electronic systems that was used for data protection purposes.

Medicines

The service used systems and processes to safely administer, record and store medicines.

The service had an up-to-date medicines policy that was version controlled and based on national guidelines for the storage, administration and recording of medicines, including controlled drugs and oxygen.

The service accessed medicine advice with a recently renewed agreement with the local NHS trust. As part of this agreement, the hospital provided support such as auditing and reviewing medicines policies. This agreement was renewed as a result of 9 medicine related incidents between April and June 2022. We saw evidence of pharmacy input in the latest medicine policies as a result of this. However, staff told us that the pharmacy staff were not always immediately available, and the service did not have any other agreements for accessing pharmacy advice.

The service performed weekly medicine audits and quarterly controlled drug submissions to local authorities. The service scored 89% as part of their last medicine audit. We saw evidence of actions being completed on the electronic audit system and evidence of submissions to controlled drug authorities.

When consultants changed medicines for children staying in the Ark, staff were able to access medicines from the local hospital if required. They had a process for the collection of prescribed controlled drug medicines for children in the Ark. In the community, responsibility lay with families to collect medications if required.

The service had an up to date procedure for the destruction of used medicines including controlled medicines. Medicines for destruction were documented in a destruction record book.

Staff completed medicines records accurately and kept them up to date. Staff followed systems and processes to administer medicines safely. Medicine administration charts were transcribed by trained staff. We saw medicine documentation completed correctly.

Staff stored and managed all medicines safely. Medicines were stored in locked patient specific cupboards in the clinic rooms or locked boxes beside the beds in the clinical areas. The service had two fridges for feeds and medicines and temperatures were recorded daily.

Staff followed national practice to check babies, children and young people had the correct medicines when they were admitted. Prior to visits in the Ark or community, medicine administration charts were completed by a trained member of staff with evidence provided by the children’s paediatric team. Medicines were provided by the family and reconciled by a trained member of staff before and after admission.

Service leaders shared national alerts with staff via email and at team meetings.

Incidents

The service managed patient safety incidents well. Staff recognised and reported incidents and near misses. Managers investigated incidents and shared lessons learned with the whole team and the wider service. When things went wrong, staff apologised and gave babies, children, young people and their families honest information and suitable support.

Staff knew what incidents to report and how to report them in line with policy. The service had a culture where reporting was encouraged. We reviewed 61 near misses and incidents in the previous 3 months. We saw evidence of identifying themes and learning from incidents which was shared individually, at team meetings and through a quarterly incident newsletter.

The service used an electronic reporting system that allowed oversight of themes and trends in the incidents reported.

Staff understood the duty of candour and managers investigated incidents thoroughly. Children, young people and their families were involved in these investigations. We saw evidence of managers being open and transparent and gave families a full explanation if and when things went wrong.

There was evidence that changes had been made as a result of feedback. The service had an unusually high number of medicine related incidents between April and June 2022. The service had reviewed medicine policies and renewed training as a result of a meeting with the controlled drugs authority.

Managers took action in response to patient safety alerts within the deadline and monitored changes. The service received patient safety alerts through the arrangement with the local hospital where it was cascaded down to staff.

Is the service effective?

Good ●

Our rating of effective stayed the same. We rated it as good.

Evidence-based care and treatment

The service provided care and treatment based on national guidance and evidenced-based practice. Managers checked to make sure staff followed guidance.

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. The service had policies for care that were based on national guidance such as Together for Short Lives and the Royal College of Nursing. All policies we reviewed were version controlled and in date.

The service had strong connections with the local specialist children’s hospital where they funded a staff member to work between the two services. Staff told us they felt supported by the shared staff member working between the two sites as they shared learning and advice. Families told us that they felt the position benefited them as it allowed for continuation of care when babies, children and young people moved between the hospital and the hospice.

Managers ensured staff followed guidance through supervision and audits. We reviewed audits for medicines management, IPC and nutrition and hydration and saw gaps had been identified and actions taken.

The service provided evidence based holistic therapies such as music therapy, art therapy and play therapy.

Nutrition and hydration

Staff gave babies, children, young people and their families enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service made adjustments for children, young people and their families' religious, cultural and other needs.

Staff made sure babies, children, young people and their families had enough to eat and drink, including those with specialist nutrition and hydration needs. Trained staff gave specialist nutrition as per the child’s care plan. Staff fully and accurately completed children and young people's fluid and nutrition charts where needed.

Hospice services for children

The service had completed an annual audit in May 2022 to measure recording of fluid balances given. Out of 16 records, 3 children had gaps in recording. In response to this the service implemented a new fluid balance chart that was embedded in the care plans.

Pain relief

Staff assessed babies, children and young people to see if they were in pain and gave pain relief in a timely way. They supported those unable to communicate using suitable assessment tools. However, the service not did monitor the effectiveness of pain relief given.

Babies, children and young people had detailed pain management plans and pain assessment specific for their age or needs in the care records we reviewed. They described behaviours indicating that the baby, child or young person was in pain and how to comfort them with non-drug and drug interventions. Care plans contained recognised tools for measuring pain levels in babies, children and young people. We saw medical records showing staff accurately recording administration of pain relief. However, we did not see evidence of staff documenting pain levels or assessing the effectiveness of pain relief using pain assessment tools once given.

Pain relief was only given by those competent in assessing babies, children and young people's pain relief as per the service's pain assessment policy.

Patient outcomes

Staff monitored the effectiveness of care and treatment and generally achieved good outcomes for babies, children and young people. However, they did not always use the findings to make improvements.

Outcomes for babies, children and young people were positive, consistent and met expectations against outcomes agreed at the point of referral and reviewed each year. The service used a bespoke outcome measure for children and their families which was developed at the point of referral. It highlighted what the expectations of the family and children and young people were, and the service measured themselves against these expectations. Examples of outcome measures include 'family to spend more time together', 'the child to have increased stimulation' or 'provide emotional support'. The service monitored the scores of these outcomes. In the previous 3 months, 61% of scores had improved since the families' last review. We saw examples of family scores being reviewed and updated.

The service monitored the data of preferred places of death for babies, children and young people at end of life. We reviewed the data from 17 babies, children and young people that had died in the last year and saw that most died in their preferred place of death. However, we did not see any actions or outcomes from the data gathered. The service told us they were holding an in-depth review of the data gathered in April 2023.

In the latest round of feedback, 90% of families said the service improved their quality of life which met the service target of 90%.

Competent staff

The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and development.

Staff were trained to deliver both inpatient and community services. This allowed the same staff to provide continuing care to the same families.

The service monitored each staff member's competencies and staff were only allowed to use equipment or perform procedures in which they had received training in. Professional staff were able to self-declare competency with evidence of external training or appropriate experience.

Staff were experienced, qualified and had the right skills and knowledge to meet the needs of babies, children, young people and their families. Staff had monthly supervisions and clinical educators supported the learning and development needs of staff. The service had a band 8 practice educator who provided or organised training in the various competencies for nursing staff and specialist carers including enteral feeding and seizure management.

The service organised additional training for nursing staff to meet specific needs of children who used the service. For example, mental health first aid training and new-born behavioural observation system training was provided. We also saw evidence of staff receiving training in the management of specific complex conditions provided by specialist nurses at the local hospital.

Managers gave all new staff a full induction tailored to their role before they started work. Staff received a 6 week supervision period where they were supernumerary to staff requirements. Staff told us the induction was thorough and they felt supported throughout and beyond.

Managers and staff identified training needs together through appraisals and managers gave them the time and opportunity to develop their skills and knowledge. The service supported staff, including paying for staff to attend a range of external events such as training events or national conferences. For example, the service funded 33 staff to attend external training on bereavement training. Information provided post inspection showed that the current appraisal rate was 100%.

Managers identified poor staff performance promptly from staff and patient feedback and supported staff to improve. Managers identified gaps in knowledge of staff through the use of reflective accounts completed after incidents.

Managers recruited, trained and supported volunteers to support babies, children, young people and their families in the service. Volunteers we spoke with told us they were supported in learning specific to their role and had clearly defined rules as to how they supported children and their families.

Multidisciplinary working

Nurses and other healthcare professionals worked together as a team to benefit babies, children, young people and their families with other external healthcare professionals. They supported each other to provide good care.

Staff held regular and effective multidisciplinary meetings involving nurses, family link workers and medical directors to discuss babies, children and young people on how to best care for them. Input was sought from the children's doctors from the local hospital when required.

The service met with community nurses from the local hospital every 2 months where they reviewed babies, children and young people on their shared caseload.

Staff worked across health care disciplines and with other agencies including social services and other charities when required to care for babies, children, young people and their families. Each family who used the service were allocated a family link worker who were social workers by background. They were a point of contact between the families and the service. Families told us the key link workers were 'hugely supportive' as they were able to help liaising with other social and care services.

Seven-day services

Key services were available seven days a week to support timely patient care.

Staff could call for support from doctors and other disciplines, including pharmacy support 24 hours a day, seven days a week as set out in agreements with the local hospital.

End of life care provided by the service was available 24/7 when required. Short break stays were booked in advance with coordination between the families and service to provide care when best suited the family and spaces were available.

Home therapies and volunteer visits were available between the hours of 7am and 11pm and were organised between families and their family link worker depending on family needs and staff availability.

The service had a nurse on call 24/7 for advice or urgent referrals.

Health promotion

Staff gave children, young people and their families practical support and advice to lead healthier lives.

The service had relevant information promoting healthy lifestyles and support in the Ark and in the community. The service had leaflets on display for other local and national agencies and charities that children and the families could use for support such as bereavement.

Staff assessed each child and young person's health when admitted and provided support for any individual needs to live a healthier lifestyle. The service had links with local foodbanks and had given out foodbank vouchers to families that needed support financially.

Consent, Mental Capacity Act and Deprivation of Liberty Safeguards

Staff supported children, young people and their families to make informed decisions about their care and treatment. They knew how to support children, young people and their families who lacked capacity to make their own decisions or were experiencing mental ill health.

Staff understood how and when to assess whether a child or young person had the capacity to make decisions about their care. Staff were up to date with consent training and understood Gillick competence.

Staff made sure children, young people and their families consented to treatment based on all the information available and made decisions on behalf of the children when they were unable to consent. We saw discussions involving the children as far as possible in clinics held by the service.

Staff recorded consent in the children and young people's records for administration of medicines of the records we reviewed. However, we could not see evidence in the services policies describing how to gain consent and what to do when consent was not given.

Outstanding ☆

Hospice services for children

Staff supported children, young people and their families to make advanced decisions about their care with their doctors. We saw evidence of discussions in records about family members preferences around do not attempt cardiopulmonary resuscitations and the preferred place of death.

Is the service caring?

Outstanding ☆

Our rating of caring improved. We rated it as outstanding.

Compassionate care

Staff always treated babies, children, young people and their families with compassion and kindness, respected their privacy and dignity, and consistently met their individual needs.

We spoke to the families of 10 children, and they consistently said all staff treated them and their children well and with kindness. They described the service as being ‘incredibly supportive and positive’. They also told us that the service was a ‘lifeline and wouldn’t know what to do without them’. Family members told us of instances where staff went the extra mile, supporting them in times of need. Examples of this included staff members liaising with physiotherapists and equipment manufacturers on behalf of families to organise specialist equipment being delivered to the family’s house that they could not access before.

Staff were discreet and responsive when caring for children, young people, and their families. We observed staff taking time to interact with children, young people, and their families in a respectful and considerate way especially those with mental health illnesses and learning disabilities. We saw staff at all levels being caring and respectful to the babies, children and young people and we clearly saw the children’s mood lift when around them. Families told us staff were ‘wonderful’ and ‘always so helpful’ when dealing with the children and young people. They told us that staff instilled confidence in them to care for their children even when they initially had difficultly leaving their children under the care of others when they had joined the service.

Emotional support

Staff provided highly personalised emotional support to children, young people, and their families to minimise their distress. They understood children and young people’s personal, cultural, and religious needs.

Staff gave children, young people and their families highly personalised help, emotional support and advice when they needed it. Families we spoke to spoke very highly of staff describing them as ‘amazing’, ‘so friendly and accommodating’ and also said ‘I wouldn’t be able to cope without them’. We observed staff care for a sibling of a child by creating an award for best sibling as they had noticed staff awards on the wall and wanted to be involved. Families told us how the service recognised the most important times of the year for them after the death of their child and contacted them to offer support during these times. A family told us how the service had reached out during a specific religious event, which was a time that had meant the most to them personally.

The service had organised a creative therapy programme in June 2022 with several partner agencies including Child Bereavement UK, All in Sound and Resonance Creative Therapy to support siblings who were experiencing loss and grief.

Families told us that staff supported children and young people who became distressed in an open environment and helped them maintain their privacy and dignity.

Staff undertook training on breaking bad news and demonstrated empathy when having difficult conversations. Families told us that staff were ‘extremely supportive and caring’ when supporting them through bereavement. The service offered a memory tree and butterfly garden where family members and staff could leave notes to remember loved ones. Families of children who had died were able to visit these memorials and grieve whenever they required.

Staff understood the emotional and social impact that a child or young person’s care, treatment or condition had on their, and their families, wellbeing. The service found innovative ways to promote wellbeing for all members of the wider family including parents, siblings and grandparents . The service offered sessions such as art classes, coffee mornings and pamper days for parents where they met and shared experiences and offered various social outings that met the needs of siblings of all ages such as cinema outings and escape rooms. Families we spoke with told us how beneficial these were for them as it allowed them to socialise and develop networks with families with similar circumstances which reduced feelings of isolation.

Staff understood and respected the personal, cultural, social, and religious needs of children, young people and their families and how they may relate to care needs. The service offered a multifaith room with access to different religious artefacts. The service had links with local religious leaders who could attend the Ark if families requested support from them.

Staff decorated bedrooms and bereavement suites that reflected the children’s personalities and family’s needs such as decorating rooms with the children’s or young person’s favourite sports team or animals. One family told us how staff had decorated a room full of specific LED lights for a child that told them how much she liked them in another location.

The service had 2 bereavement suites where families could stay with their child after they had died.

Families told us staff reached out and offered support when they were at the most distressed and vulnerable. We were told of numerous occasions where family link workers and specialist carers visited families in hospital when their child was acutely unwell, often times at short notice.

Understanding and involvement of patients and those close to them

Staff supported and involved children, young people, and their families to understand their condition and make decisions about their care and treatment. They ensured a family centred approach.

Staff made sure children, young people and their families understood their care and treatment. The service organised event days and sessions for family members to meet and share experiences including regular lunches, art sessions, days out and coffee mornings. They also hosted family events throughout the year including a Winter event with Santa.

Staff talked with children, young people, and their families in a way they could understand, using communication aids where necessary. We observed staff using toys and music to communicate with a nonverbal child. In care records we reviewed, there were clear details of the children’s preferred method of communication, including details of verbal and nonverbal cues for the staff, which highlighted how the child was feeling at the time.

Children and young people and their families gave consistent positive feedback about the service. The service had received over 100 compliments from children and young people, family members and visiting health care professionals in the past 12 months.

Outstanding ☆

Hospice services for children

Children, young people and their families could give feedback on the service with easy read feedback forms and staff supported them to do this. Families told us that the service was always asking for feedback and ways to improve and gave us examples of changes that had been implemented such as implementing online and in person information session for parents.

Is the service responsive?

Outstanding ☆

Our rating of responsive improved. We rated it as outstanding.

Service delivery to meet the needs of local people

The service planned and provided care in a way that met the needs of local people and the communities served. It also worked with others in the wider system and local organisations to plan care.

The service was available to all children with a life limiting or life threatening condition. The bereavement service was available to families for up to three years post death of the child even if the children were not treated at the Ark. The service had recently received a referral from the local specialist children's hospital for use of the bereavement suite and support even though the family had never used the hospice services before.

The service worked flexibly to meet the needs of families who needed it most. They could offer day or overnight respite care with space for families to stay as well. They scored clinical and social care needs and gave priority to those families who had the greatest needs. Families with lesser requirements received contact and access to services at least once a month while the families with greater requirements received at least once a week contact or care. Most families we spoke to told us the arrangement suited them as their own needs were constantly changing and so preferred that the service was so flexible to access. Some families told us they would prefer guaranteed times for organised care but understood that this could not always be possible.

The service hosted clinic rooms for children and their families to meet their doctor instead of travelling to the hospital. Families told us how they felt this service was beneficial to their children as the children felt more comfortable in the service.

The service had suitable facilities and premises to meet the wide range needs of children and young people's families. The service had a hydrotherapy room, sensory room, music room and playroom that were accessible to children of all needs. They were equipped with wheelchair access. The service had a wheelchair friendly play area and access path to a sensory garden and nature reserve behind the Ark. The design of the building had been completed with input from users of the service, including the 'den' which was an area specific for older children which was themed more appropriately for their age. The service had an entrance dedicated to the members of the Jewish orthodox faith who could not use electronic locks on religious days. They had access to the location and to a family suite with a non-electronic key.

The service had 6 children's bedrooms with adjoining bathrooms and 3 family suites and well-equipped kitchen for families to use. It also contained a range of activity rooms such as a sensory room, a soft playroom, a creative room, a music room and a multifaith room. The service has a discrete ambulance entrance which could be accessed from the rear of the building.

There was a quiet room available to staff and visitors which allow for peaceful reflection.

Meeting people’s individual needs

The service was holistic, inclusive and tailored to meet the individual physical, emotional, religious and social needs of children, young people and their families'. Staff helped children, young people and their families access services. They coordinated care with other services and providers.

Staff supported children and young people living with complex health care needs. Each care plan we reviewed contained a ‘this is me’ passport of the child which contained an overview of the diagnosis and physical and mental health needs. We reviewed a care plan for a child approaching end of life and the care plan described in detail the child’s preference and recommendations of care using a nationally recognised form.

The service was responsive and flexible to meet the needs of the children that used the service. We were told how the service organised specific training for nursing staff from a specialist in the management of a complex skin condition so that the service could enhance the care provided to the child and family. The service then worked with the child’s school to enable the return of the child back to education. Families told us that the link workers worked closely with the schools to highlight and meet the needs of the children attending. One family told us of the key link worker organising after school care with the authorities after being initially refused due to the complexity of the children’s needs. The key link worker met with the school to create a plan of care which would allow the school to safely provide care. The service also offered pet therapy for babies, children and young people and their families if they requested it. One family told us that the service organised a visit from a dog as their child loved dogs.

A family told us the link workers helped them to access food banks and liaised with the local authorities to organise additional support for them. The service had a minibus and were able to offer transport for certain activities to outings and to the Ark for those who required it. Following the inspection, we were told by the service they also offered financial support for families who needed it most through an internal hardship fund.

Staff used transition plans to support young people moving on to adult services. The service started planning transition services at the age of 14 where the children had a yearly assessment of services available to them. The service had links with local adult hospices where they had gradual transition meetings that allowed visits to the adult hospices for children to get acquainted. The service also liaised with adult social services to help the transitioning children and their families receive continuing care. The service celebrated children who graduated from their service.

The service had held a parent workshop funded by the Council for Disabled Children on transition of child services to adult services. We saw positive feedback from parents describing that the workshop was informative and helped them to prepare for their child’s transition into adult services.

Staff understood and applied the policy on meeting the information and communication needs of children and young people with a disability or sensory loss. The service held training sessions on a simple sign language that was in common use and displayed common words and phrases on the staff notice board.

The service had access to translation services and information leaflets available in other languages. We saw leaflets available in Arabic.

Children and young people staying at the Ark were given a choice of meals and snacks to meet their cultural and religious preferences. Families of the babies, children and young people were responsible for providing meals if they required specialist nutrition. The services kitchen offered various meals and drinks to meet the needs and preferences of families and visitors.

Access and flow

Babies, children and young people and their families could access the service when they needed it and received the right care promptly.

The service currently had no waiting list to be accepted to the service. Babies, children and young people requiring end of life care received it promptly.

The service monitored when routine care and appointments were cancelled because of the prioritisation of end of life care. The service had cancelled 122 hours of care in 2022 vs 400 hours of care cancelled by families. When cancellations happened, the service worked to reorganise these services to a time that best suited the children and their families.

The service had provided training to 700 healthcare workers and members of other agencies to promote understanding of children’s hospice care and referrals to the service through open days and hosting workshops at national conferences.

Referrals were discussed as part of a pathway meeting lead by a medical director with input from a clinical staff member and a social work staff member.

The service had a process for emergency referrals from other healthcare professionals so that families could access the service in a time of need. The service had a designated nurse on duty during opening hours as a point of contact for advice for families of the service and had a nurse on call 24/7 for out of hours advice or emergency referrals. The service had a procedure that could action emergency referrals within 24 hours.

Managers monitored and took action to minimise missed appointments. The family link staff worked with the families to organise visits and stays when it suited them. If the family could no longer make the appointment for the stay, staff would work with them to reorganise it for another suitable date.

Learning from complaints and concerns

It was easy for people to give feedback and raise concerns about care received. The service treated concerns and complaints seriously, investigated them and shared lessons learned with all staff. The service included children, young people and their families in the investigation of their complaint.

Children, young people and their families we spoke to knew how to complain or raise concerns. They told us that they felt comfortable approaching staff with any concerns and gave examples of when the service had actioned their concerns or complaints. These included when a family member raised concerns about how long it took to check in a child into the service. Following the feedback, the service simplified the check in process for a timelier admission. Other families described to us other instances where the service had made changes to feedback including adding streaming platforms to family rooms and offering swimming lessons for families.

The service displayed leaflets for children and families to feedback on the service in public areas.

Staff understood the policy on complaints and knew how to handle them. Managers investigated complaints in a timely manner. We reviewed the last 3 complaints the service had received and saw they were responded to in a timely manner with learning and actions identified. Learning was shared in the staff newsletter and at 1:1s. We saw evidence that families that had complained received feedback from the service after investigations had taken place.

Is the service well-led?

Good ●

Our rating of well-led stayed the same. We rated it as good.

Leadership

Leaders had the skills and abilities to run the service. They understood and managed the priorities and issues the service faced. They were visible and approachable in the service for patients and staff. They supported staff to develop their skills.

The services senior leadership team was made up of a chief executive officer, deputy chief executive officer, director of finance, director of fundraising and communication, director of care, medical directors and associate medical directors with relevant background experience in providing care for babies, children and young people.

The board was made up of trustees from a range of backgrounds including healthcare, finance, communication and marketing who participated in various committees giving relevant advice from their experience. For example, an experienced children’s consultant on the board chaired the care and clinical governance subcommittee.

Leaders held regular monthly meetings to celebrate successes and update staff on learning within the service.

Staff and families told us that senior leaders were approachable and friendly and felt they could approach leaders with any issues.

Staff spoke highly of the clinical leadership team and felt supported by them through supervision and training.

Vision and Strategy

The service had a vision for what it wanted to achieve and a strategy to turn it into action. The vision and strategy were focused on sustainability of services and aligned to local plans within the wider health economy. Leaders and staff understood and knew how to apply them and monitor progress.

The service had a clear 3 year vision and strategy with clear objectives and targets to be achieved between 2022 and 2025. Objectives included providing the best standards of care, attracting and retaining staff and increasing awareness of the service and promoting diversity, equity and inclusion. The strategy involved a model of care that was family focused, individual, empowering, flexible and holistic.

The service’s values were kindness, excellence and courage. We observed staff adhering to the values and staff told us they strongly agreed with them. The latest staff survey showed that 100% of staff agreed with the services vision, strategy and values.

Outstanding ☆

Hospice services for children

Culture

Staff felt respected, supported and valued. They were focused on the needs of patients receiving care. The service promoted equality and diversity in daily work and provided opportunities for career development. The service had an open culture where patients, their families and staff could raise concerns without fear.

All staff members we spoke to told us they felt supported and valued. In the latest staff survey (June 2022) 94% of staff told us they felt comfortable being themselves and 94% felt appreciated in the role.

Staff told us leaders were visible and approachable and actively engaged with staff on a day to day basis.

The service recognised when staff went above and beyond and displayed staff who had been nominated by their peers for providing exceptional care each month.

Staff felt comfortable raising issues. There was a whistleblowing policy that staff could follow. The service had access to an external HR company that staff could use for employee assistance. The service also hosted staff forums for staff to raise issues. Staff told us they felt listened to and changes had been made as a result of the forums.

The service supported the wellbeing of staff through the use of an external assistance programme, staff wellbeing events, mental health first aiders and through regular wellbeing assessments.

The service had recently set up a diversity, equality and inclusion committee which had set out terms and tasks such as unconscious bias training, education and celebration of religious holidays and anti-racism training.

Governance

Leaders operated effective governance processes, throughout the service and with partner organisations. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.

The service had a number of committees who held quarterly meetings including a care and clinical governance committee, a financial committee, a people committee and communications committee among others. These committees had members of the board with relevant experience chairing or attending providing advice and direction. We reviewed a sample of the latest committee meeting minutes and saw they were well attended and discussed a range of issues. We saw actions from previous meetings discussed and new actions created with a nominated individual responsible for each action.

The service offered clinical rooms to paediatric consultants from the local specialist children's hospital who shared care of children with the Ark. This allowed for families to attend clinics at the Ark if they would prefer. However, the service did not have a service level agreement with the consultants from the hospitals about what care would be provided by the service and what care would be provided by the consultant.

Policies provided by the service post inspection were up-to-date version monitored and referenced national guidance.

The service produced an annual report highlighting the years performance including performance of care, operations and financial status. This report was available publicly online.

Management of risk, issues and performance

Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and issues and identified actions to reduce their impact. They had plans to cope with unexpected events.

The leadership were able to identify local and national risks. The service had a risk register that was regularly updated. The top three risks on the risk register were nurse staffing, funding, and incidents relating to medicines management. We reviewed the risk register and could see updates were reviewed recently with new dates set for the next review. Each risk had owners who were responsible for the completion of actions.

The service also identified that IT systems used for care planning could be improved and found it challenging to purchase a suitable system for their needs.

Information Management

The service collected reliable data and analysed it. Staff could find the data they needed, in easily accessible formats, to understand performance, make decisions and improvements. Data or notifications were consistently submitted to external organisations as required. The information systems were generally secure.

The service collected data through audits, surveys and feedback on topics such as preferred place of death for babies, children and young people and Infection Prevention and Control (IPC). However, the data we reviewed was not referenced in any of the relevant committee meeting minutes and we could not see actions taken as a result of the audit data. For example, we reviewed the latest audit on IPC where the service scored 100%. This was not discussed at the IPC committee meeting.

The service had recently had an incident involving a data breach affecting many of the families that were using the service. The incident was reported to the relevant authorities and was discussed at the trustee board meetings. We reviewed the risk register and saw that it had been updated to reflect the incident and actions had been put in place.

Engagement

Leaders and staff actively and openly engaged with patients, staff, equality groups, the public and local organisations to plan and manage services. They collaborated with partner organisations to help improve services for patients.

The service had strong links with the local NHS integrated care board. They had recently secured joint funding for the appointment of 3 positions aimed at developing pathways in transition services, education and training, and health inequalities and extended hours. The position for the transition service project had recently been appointed and was due to start in March 2023.

Leaders in the service worked in collaboration with other leaders of similar services and other relevant organisations across London. For example, the service's chief executive chaired a monthly meeting between directors of other children's hospices in London. We saw challenges in the sector were discussed and actions agreed for the following meetings.

The service undertook external yearly staff surveys and benchmarked the results against similar services. The latest staff survey results showed that 94% of staff felt proud to proud to work for the service and 94% felt appreciated in their role.

The service had set up a 'green team' committee which aimed to reduce the environmental impact of the service in response to feedback from staff.

The Ark was built in consultation with the families who used the community services. We spoke to families who told us of their input into the design of the environment.

The service had held open days for healthcare professionals, particularly children's healthcare professionals to attend the Ark to show the services they can offer. Healthcare professionals that attended spoke highly of the sessions. For example, the service hosted a case study day on London neo-natal pathways in November 2022. Feedback included, "The insight into the hospice was brilliant. It gives me a greater ability to discuss hospice care with families."

Learning, continuous improvement and innovation

All staff were committed to continually learning and improving services. They had a good understanding of quality improvement methods and the skills to use them. Leaders encouraged innovation and participation in research.

The service supported staff and service users in the participation of research. For example, one staff member led a case study of the use of music therapy in the palliative pathway. This research was published in the Journal of Neonatal Nursing**.**

The service had commissioned a small research project at the local hospital undertaken by a senior registrar to gather information on the perception of what children's hospice care was. Before the intervention of the project, only 23% of local health practitioners understood the referral criteria to the hospice. After the intervention of the project 97% of those who did not understand the criteria beforehand were now more likely to refer to the service earlier than they thought. This project was recognised by the Minister of State for Care and Mental Health.

The service also funded external training and paid for attending national conferences to develop staff and promote the service.

The service was involved in a national paediatric palliative care network aimed at fostering research into paediatric palliative care with the service involved in the areas of transition into adulthood and measuring outcomes of paediatric palliative care. The research is currently ongoing until July 2023.