Alexander Devine Children's Cancer Trust

Alexander Devine Children's Hospice Service

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	Good
Are services safe?	Good
Are services effective?	Good
Are services caring?	Good
Are services responsive to people's needs?	Good
Are services well-led?	Good

Summary of findings

Overall summary

Alexander Devine Children's Hospice Service was founded in 2007 providing specialist care and support to children and young people with life-limiting and life-threatening conditions, and their families, across Berkshire and into surrounding counties in their own homes.

In June 2018 a purpose built facility was opened offering day-care and respite services in addition to the care in the home and shortly after a symptom management service was made available and the hydrotherapy pool was opened. In 2021 overnight respite was established.

Alexander Devine offers a multi-professional approach to the health, social care and education of children and young people who attend the service. At the time of our inspection, there were 150+ children, young people and their families supported in a variety of ways.

In addition to the respite care offered to children and young people at Alexander Devine, there was support for parents and siblings. This support ranged from complimentary therapies and bereavement support for parents and siblings to accommodation enabling families to stay in adjacent accommodation so they could be near their children. Alexander Devine provided 14,450+ hours of care and support for families in the year ending March 2021.

The hospice had a registered manager in post. A registered manager is a person who has registered with the Care Quality Commission (CQC) to manage the service. Like registered providers, they are 'registered persons'. Registered persons have a legal responsibility for meeting the requirements in the Health and Social Care Act and associated Regulations about how the service is run.

The service receives over 80% of its income from charitable donations and fundraising.

This location had not been previously rated. We rated it as good because:

- The service had enough staff to care for children and young people and keep them safe. 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, acted on them 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, and gave them pain relief when they needed it. Managers monitored the effectiveness of the service and made sure staff were competent. Staff worked well together for the benefit of children and young people, supported them to make decisions about their care, and provided support for their siblings and parents in times of bereavement.
- Staff 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.

Summary of findings

- 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.

Summary of findings

Our judgements about each of the main services

Service	Rating	Summary of each main service
Hospice services for children	Good 	**Outstanding practice** We found the following outstanding practice: • There was a strong family centred culture where families, as well as the children and young people within the hospice's care were supported. Staff were focused on the needs of the whole family and took action to address these needs in a way that was flexible and person centred. • Service leaders welcomed challenge and had developed an open and transparent culture at all levels. Staff unanimously spoke about the supportive and effective leadership in place both locally and executively. • Staff went the extra mile in their care and were committed to find ways to make a difference to children, young people and their families. Staff got to know children young people and their families as individuals, and built up a strong rapport with them to enable innovative care. • The links with local NHS both in terms of increasing awareness of the service and enabling staff to maintain clinical competencies in skills not often practiced in the hospice setting was outstanding. • The two flats where families could stay, and the bereavement / end of life area with the lounge with two sofa beds and a self-contained kitchen / dining area; were designed, built and furnished to an exceptional standard.

Summary of findings

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Summary of this inspection

Background to Alexander Devine Children's Hospice Service

Alexander Devine Children's Hospice is operated by the Alexander Devine Children's Cancer Trust and provides palliative care for children and young people (CYP) with life-limiting and life-threatening conditions, along with support for the whole family both during the young person's life and following their death. The service operates from Maidenhead and predominantly provides care for children and young people living in Berkshire and the surrounding counties in their own homes.

In 2018 the charity raised funds to open a brand-new purpose-built hospice and opened for day care and hydrotherapy. Since mid-2020 they have been able to provide overnight respite and end-of-life care for CYP and their families.

The hospice has six en-suite bedrooms. At the time of the inspection two were used for day care, three for overnight care, with one used as a nurses station when rooms were occupied overnight. In addition the hospice had two flats where families could stay, a bereavement / end of life area which has a cool room and a lounge with two sofa beds and a self-contained kitchen / dining area.

Services Provided included:

- Day care
- Play therapy
- Music therapy
- Physiotherapy
- Hydrotherapy
- Complementary therapies
- Symptom management
- End of life care
- Short breaks and respite
- Transition support
- Education and training for families, professionals and staff
- Family Support
- Counselling
- Memory Day
- Pastoral and Spiritual Support

The hospice was registered with CQC to provide the regulated activity, treatment of disease, disorder or injury.

The director of care was the registered manager.

Alexander Devine Hospice was inspected previously in 2016 under a different CQC inspection methodology and was rated as good.

How we carried out this inspection

We carried out a short-announced inspection on 11 March 2022.

Summary of this inspection

We visited the hospice and spoke with staff who deliver services, members of the senior team and organisation trustees. We also accompanied a clinical nurse specialist when visiting a family in their own home and observed care provision.

We spoke with 14 members of staff, which included nursing, administrative, executives and other non-clinical staff. We also spoke with two service users and one carer.

We reviewed six sets of care records.

We inspected Alexander Devine Hospice using our comprehensive inspection methodology. 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:

- There was a strong family centred culture where families, as well as the children and young people within the hospice's care were supported. Staff were focused on the needs of the whole family and took action to address these needs in way that was flexible and person centred.
- Service leaders welcomed challenge and had developed an open and transparent culture at all levels. Staff unanimously spoke about the supportive and effective leadership in place both locally and executively.
- Staff went the extra mile in their care and were committed to find ways to make a difference to children and their families. Staff got to know children and their families as individuals and built up a strong rapport with them to enable innovative care.
- The links with local NHS both in terms of increasing awareness of the service and enabling staff to maintain clinical competencies in skills not often practiced in the hospice setting was outstanding.
- The two flats where families could stay, and the bereavement / end of life area with the lounge with two sofa beds and a self-contained kitchen / dining area; were designed, built and furnished to an exceptional standard.

Our findings

Overview of ratings

Our ratings for this location are:

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

Good

Hospice services for children

Safe	Good
Effective	Good
Caring	Good
Responsive	Good
Well-led	Good

Are Hospice services for children safe?

Good

This location had not previously been rated for safe. 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 received and kept up-to-date with their mandatory training. Methods of training could be on-line or face to face; staff received reminders when any mandatory training was due.

Managers organised regular training days to ensure all staff had access to the required training.

Statutory and mandatory training for all staff included; fire safety, health and safety, risk and diversity, child safeguarding, prevent, infection control, and moving and handling. Staff compliance was 100% at the time of our inspection.

All clinical staff also received training annually in; Paediatric Immediate Life Support (PILS), medicines management, syringe driver management, tracheostomy care, mechanical ventilation hydrotherapy, DNACPR decision making, record keeping and food handling.

Additional training for all included; adult safeguarding, consent and mental capacity, deprivation of liberty standards.

Safeguarding

Staff understood how to protect people from abuse and the service worked well with other agencies to do so. Staff knew how to recognise and report abuse. All staff had completed mandatory safeguarding training.

The recruitment procedures at the Alexander Devine Hospice included relevant enhanced DBS checks which staff adhered to strictly.

Staff received child safeguarding training appropriate to their role; all staff including non-clinical managers were trained to level one. Staff who had any contact with the children and young people and their families using the service were trained to level two. All clinical staff working with the children and young people were trained to level three. This included any adult who could pose a risk to children and young people, who could potentially contribute to assessing, planning, intervening or evaluating the needs of a child or young person.

The lead for safeguarding within the service was the governance lead for the care team; they were trained to level four. This followed the guidance detailed in the 'Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff' intercollegiate document.

Staff knew how to identify children and young people at risk of, or suffering significant harm and worked with other agencies to protect them. The service safeguarding policy was compliant with the local safeguarding children's board child protection procedures and referenced other national and international child protection guidance and law.

The safeguarding procedure outlined the types of abuse staff may come across and contained contact details for the local authority social services duty teams, including the out of hours contact details. Staff we spoke with understood safeguarding issues and knew how to make a safeguarding referral and who to inform if they had concerns.

Cleanliness, infection control and hygiene

The service controlled infection risk well. Staff used equipment and control measures to protect patients, themselves and others from infection. They kept equipment and the premises visibly clean.

All areas were visibly 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; this included daily cleaning schedules of communal areas and bedrooms.

Staff received training in infection prevention and control (IPC), records showed that staff were 100% compliant with training requirements.

Staff followed guidance on the use of personal protective equipment (PPE), and we observed all staff wearing face masks when in the hospice. Staff had received training in the appropriate use of PPE and used it when in the hospice and in people's homes.

Managers told us the hospice had a contract with an external specialist cleaning company to support infection prevention and control and undertake annual audits. The service provided the last three audit reports which demonstrated full compliance with clinical practice to ensure the risk of cross infection was minimised.

The service employed a housekeeper who was able to explain the cleaning routine and understood the necessary enhanced cleaning required since the start of the COVID-19 pandemic.

We saw the cleaning trolley contained different coloured mops and buckets for different tasks. The cleaning cupboard was secure, extremely neat and organised, with nothing stored on the floor. All cleaning fluids were stored correctly, in line with 'Control of Substances Hazardous to Health' (COSHH) regulations.

Environment and equipment

Good

Hospice services for children

The design, maintenance and use of facilities, premises and equipment kept people safe. Staff had appropriate training to use the equipment. Staff managed clinical waste well.

The service had suitable facilities to meet the needs of children, young people, (CYP) and their families.

The building was designed to be open and welcoming and not feel like a hospital. The environment had been planned to ensure it was suitable for CYP with sensory, behavioural and mental health needs.

Communal rooms and corridors were spacious which provided suitable wheelchair access and were well lit with both natural and artificial light. The corridors were wide enough to allow two wheel chairs to travel side by side which facilitated face to face conversation for the service users.

There was a special sensory room which provided relaxing light and sounds facilitating relaxation for the CYP when required.

The service had enough suitable equipment to help staff to care safely for CYP. Each inpatient bedroom was equipped with suitable equipment and had access to an ensuite bathroom.

There was suitable hoisting equipment available for children and young people who required assistance to transfer throughout the building, including in the pool area, sensory room, bedrooms, bathrooms and therapy rooms.

The hydrotherapy pool was well maintained with water temperature maintained at a temperature to suit the needs of CYP using it. A comprehensive risk assessment for using the pool was completed for each user. Safety advice and contact numbers were displayed in the area for staff and users.

Water systems were tested every six months for general bacteria and coliforms by an external company.

The service maintained an electronic asset list, along with maintenance contracts and service level agreements on equipment. Staff kept a log of all maintenance requirements with dates which demonstrated maintenance checks were up to date. Emergency alarms were fitted and tested regularly.

We saw staff cleaned equipment after patient contact, however an audit which took place last Summer found a small section of the environment did not achieve 100% (93%)

Security was a priority; there were clear security measures at the entrance to the hospice so that visitors were greeted by staff and screened on arrival. All staff and visitors signed in and out of the premises.

Clinical waste was managed safely and effectively; all waste bins were fully enclosed, lidded, foot operated, clean and in good working order. The bins were labelled with the category of waste or colour coded. There was a clean designated storage area for waste bags/containers awaiting collection, and the storage area was lockable and inaccessible to unauthorised people. Clinical and domestic waste bags were segregated whilst awaiting collection.

Assessing and responding to patient risk

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

Staff completed risk assessments for each child or young person. We reviewed the records of six children and young people and saw that appropriate risk assessments had been completed. These included an initial assessment, an holistic assessment, an evaluation and full care plan.

Key information meant staff knew about and dealt with any specific risk issues. The care plans were detailed with guidance for every aspect of the child's needs; for example, step by step measures for the parent or carer to manage each stage of their child's pain.

The service completed risk assessments to support CYP to use the hospice's facilities. For example, there was a complex risk assessment for naso-gastric tube feeding.

Staff liaised closely with colleagues working within integrated local services, including acute and community children's services. There were established lines of communication and staff regularly met with staff working within other services to discuss care.

There were grab bags available around the site for emergencies; these included the necessary range of equipment and medicines for first response, to a rapid and unexpected deterioration in a child or young person's condition.

The service had equipped each room with call points, from which staff or visitors could request routine and urgent medical assistance, in the event of the deterioration of a child.

Staffing

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

The service was nurse led and had enough nursing and support staff to keep patients safe. There was a mix of clinical nurse specialists, registered nurses, care assistants, play specialists, and administrative staff. A matron led the care team, supported by senior clinically qualified management executives.

Other staff such as a music therapist and pharmacist were employed on service level agreements. Managers made sure all bank staff had a full induction and understood the service. At Alexander Devine bank staff were employed from a regular pool and were familiar with the team, and the CYP who used the service.

Two local consultant paediatrician's supported the service, forming part of the multi-disciplinary team.

Managers adjusted staffing levels daily according to need. Senior staff reviewed staffing in advance, based on planned day care attendees, respite admissions and the individual needs of each child or young person attending.

At the time of the inspection there were a number of staff vacancies; this included band five and six nurses and band four care assistants. Difficulties in recruiting suitable care staff limited the ability of the service to routinely admit CPY for overnight stays.

Records

Good

Hospice services for children

Staff kept detailed records of children and young people's care and treatment. Records were clear, up-to-date, stored securely and easily available to all staff providing care.

Patient notes were comprehensive, and all staff could access them easily.

Paper records were in use and these contained relevant and up to date information. Care plans were individualised, and records included contributions from nursing, medical and support staff.

Records we reviewed were detailed, and completed with the date, time, signature and patient lifestyle on each occasion. The care plans detailed straightforward steps and guidelines for parents to follow for every aspect of their child's care.

Records were stored securely in the team office.

A procurement process for an electronic record system was underway at the time of our inspection with a general end of life / hospice model preferred. An evaluation and user group was established and the plan is to get a system to 'talk' to other systems.

Medicines

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

A small stock of non-controlled drugs was kept on the premises which included, paracetamol, dioralyte, ibuprofen and adrenaline. We found these to be in date and properly stored.

Staff followed systems and processes to prescribe and administer medicines safely.

We reviewed five medicines charts; they were all fully and correctly completed. Each was legible and documented the date, medication dose, patient's weight, any concerns, last review. All were properly signed.

The service had a policy for medicines brought into the premises; the process was clear and records checked showed that the process was followed and there were no concerns identified. Children and young people are required to bring in all medicines from home and where possible drug charts were completed by a doctor and a pharmacist before a child attended the hospice. Where this was not possible, medicines were transcribed by two registered nurses.

The nurses were trained to transcribe by the pharmacist. Registered nurses who were already experienced in transcribing supported the new transcribers.

The service did not store controlled drugs on the premises at the time of the inspection. We reviewed the log book and found some discrepancies with the recording of the controlled medicines. In line with the provider policy the log entries should have been recorded as '0' as all medicines were marked as 'returned home'. However we found some correctly recorded, some recorded with a dash and some incorrectly recorded with a number even though they had been returned home.

Incidents

Good

Hospice services for children

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 children, young people and their families honest information and suitable support. Managers ensured that actions from patient safety alerts were implemented and monitored.

Staff knew what incidents to report and how to report them. This included when anything went wrong, near misses and accidents within the service. Staff understood what constituted an incident and reported these appropriately and in line with the provider policy.

The paper incident reporting form included the outcomes measures which were revisited to ensure actions were completed and lessons learnt. Staff received feedback from investigation of incidents, both internal and external to the service.

We saw an example of the monthly risks and incidents which identified patterns and trends. Examples of incidents included some relating to medicines errors, equipment and trips and falls.

Incidents were discussed with staff at the monthly team meetings and learning shared. The team is very small and in constant communication with each other so any changes to practice as a result of an incident is quickly learned and understood.

Staff understood the duty of candour. They were open and transparent, and gave children, young people and their families a full explanation if things went wrong.

Incidents relating to medicines management are reviewed by the pharmacist and where necessary they provide any further training for clinical staff.

Thorough risk assessments helped minimise the number of incidents occurring at the service.

Are Hospice services for children effective?

Good

This location had not previously been rated for effective. We rated it as good.

Evidence-based care and treatment

The service provided care and treatment based on national guidance and evidence-based practice. Managers checked to make sure staff followed guidance. Staff protected the rights of children and young people (CYP) subject to the Mental Health Act 1983.

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. Care and treatment was evidence-based and staff managed end of life care in accordance with the National Institute of

Good

Hospice services for children

Health and Care Excellence guidance NG61 (End of life care for infants, children and young people with life limiting conditions). Staff followed policies based on guidance in 'Together for short Lives'; guidance for children and young people who are expected to have short lives. Senior care staff monitored compliance with national guidance and evidenced-based practice.

Families were supported in developing advance care plans for children and young people with life limiting conditions. Children, young people and their families could communicate their health care wishes so that these could be followed when a child or young person's condition deteriorated. A framework was provided for discussing and documenting the agreed wishes of a child or young person and their parents when the child or young person developed potentially life-threatening complications of their condition. The service used the 'Recommended summary Plan for Emergency Care and Treatment' (ReSPECT), which included decisions concerning resuscitation. Staff worked collaboratively with other professionals to ensure that the holistic and clinical needs of the child or young person and their family were met. Records we reviewed demonstrated that advance care plans contained information about a child or young person's wishes.

At the time of our inspection, the service was working with the Thames Valley Children's Palliative Care Network to develop a Children's Palliative Care Managed Clinical Network (MCN). This aimed to ensure improved outcomes for CYP through engagement with organisations and professionals from hospice services, paediatric community services and hospitals informing and shaping the MCN.

Managers had scoped the current service to determine gaps in delivery in line with the NHS Long Term Plan (NHS 2019) and the Children's and Young People's Palliative and End of Life Care Service specification (NHS 2021).

The hospice provided evidence based holistic therapies such as music therapy, physiotherapy, and hydrotherapy.

Nutrition and hydration

Staff gave children, young people (CYP), and their families enough food and drink to meet their needs and improve their health.

Alexander Devine worked with families to ensure the children and young adults in their care received nutrition in line with the documented care plan. As part of meeting a child's physical needs, nutrition and hydration were prioritised to ensure needs were met at every stage in the palliative journey. Staff were able to provide nutritious meals taking into account the cultural and religious needs of CYP.

Clinical staff were trained to provide enteral feeds; they risk assessed CYP requiring nasogastric / nasojejunal tube feeding using a detailed tool which included for example; feeding tube dislodgement, and nutritional deficiency, the consequence of the problem, control measures to minimise the problem with impact scoring, and any other comments by the assessor.

A dining room kitchen was available on site with refreshments and lite meals, and an industrial kitchen was also available for service development when in-patient stays became more permanent.

Pain relief

Good

Hospice services for children

Staff assessed and monitored children and young people regularly 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 and gave additional pain relief to ease pain.

Staff assessed patients' pain using a recognised tool and gave pain relief in line with individual needs and best practice. The 'Faces Pain Assessment Tool' directs staff to ask the child to describe the type/level of pain in their own words and asks the child to indicate the number or face which best fits their pain. The face pictures used in the tool are very simple, making it easy for children and young people of all capabilities to understand.

Staff developed a thorough understanding of the children and young people in their care and looked for non-verbal cues that indicated if pain was a concern. They administered pain relief promptly and evaluated how effective it was.

Staff prescribed, administered and recorded pain relief accurately. When children or young people were approaching the end of life, anticipatory medicines were appropriately prescribed and documented in the care plan.

Patient outcomes

Staff monitored the effectiveness of care and treatment. They used the findings to make improvements and achieved good outcomes for children and young people.

There was a clear approach to monitoring, auditing and benchmarking the quality of the services and outcomes for children and young people receiving care and treatment. The service participated in clinical audits.

There were no national audits which related specifically to specialist paediatric palliative care. Alexander Devine submitted to the child death overview panel.

When a child dies, in any circumstances, it is important for parents and families to understand what has happened and whether there are any lessons to be learned. The responsibility for ensuring child death reviews are carried out is held by 'child death review partners, who, in relation to a local authority area in England, are defined as the local authority for that area and any clinical commissioning groups operating in the local authority area. The analysis of information from all deaths is reviewed to identify any matters relating to the death, or deaths, that are relevant to the welfare of children and young people in the area.

The hospice formed part of the specific children's end of life pathway across the Integrated Care System (ICS) with NHS partners in Berkshire and the surrounding counties. The hospice were also involved with 'Together for Short Lives' on a mapping exercise for children's end of life and palliative care.

Together for Short Lives is the UK registered charity for children's palliative care. The charity's vision is for children and young people in the UK with life-limiting and life-threatening conditions and their families to have as fulfilling lives as possible, and the best care at the end of life.

Outcomes for children and young people were positive, consistent and met expectations, such as national standards. All children and young people had an individualised care plan in place, that set out their advance care preferences. It covered activities of daily living, family and carer support, infection control, mental capacity, tissue viability, advance care planning and symptom management. There was provision for recording preferred place of care and death within records. The records were regularly reviewed and audited.

Alexander Devine had a rolling programme of local audits and managers used information from the audits to improve care and treatment. Recent audits include for example, ventilation, tracheostomy and use of humidifiers with integrated flow generators to ensure safe clinical practice. This involved review of care plans to ensure accurate information for delivering care. Another example was the risks and incidents audit which identified, shared and implemented specific actions following medicines incidents leading to a review of medicines management processes and training for staff

The service monitored the results and completion of audits and their associated action plans through quality meetings, and agreed additional re-audits.

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.

Managers checked qualified staff had professional registration and we saw 100% of eligible staff had completed revalidation with their professional body. Staff were experienced, qualified and had the right skills and knowledge to meet the needs of patients.

New staff completed a comprehensive induction and were enrolled onto the training programme. New staff were required to complete competency booklets which included modules relevant for the role, for example management of tracheostomies. Induction programmes were normally completed within the first three to six weeks of commencing employment within the organisation.

The Alexander Devine competency framework supported individual and generic competencies for all staff. There were specific competencies for carers and nurses to ensure the care team had the necessary knowledge, skills and confidence to fulfil their roles and ensure safe and effective care delivery. Each member of the team received a competency folder which they maintained to support their personal safe, effective practice.

Core competencies included:

- Communication
- Basic and complex care
- Assessment
- End of life and bereavement care
- Safeguarding

Managers supported staff to develop through yearly, constructive appraisals of their work. Staff had the opportunity to discuss training needs with their line manager and were supported to develop their skills and knowledge. Appraisal compliance was 100% with delivery of staff appraisals ongoing. We saw the service had a data base which identified when appraisals were due and when applicable the reasons if they had not such as maternity leave.

Staff told us they found the appraisals beneficial and an example we were given was the request for further intravenous medicines training during an appraisal which was actioned by the manager. Another nurse had completed an advanced assessment and clinical reasoning course and was taking an MSc in palliative medicine for Health Care Professionals which was funded by the hospice.

A clinical practice educator supported the learning and development needs of health and care support workers. There were plans to offer placements to student nurses to attract and retain staff as well as increase awareness for general children's nurses.

The service provided clinical supervision for staff though some felt this needed further input.

Clinical nurse specialists (CNSs) in palliative care and symptom control worked with other professionals such as pharmacists and consultants, to support the children, young people, and their families. The CNSs held a community caseload and linked with acute hospitals, GPs, and others to evaluate if referrals to the hospice were right for the child and the family.

A clinical nurse specialist had been appointed to support children and young people with respiratory and long term ventilation (LTV). This specialist nurse was also employed to update the competencies of staff in the management of LTV; and upskill the care team in respiratory management, including medicines, respiratory standard operating procedures, and LTV scenarios.

Other competencies included, neurological (seizure management), feeding and elimination (stoma device practice, blended diet theory), end of life (scenario training, medicines, tissue viability updates).

Staff told us 'they were very happy in their roles and felt they were able to offer the best care everywhere; they wanted to provide more but were limited by lack of staffing.'

Managers recruited, trained and supported volunteers to support patients in the service. At the time of our inspection there were 131 volunteers with roles across the organisation. The volunteers went through a strict recruitment process and interviews. All received training both online and face to face. All volunteers working in the hospice had enhanced Disclosure and Barring Service (DBS) checks.

Volunteers in the care team were required to give a minimum commitment of six months and come in regularly, due to the extra training needed and to keep consistency for the children, young people, and families.

The Volunteer Development Manager for the service told us they were involved with 'short lives matters' and twice a year met up with other volunteer managers from other children's hospices. They also visited other hospices to see how they use volunteers to learn from good practice, such as a family support volunteer scheme.

The service had a measured approach to introducing new things and services; detailed checks were always instigated to match families with volunteers and plans to deal with any adverse issues which may arise.

Managers told us that before the pandemic they organised a 'one team' training day for volunteers and hospice staff. There were speakers and team building activities and thought to be very successful. As COVID-19 restrictions have now reduced there were plans for another one in October 2022 to bring everyone together again.

Multidisciplinary working

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

Good

Hospice services for children

Staff worked with other professionals involved in the child or young person's life. For example, schools, community therapy teams and social workers.

The consultants who supported the hospice were employed at local NHS trusts; nurses were supported to remain current in their practice by maintaining and improving links with the local NHS hospitals.

The service was working with the other two children's hospices in the Thames Valley area to provide continuous care for families. Staff described a recent situation when it was necessary to transfer a child receiving end of life care from one hospice to Alexander Devine. Staff acknowledged transferring a child at this time was not ideal but were able to ensure sustained care for the family. This prompted discussions about sharing staff between the services in the area, ensuring staff worked across each location to ensure continuity of care and to ensure children and young people did not have to be transferred.

There was no lead for transition at Alexander Devine but the service had begun to develop a partnership with a local adult hospice to support the transition for patients and families from children's and young people's services into adult services. with the nearby adult hospice to effectively plan a young person's transition and to share broader good practice. One young person we spoke with told us that this was something they appreciated very much.

Staff held regular and effective multidisciplinary meetings to discuss children and young people and improve their care. These included the nursing team, pharmacist and the paediatricians as well as other healthcare professionals as appropriate. The children and young people accessing the service had their care plans reviewed and updated with any new changes to their circumstances, their condition or social needs in a timely way.

As part of 'wrap around care' Alexander Devine had aspirations to include a social worker as part of the permanent team. At the time of out inspection this was not a viable option, but the service linked with the local authority social workers involved in the care and development of any child or young person who accessed the service.

Seven-day services

The service did not operate seven days per week on a regular basis at the time of the inspection. Planned admission for respite care and for families to occupy the designated accommodation could be arranged when the hospice could allocate sufficient and appropriate staff.

Health promotion

Staff gave children and young people practical support to help them have heathier lives and live well until they died.

Staff gave advice to children and young people and their families to live healthier lives. Staff worked closely with children, young people and their families, as well as other professionals to maximise health and wellbeing. Care was planned on an individual basis and took account of individual health needs.

Staff told us during the review of each child or young person's holistic needs assessment, they discussed any goals or aspirations for siblings too. The assessments looked at the clinical needs of the patient and the wellbeing of the whole family.

Good

Hospice services for children

The service was able to provide patients and their families goal-based therapy support through counsellors, music therapists, play specialists and spiritual care advisors.

Consent and Mental Capacity Act

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. There were clear policies and guidance available and staff had received training in mental capacity and best interest decision making.

Staff made sure children and young people consented to treatment based on all the information available. They gained consent from children and young people for their care and treatment in line with legislation and guidance, and recorded this clearly in their records. Staff understood how and when to assess whether a child or young person had the capacity to make decisions about their care. When they could not give consent, staff made decisions in their best interest, considering their wishes, culture and traditions.

Consent forms were linked to care plans and reviewed regularly, and these were subject to audit on a quarterly basis.

Are Hospice services for children caring?

Good

This location had not previously been rated for caring. We rated it as good.

Compassionate care

Children, young people and their families were valued as individuals, and empowered as partners in their care. There was a culture of inclusivity and staff made sure all care was tailored to the individual.

Staff were discreet and responsive when caring for patients. Staff took time to interact with patients and those close to them in a respectful and considerate way. Children, young people and their families were at the heart of everything staff and volunteers did. Support was always given by caring and empathetic staff to meet the needs of the whole family.

Staff reviewed shifts and liaised with different agencies to make sure the correct equipment and support were available at the point of need. The end of life care room demonstrated that staff aspired to go above and beyond to achieve excellent end of life care.

Staff meeting minutes sometimes began with a few minutes “to remember the children and individual family members who have died”

The volunteer counsellors were available once a week for parents and siblings to talk to and discuss any concerns or worries they may have.

Parents described the play therapists as 'life changers'. The sick child's siblings went to the hospice where they were able to talk freely about their situation and feelings, things they felt unable to say to their family members. They also met other children and young people in a similar situation to themselves and made friends and formed WhatsApp groups. The play therapist was key to engaging each child and cohorting children andyoung people with similar interests. For example a number of children, young people and their siblings liked to cook at the hospice.

Feedback from people who used the service was positive; people spoke highly of the service and said that the needs of the whole family were considered as part of the overall care.

The service could take account of cultural and religious needs for example access to chaplaincy services.

Emotional support

Feedback about the service was continually positive. Staff went the extra mile and the care and support exceeded expectation. There was a clear person-centred culture. We found that staff were highly motivated to offer care. Relationships between staff and those that used the service were respectful and supportive, and highly valued.

Staff understood that emotional needs of children, young people and their families were as important as physical needs. Staff could provide emotional support for children and young people who were at the end of their life and provided support to the whole family both emotionally and practically.

The service had several ways to identify and meet the emotional needs of wider family members, for example counselling. The service arranged different activities for users of the service and we saw that staff could use informal settings to get to know family members better and identify any extra needs around wellbeing.

Staff arranged memory days for families for which the service received positive feedback. This meant families could contact other families and provide support to each other.

Staff went the extra mile for families of children and young people who were near the end of their life. For example, staff would change their shifts to provide continuity of care and ensure the child and their family knew at least one person in the team.

Users of the service could access complementary therapy, and staff organised sibling events and fun days.

One family described the service and said "The facilities are amazing and the team are always warm, friendly and incredibly kind and helpful. We are very lucky to be a part of it all."

Another family said Alexander Devine was 'a lifeline, don't know what we would do without them. They come out to me when the GPs won't, they give me peace of mind. I can discuss anything with them.'

Understanding and involvement of patients and those close to them

Staff supported and involved children, young people and their families to be partners in their care. Staff ensured that they understood their condition and made decisions about their care and treatment. They ensured a family centred approach.

Good

Hospice services for children

Staff had different ways to involve children and young people of different age groups in planning their care. For example, we heard from one anxious family, whose child had been referred to the hospice, how supportive the hospice staff had been. The staff took time to encourage the child to come to day care, and then support the child to stay with the team without other family members. Eventually the family were happy to leave the child in the care of hospice staff while the family spent time in the family accommodation. This eventually proved to be a positive experience for the child and the family.

The service used the 'What is Important to Me' document which details the child or young person's feelings such as what makes them feel good or down; their hopes and aspirations which included their goals such as learning new skills or projects they wished to complete.

Staff supported children, young people and their families to make advance decisions about their care. Staff had received training in advance care planning, and we saw that this was integral to care planning and decisions around preferred place of care and other care wishes. When children or young people were approaching the end of live regular multidisciplinary meetings and discussions were held with them and their family to ensure their wishes were met.

Patients and their families gave positive feedback about the service. One patient we spoke with described the care they received as 'one of the best places that exist, the team are giving and supportive. I feel really listened to by everyone.' They went on to tell us that they felt fully involved and understood by the team. Their interests were considered as a young person not as a child and they considered the team at Alexander Devine as part of their family.

Are Hospice services for children responsive?

Good

This location had not previously been rated for responsive. We rated it as good.

Service delivery to meet the needs of local people

Children'sand young people's individual needs and preferences were central to the delivery of services and managers planned and organised services so they met the changing needs of the local population.

Managers planned and organised services so they met the needs of the local population. The hospice provided day care, respite, bereavement support, counselling and a homecare service for children and young people who had a life limiting illness. Care and support were provided not only to the child or young person but included their entire family including parents, siblings and grandparents and others who cared for them. An inpatient service was in it's infancy at the time of our inspection.

The leadership team engaged with the local paediatric palliative care network and attended regular network meetings. Clinical leads also engaged regularly with heads of care from other local hospices. This ensured hospice leads were engaged with the wider hospice and paediatric care systems and had an understanding of the needs of the local population as a result. Staff and managers were actively involved in building links with local services and the community to ensure that they continued to meet the needs of patients.

Good

Hospice services for children

Facilities and premises were purpose built and excellent for the services being delivered. All areas of the hospice were accessible to people with a range of disabilities. Corridors and doorways were wide enough to accommodate large electronic mobility chairs and fixed hoists were available in all areas. The hospice had large and extensive gardens with level access pathways to enable wheelchair access and a range of play equipment.

Age appropriate activities included televisions and electronic games; there were appropriate toys and play facilities including soft and sensory play areas. The hydrotherapy pool was available to children and young people for physical therapy, and as a leisure activity for their families through a booking system.

A bereavement area included a bedroom and a lounge with sofa beds and a kitchen facility. A cooling facility was available for a baby, child or young person who had died; and the room was quiet and peaceful for the bereaved families.

The service had systems to help care for patients in need of additional support or specialist intervention and planning for transition to adult services. Hospice leads understood the issues faced by young people transitioning to adult services and supported the planning for this by working collaboratively with other providers to develop solutions. We met an individual who confirmed that this was an enormous benefit for them as designated Alexander Devine staff supported them whenever they were needed.

Meeting people's individual needs

The service was inclusive and took account of children, young people and their families' individual needs and preferences. There was a proactive approach to understanding the needs and preferences of different groups of children and young people to delivering care in a way that met these needs. Staff made reasonable adjustments to help children, young people and their families access services.

Staff made sure children and young people living with mental health problems, learning disabilities and long term conditions received the necessary care to meet all their needs. This included support with accessing other services.

The homecare service provided support to families in their own home and this was provided to those with additional requirements. The team would also make arrangements for children and young people to be assessed for suitable equipment through the local NHS community nursing service, or the local authority. The range of support for homecare included providing at home respite care so that parents could go out where they might otherwise be unable to. Day service provision was also provided to support the families' respite needs.

Staff supported children and young people living with complex health care needs by using personalised care plans. They assessed needs prior to and during admission to the service on a continual basis. In order to understand the needs of individual children and young people, staff worked closely with other services throughout the referral process.

The service had a bespoke advance care planning document and staff supported patients to complete it. End of life care discussions with children, young people and their families with reference to the children and young people's preferences were embedded and reviewed frequently as preferences changed during disease progression and deterioration in the young person's condition. Staff also used a ' What is important to Me' document to support children and young people's independence and decision making and documented their likes and dislikes.

Crisis and emergency admissions were available for children, young people and their families. Staff told us of a recent emergency admission facilitated in corroboration with another local children's hospice.

There were multiple quiet rooms which were used for sensitive and confidential conversations and meetings.

Staff understood and applied the policy on meeting the information and communication needs of children and young people with a disability or sensory loss.

One of the senior management team worked with multifaith groups in the area; the multifaith committee was chaired by the local chaplain and Alexander Devine had arranged open days for them to see what facilities could be made available to them.

The local population was 90% English speaking but staff have access to an interpretation service if they needed it.

Access to the right care at the right time

People could access the service when they needed it and received the right care promptly. The service ensured children, young people and their parents did not have to wait for end of life care and ensured they achieved their preferred place of care and death.

Managers monitored the service and made sure children, young people and their families could access services and receive treatment when they needed it most. Nursing teams had a caseload of children and young people who they saw frequently and could discuss children, young people and their care needs at clinical and team meetings to decide with the operational management team what care planning could be offered. Depending on the circumstances, this could include access to hospice facilities and therapy sessions, such as hydrotherapy or music therapy, or the facilitation of planned short break stays.

The service had a clear eligibility criteria and could adapt these for urgent or complicated situations.

The amount of planned short break care available was based on staffing levels and other demands on the service such as end of life care provision. At the time of the inspection the service was focussing on recruitment in order to facilitate increased admissions to their in-patient facilities on a more regular basis. We saw, however that staff were committed and went out of their way to provide a service by swapping shifts and working with other hospices to do so particularly to support a short notice need. All families who request overnight stays were placed on a waiting list which, at the time of the inspection, was on average six months.

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 had an up to date complaints policy which included staff roles and responsibilities and timescales for dealing with complaints.

Alexander Devine had not received any formal complaints in the months between September 2021 and the time of our inspection. A leaflet was provided to families in the family pack they received at the time of referral detailing the methods available to them if they wished to discuss any concerns.

Good

Hospice services for children

We saw from team meeting minutes that complaints were a standing item on the agenda for all meetings. Staff told us that informal complaints would be addressed at the earliest opportunity; these were normally direct issues raised by the children and young people which were usually minor things related to activities.

The service received lots of compliments which expressed how staff have gone the extra mile to meet a family's needs, the professionalism of the service, the compassion and empathy of staff, and on the service's responsiveness to their needs.

Are Hospice services for children well-led?

Good

This location had not previously been rated for well-led. We rated it as good.

Leadership

There was compassionate, inclusive and effective leadership at all levels. Leaders had high levels of experience, capacity and capability needed to deliver excellent and sustainable care.

The hospice was led by the chief executive and the director of care who was also the CQC registered manager.

Leaders within the service had a deep understanding of issues, challenges and priorities in their service, the wider organisation and the children's hospice sector. These included funding, staff recruitment and future service demand. Managers were aware of the challenges to sustainability and had clear sight on issues around finance and risk.

Trustees and the board met regularly, and staff knew lines of accountability. Relationships between different levels of staff were effective. Senior managers were based at the hospice and had an open-door policy which we saw during the inspection.

Teams in the community managed their own caseloads and were supported by clinical leads and the director of care. Staff we spoke with told us that leads were supportive, accessible and approachable.

Trustees expressed their view that the management and staff of Alexander Devine 'are an absolute privilege to work with.

Vision and strategy

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

The hospice had a vision 'to provide a children's hospice service within Berkshire and surrounding counties that will give children, young people and families a choice of care and support from a dedicated team.' The service had a mission 'To reach out to every child and family who needs us, offering support and care from people who understand.'

Funding streams were good and the majority was raised through charitable donations. We saw that there were clear well considered plans for expansion. During the pandemic leaders were able to extend service provision with the extended clinical nurse specialist (CNS) service and opening overnight. Leaders explained they wanted to be able to do more for families but the pace of progression continued to be inhibited due to struggles to recruit registered nurses.

Service commissioning was complex as demands and expectations were different in east and west Berkshire; this impacted the care provision as the service was working with different community teams, and developing joint documentation/policies was labour intensive for staff.

The senior leaders worked with the Thames Valley clinical network for children's nurses and paediatricians in order to ensure a sustainable approach.

Culture

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

Staff felt positive about working at Alexander Devine. They were focused on providing a family centred approach to care and felt proud about the service provided. There was a strong sense of teamwork.

The service had a set of core values which were presented as follows:

Determined and resolute in our service to all those that need us.

Empowering; to enable whoever comes into contact with us, the power and courage to make decisions, ask questions or simply to be.

Valuing others; we value you and each other, because we are all unique and special in our own way.

Integrity; to be consistent in our ethos and values, principles and actions. To always behave and hold the integrity of our charity as core.

Nurture; to provide an environment of protection, support, growth and encouragement

Empathy; to know that we will provide a place of safety for everyone to express their feelings, thoughts and emotions, without judgment.

Everyone we spoke with during our inspection demonstrated that they believed in these, and endeavoured to live up to them to benefit the families they worked with, and for each other.

Managers led by example and the positive culture was developed and maintained by the senior leadership team. A culture of continuous improvement and service development was embedded throughout the service.

The service had not undertaken a staff survey as numbers were very small. All staff we spoke with told us they always felt they had someone to share experiences with. There was an open culture at all levels and staff told us they were able to raise concerns with assurance that these would be addressed. Managers were visible and staff told us they were approachable.

Staff told us they felt valued members of the team, and valued by managers and leaders, indeed some stated that being part the of team was their most valued part of the job. One staff member said they 'loved working at the hospice, as a small organisation I can get involved with everything, so can support where needed.' Another told us 'the culture at the hospice is amazing, I am involved in decision making, things aren't just done to us. The senior management team like to keep everyone informed. They are family.'

The service promoted the 'Employee Assistance Programme' and there were two members of staff with appropriate training as Mental Health First Aiders, for those who may need some extra support.

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.

There was a clear governance structure and effective governance processes. Governance accountability was from the board of trustees, delegated through to the chief executive, senior managers and staff for operational management. Close working meant that managers were assured about the quality of information, and themes and issues were presented at governance meetings.

Trustees met formerly on a bi-monthly basis and reviewed activity, risk and performance data; as well as information relating to human resources such as staff absence and sickness rates. We were told papers were received in advance with enough time for the trustees to read them and report authors usually presented them in person.

Trustees explained that the board had worked with senior managers over the years to improve the narrative around the data, which presented a full picture of issues and led to a better understanding for all. For example trustees were clear about the issues around recruitment and the strategy to work with network partners to share roles and open the hospice to placements for student nurses.

The service had a quality and governance lead who was also the safeguarding lead for the organisation. They explained that they had worked as a nurse and matron in the locality for many years and developed links with local hospitals, community teams as well as palliative and end of life teams. There was also a close working relationship with out of hours doctors teams.

Other meetings held at Alexander Devine included; 'whole hospice' meetings; care team meetings; monthly senior management meetings. Managers made sure staff attended team meetings or had access to full notes when they could not attend.

Most meetings had a structured agenda, for example the care team meetings were divided into updates around the CQC domains, lasted up to three hours and included the wider multidisciplinary team. These meetings included information and discussions on incident reporting, complaints, infection control and training.

The clinical committee was led by the paediatricians and included medicines management along with all other healthcare professionals associated with the referrals and other cases to be discussed.

Service policies were available to all staff they were clearly indexed and we saw that they were dated, reviewed and next review clearly marked. The senior management team that signed off new policies and procedures following review, with major policies signed off by the trustees.

Managing risks, issues and performance

The service identified risk and collected reliable data to review and mitigate against risks.

There were appropriate arrangements for identifying, recording and managing risks, issues and mitigating actions. The service had clear up to date policies and procedures available to staff which were developed to minimise risk to staff and families who use the service.

There was a programme of internal audit which focussed on incidents, analysing themes, and sharing the learning. Results were used to identify where improvement action should be taken, for example medication incidents, and clinical care adverse events such as manging children's seizures.

The clinical governance leads played a key role and function in the management of risks within the service. All team meetings included information about risks within the service and ensured action was taken to mitigate them.

Individual risk assessments were carried out for each child and young person on admission to the service. These were documented in the care plans and reviewed regularly with action taken to minimise any potential harm such as infection control and any social or safeguarding risks.

The service had a risk register which documented identified risks. These were detailed and scored with a likelihood and impact rating. Managers provided us with an updated risk log, which did not reflect staffing as a high risk, though everyone we spoke with said that the biggest risk to the service expansion and development at the time of the inspection was staffing.

We were told about the imminent procurement of an electronic records management system. This was partly to relieve time pressure on clinical staff and to minimise the risk of associated with paper records regularly taken out into the community; this was not on the risk register.

The risk register did not accurately reflect the impact of these two issues on the service. We saw three sets of minutes from recent board meetings which also did not detail these issues. This meant there was potential for the trustees understanding of the highest risks to the service provision to be incorrect.

Managing information

The service collected reliable data and analysed it to drive forward improvements. The information systems were integrated and secure. Data or notifications were consistently submitted to external organisations as required.

There were effective arrangements to ensure data and statutory notifications were submitted to external bodies as required, such as local commissioners and the Care Quality Commission (CQC). There was transparency and openness with all stakeholders about performance

General Data Protection Regulation (GDPR) concerns were included in incident audits and on the risk register. All staff received training in GDPR at induction and understood their responsibilities regarding information management.

The service had information governance policies and standard operating policies. There were clear processes for reporting data breaches and recording breaches. Staff had access to up-to-date and comprehensive information regarding patients' care and treatment. Computers and laptops were password protected to prevent unauthorised persons from accessing confidential patient information.

Paper records were stored in locked cabinets within an office, that only authorised personnel had access to.

Engagement

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

Hospice leads engaged with local and regional networks and were members of relevant national associations such as Hospice UK, Together for Short Lives forum and the Association for Paediatric Palliative Medicine. Through these national associations' hospice leads worked to share best practice in future developments for palliative and end of life care for children and young people.

Senior staff attended regional network meetings, including the local palliative care network, informal meetings with the other local children's hospices within the Berkshire, Oxfordshire and Buckinghamshire locality.

Staff within the service gave examples of how they actively sought the input of local faith and community groups to ensure services were delivered in line with individual patient needs.

There was no recent formal staff survey that allowed staff to provide anonymous feedback on the management, leadership and delivery of services. Staff told us, however that they felt able to feedback if there were any concerns and managers held regular staff meetings where staff were encouraged to share their views.

Children, young people and their families' views and experiences were encouraged and gathered to shape and improve the service and culture. Feedback was reviewed by staff and used to inform improvements and learning, where possible.

The service organised events for both staff and families such as Valentine's Day team breakfast, spring fun day, dads and lads event, scrummy mummy day, cheese and wine quiz night, and many more.

Managers used feedback from families, including from feedback from complaints, concerns and compliments to make improvements to the service. For example, managers explained the service used feedback and evaluation forms following events, such as annual bereavement memory days, to analyse the impact it had on families, and used this to develop future events to better meet their needs.

There were special events for the volunteers who supported the service. These included coffee mornings, a summer BBQ and volunteer Christmas cheer. The volunteers' manager also produced a twice-yearly bulletin full of information for the volunteer group. This included notices about events and diary dates, patient stories of how their care has impacted their lives, community events for fund raising, opportunities to support the hospice such as garden club and Christmas tree recycling.

Learning, continuous improvement and innovation

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

The service was proactive in developing links with partners to improve the quality of care and pathways between services. This included local NHS trusts, children and adult hospices and schools. For example staff had begun work to improve the transition between children and adult palliative care services.

Staff had formed links with local NHS services and universities to develop training opportunities for general children's nurses and student nurses to learn and understand palliative and end of life care.