

Alexander Devine Children's Hospice Service



QUALITY ACCOUNT
2021/22

Reaching out to every child
and family that needs us



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Accountability statement

This annual Quality Account for Alexander Devine Children’s Hospice Service is compiled from data between April 2021 and March 2022. It has been produced by the Director of Care with support from the Senior Management Team. It draws on audit evaluations and information from other reports such as the year-end report.

The report has been reviewed and approved by the Senior Management Team and Chair of Trustees.

To the best of our knowledge this document and the information in the report is an accurate and fair representation of the quality of services provided by Alexander Devine Children’s Hospice Service.

Helen Bennett	Director of Care
Fiona Devine	Co-Founder and CEO
Andrew Rice	Director of Finance
Warren King	Director of HR and Wellbeing
Julie Hughes	Lead for Quality and Governance
John Devine	Co-Founder and Chair of Trustees

Quality Account statement

A Quality Account is a report about the quality of services by a healthcare provider. The reports are published annually by each provider including the independent sector and are available to the public. The Quality Account is an important way for providers to report on quality and show improvements in the services they deliver to communities and stakeholders. The quality of services is measured by looking at patient safety, effectiveness, patient experience and care provided.

The report is published on our website and NHS Choices.

The report is shared with our stakeholders, our local Clinical Commissioning Groups, Integrated Care Systems and the Care Quality Commission.

Part 1 Statement on quality

1.1 Statement of assurance from the CEO



Fiona Devine, CEO and Co-Founder

On behalf of the Trustees and Senior Management Team, I am pleased to present the annual Alexander Devine Children's Hospice Service (Alexander Devine) Quality Account for the year ended 31st March 2022.

I want to acknowledge the ongoing challenges that COVID-19 has continued to present in the last year and to congratulate the immense effort of the whole team at Alexander Devine in continuing to provide a safe and high quality service to the children and young people that need us. I could not be prouder of how staff, volunteers and supporters rallied and went above and beyond in supporting the charity at a critical time.

During this extraordinary time, I am delighted to report the charity has continued to grow and we have expanded all aspects of service delivery. In particular, the development of the Clinical Nurse Specialist service and end of life care in the hospice, including the opening of the Dolphin suite and the development of the Dolphin garden. This dedicated area has been specially designed to facilitate bereavement support.

We have adjusted to changes in practice from our experience of COVID-19 and the hospice has continued to provide specialist palliative care and respite care to more children and families. Continued investment in the steady growth of our service has been made possible to some extent through partnerships with local Clinical Commissioning Groups. As always we are indebted for the support shown to us by our local community. We are deeply grateful for the friendship and commitment offered by local residents and businesses.



Whilst we have been able to extend our children's hospice service, recruitment of nurses remains a critical challenge as recognised by the hospice sector nationwide.



Over the next year our focus will be on maintaining the financial stability of the charity and delivering our three key care priorities:



To extend and develop our workforce.



To maintain and build on relationships with colleagues and other organisations.



To ensure meaningful engagement with commissioners.

I have no doubt the challenges and changing world around us will test our resilience and resolve in the coming months and years, but I look forward to the continued development of Alexander Devine and to see the impact the service makes to the most vulnerable within our community.

To the best of my knowledge the information reported in this Quality account is accurate and a fair representation of the quality of health services provided at Alexander Devine Children's Hospice Service.

Fiona Devine **Chief Executive and Co-Founder**

June 2022



In the last 12 months,
we supported

151

babies, children and young people with life-limiting and life-threatening conditions, and their families, across Berkshire and into surrounding counties.

1.2 Welcome to Alexander Devine Children's Hospice Service

Alexander Devine Children's Hospice Service is a registered charity (No. 1118947) and company limited by guarantee (No. 5757493).

We are registered as a service provider under the Health and Social Care Act 2008 to carry out regulated activity of treatment of disease, disorder and injury. We are required to register with the Care Quality Commission and the current rating is **Good**.



John and Fiona Devine from Windsor set up the charity in memory of their extraordinary little boy, Alexander, who in early 2006 sadly passed away at the age of eight from a rare brain tumour. Their personal experience, and subsequent extensive research, led them to realise that there was a vital need for a local children's hospice service with an inpatient respite facility in Berkshire.

Alexander Devine Children's Hospice Service was established in 2007 and has grown to become the key provider for children's palliative care in Berkshire. The hospice building opened in the summer of 2018 extending our service to offer community, day care and overnight respite.



Alexander Devine

Our vision & aims

We deliver palliative care to children and families through an holistic approach that meets the individual needs of each child and their family.

Our vision is to provide a service within Berkshire and into surrounding counties that will give children and families a choice of care and support from a skilled and dedicated team. We work closely with the NHS, local authorities and other services to deliver care in the community and in the hospice.

Our mission

Reaching out to every child and family who needs us, offering support and care from people who understand.

Our values



Determined

And resolute in our service to 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 judgement.



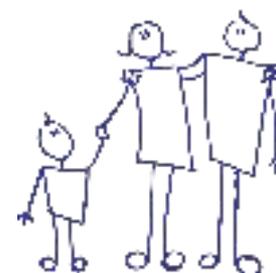
The child is at the heart of everything we do at Alexander Devine Children's Hospice Service.

Our service

Alexander Devine Children's Hospice Service provides palliative and end of life care to babies, children and young people with a life-limiting or life-threatening condition aged 0 – 19. We care for a wide range of different conditions and our staff is skilled in meeting the individual and complex needs of each individual child. The support we provide extends to the whole family from diagnosis through to bereavement. With more than 1,370 children with life-limiting conditions across Berkshire our service and support is vital.

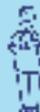
We work closely with our NHS colleagues and Children's Community Nursing teams to ensure families have timely access and seamless care.

For children who meet our eligibility criteria we provide:



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babies, children, young people and their families supported across Berkshire and surrounding counties during 2022/22.

 Community respite care	 Family support for all family members members before and into bereavement
 End of life care	 Specialist play
 Day care and overnight respite	 Sibling support
 Hydrotherapy	 Music therapy
 Symptom management	 Counselling

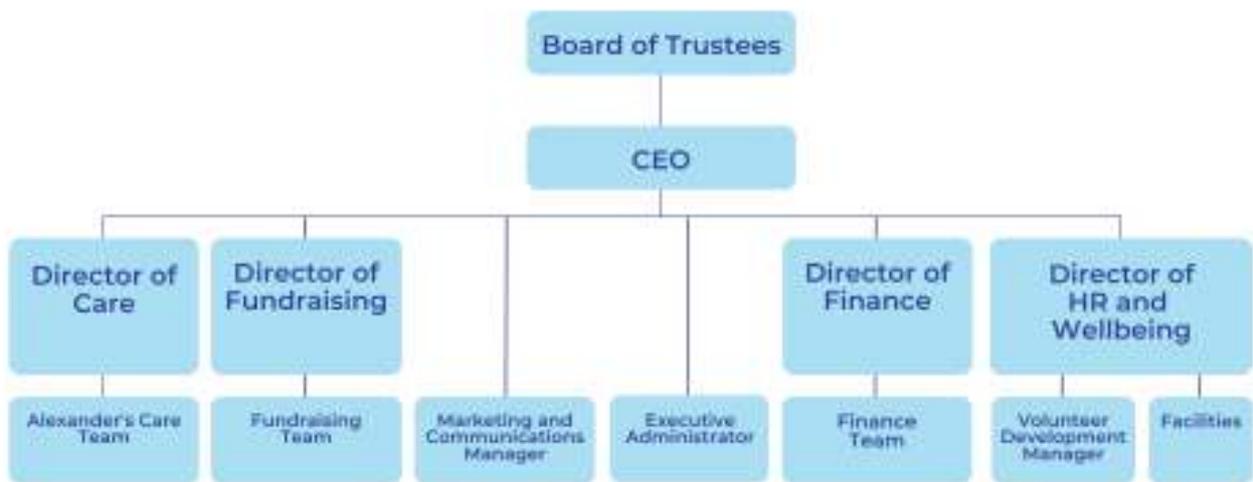
All services are free at point of delivery and are funded through a combination of fundraising activity, NHS England and local commissioning groups. Funding received from statutory sources amounts to just 22% of the total income we need to deliver our children's hospice service.



We provide Day care and overnight respite at our hospice as well as delivering care across our community in a family's home, in schools and within hospitals.



Our organisation structure



1.3 Introduction to the Quality Account

This Quality Account is Alexander Devine Children's Hospice Service's annual report to the public and other stakeholders about the quality of the services we provide.

It presents our achievements in terms of clinical excellence, effectiveness, safety and patient experience and demonstrates that our managers, clinicians and staff are all committed to providing continuous, evidence based, quality care to those children for whom we care.

It will also show that we regularly scrutinise the service we provide with a view to improving it and ensuring that the children, young people and families in our care receive the best outcomes they can. It will give a balanced view of what we are good at and what we need to improve on.

Part 2 Statement of assurance

2.1 What we have achieved in the previous financial year

We have invested in care delivery to support quality and safe care to improve the experience and outcome for babies, children and young people who require specialist palliative care.

Care is delivered by a skilled multi professional team made up of qualified nurses, clinical nurse specialists, carers, play specialists, music therapists, counsellors, pharmacist and doctors.

Of note our achievements this year include:



End of life care in the hospice.



Opening our Dolphin Suite, a dedicated space at the hospice for end of life care and bereavement support.



Reaching out to more families. We have increased our caseload of children to 151 (including 40 bereaved families).



Extended our Family Support service including holding our first remembrance event at the hospice.



Our children's hospice service continues to grow and develop reaching out to more children and their families.

2.2 Data reporting

We collect data to measure outcomes and impact.



32
referrals in the
past 12
months.



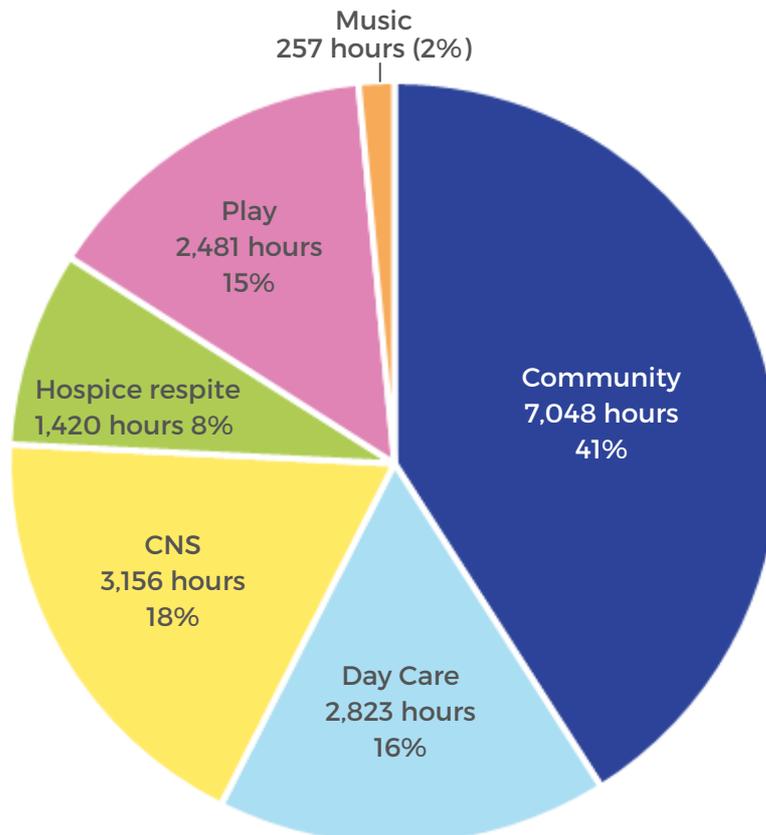
151
Caseload,
including 40
bereaved families.



2
Discharges.

Care delivered

Service area	Number of children using each service area in 2021/22
Community respite and end of life care	110
Day care	55
Clinical Nurse Specialist (CNS) service	58
Overnight hospice respite	26
Inpatient end of life	2
Bereavement suite	1
Play	53
Music	42



2.3 Participation in national audits

During the period 2021/22 no national clinical audits and no confidential enquiries covered NHS services provided by Alexander Devine Children's Hospice Service (ADCHS).

The national clinical audits and national confidential enquiries that ADCHS was eligible to participate in during 2021/22 are as follows: NONE

As a result, ADCHS participated in **zero (0%)** national clinical audits and **zero (0%)** national confidential enquiries.

2.3.1 Local audit

ADCHS has an annual audit programme to ensure that the organisation strives to continually improve the services we provide. The process ensures we monitor and measure our aims and objectives outlined in our strategic and operational plans.

ADCHS has a rolling programme of local audits and the organisation completed **18** local audits in 2021/22.

Summary of audit findings:

Audit undertaken	Actions required	Outcome and impact following actions
Ongoing monitoring of PPE practice and stock	Ongoing review of practice and availability of equipment.	To ensure safe COVID-19 working practice.
Medicines	To ensure any outstanding requirements for completion of medicines charts are dealt with promptly.	To ensure medicine charts are complete and accurate for safe medicine administration.
Information governance and data security	To review data security standards. To establish robust data systems, structure, roles and responsibilities. Revise policy notice. To implement decision log. To review consent forms to establish a process for data breach.	To maintain and improve standards for data security.
Care plans	To ensure care plans are dated and all reviews dated. To complete all boxes and N/A if nothing to record. Completion of daily observations. Completion of consent forms and FROMs	To ensure safe care.

Audit undertaken	Actions required	Outcome and impact following actions
Learning from debriefs	How to manage confidential information sharing. To further develop relationships with oncology services and to promote earlier referral. To strengthen collaborative working between and across services and agencies.	To enable learning to improve end of life care.
Medicines	To ensure accurate completion of charts including allergies, updated weight and photo.	To maintain safe medicine standards.
Risk assessment (re-audit)	Re-audit demonstrated improved completion. Identify children requiring a risk feeding assessment. To audit annually.	To maintain standards to ensure safe care.
ACP	To establish effective communication pathways for revision and updates for ACP.	To ensure current version of ACP is correct.
IPC	Ensure walls have no defects which reduce effectiveness of cleaning - repair damaged areas, the bathroom and all equipment to be kept clean.	To maintain IPC standards.
Checklists	Hydrotherapy checklist to include a signature. To complete toy cleaning checklist. Checklists to be completed on a daily basis.	To ensure checklists are complete. To maintain standards and provide evidence of compliance,
Family Reported Outcome Measures (FROMs)	Ensure NHS number recorded. Explanation to families outlining aims and purposes of FROMs. Annual audit.	Information gathered to inform service development.
Respiratory care	Completion of all breathing care plans and respiratory risk assessments. Include detailed information including the reason for ventilation and make and size of mask. All care plans must include photos of all circuits used. Every child to have a current ventilation prescription and oxygen parameters. Safety checks to be undertaken at the start of each shift. The development of an LTV workbook.	All children have current and detailed ventilation care plans and staff are aware of the standards of respiratory care.
Medicines chart	For staff to manage outstanding requests to ensure completion of medicine charts. To ensure reconciliation evidence for all medicines. Photos required for each chart.	Completed drug charts that include all necessary information.
Oxygen prescription	To ensure all children that may require oxygen have it transcribed/prescribed on their MAR chart. To ensure all oxygen care plans are in date and contain detailed information regarding oxygen delivery, which matches the MAR chart. The source of evidence, care plan and MAR chart should all match and not be contradictory. To obtain a source of evidence to support the prescription and ensure they are in date, such as a ventilation / oxygen prescription from their tertiary respiratory team.	Safe standards for prescribed oxygen.

Audit undertaken	Actions required	Outcome and impact following actions
Risks and incidents 2021	<p>To ensure appropriate learning from incidents is identified, shared and implemented.</p> <p>To ensure specific actions are followed through and communicated effectively across the team.</p> <p>As the team grows to maintain standards of incident reporting and open culture of learning from incidents.</p>	<p>To maintain accurate documentation and processes.</p>
Referral process	<p>Recording date of referral on referral form in care notes.</p> <p>Recording date and initial on all correspondence / medical letters in care notes.</p> <p>To improve initial contact with families following initial referral.</p> <p>To document reasons for delay.</p>	<p>To maintain standards set out in referral process.</p>
Record keeping audit	<p>To remind staff to date and sign all entries.</p> <p>To correct errors with a single line and initials.</p> <p>To clarify counter signatory for volunteers.</p>	<p>To ensure safe and legal record keeping.</p>
Competencies	<p>Practice Educator to meet with each nurse and carer to revisit competencies and understand their level of competence and confidence.</p> <p>Remove repetitive generic competencies from all clinical competencies such as "Do I understand my accountability within the organisation and/or my responsibility within the law?" and create just one generic clinical responsibility competency.</p> <p>Ensure that appraisal framework assesses mandatory training and competency status.</p> <p>Adapt induction paperwork and algorithm to incorporate the above changes.</p>	<p>To ensure skilled workforce confident in the delivery of care.</p>

2.4 Stakeholder views

Care Quality Commission

Alexander Devine Children's Hospice Service (ADCHS) is registered with the Care Quality Commission (CQC), which carried out an inspection in March 2022. The CQC found no areas of concern and identified some outstanding areas of practice.

Inspected and rated

Good



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 focussed 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 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.

Children and families

We regularly gain feedback from families and encourage them to share their own outcome measures.



I have found the support offered by Alexander Devine absolutely invaluable, literally a lifeline.



Couldn't do without you, absolute angels all of you.



There aren't the words to say how grateful we are for the support you provide.



Staff are very friendly and approachable! I feel safe leaving my children in their care.

External agencies and organisations

ADCCHS works consistently with other services and organisations and has received positive feedback from healthcare professionals relating to Alexander's Care Team. Professionals have said:

”

You do an amazing job advocating for inclusion of children and young people.



”

Wonderful to be in the heart of such a caring team.



”

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.

2.5 Mandatory statements / outcomes relating to NHS quality improvements

Participation in research

The number of patients receiving NHS services provided or subcontracted by ADCHS in 2021/22 that were recruited during that period to participate in research approved by a Research Ethics Committee was **nil**.

Use of Commissioning for Quality Improvement and Innovation (CQUIN) payment framework

ADCHS income was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework because ADCHS does not use any of the NHS standard contracts and is therefore not eligible to negotiate a CQUIN scheme.

CQC special reviews and investigations

ADCHS has not participated in any special reviews or investigations by the Care Quality Commission in this period.

Clinical coding error rate

ADCHS was not subject to the Payment by Results clinical coding audit during 2020/21 by the Audit Commission.

Data quality

ADCHS has attained the standards required in the NHS Data Security and Protection Toolkit 2021.

Learning from deaths

ADCHS supports children at the end of life. We work in partnership with the local CCN teams to provide care in the community to offer choice for families in place of care and place of death. We provide on call and symptom management advice and with the support from the ADCHS CNS and Doctor we can provide symptom management and advance care plans for all patients.

In the last year we have supported 13 children at the end of life. All deaths are reported to CDOP where they are subject to case review.

Following the death of a child a debrief is held with other services. The opportunity for reflection and learning is a vital part of the ongoing care we provide.

Key learnings in the last year have been:

- To support effective use of shared documentation.
- To support training and competence of staff in end of life care.
- To develop shared protocols for the management of medicines.
- To develop a process to support the effective transfer of children from one organisation to another.

2.6 Priorities for improvement 2022/23

Our priorities for improvement are detailed in our strategic and quality and improvement plan. These priorities aim to further improve upon the safety, experiences and outcomes for children and families cared for by ADCHS.

The three key priorities have been informed by:

- Our strategic aims and objectives.
- Our annual programme of audit and learning from recommendations and actions.
- Feedback from stakeholders through our annual satisfaction survey and through our Family Reported Outcome Measures (FROMs).

 <p>Priority 1</p> <p>To extend and develop our workforce</p> <p>The priority will be achieved by:</p> <ul style="list-style-type: none"> • Developing creative recruitment strategies. • Identifying and providing opportunities for career development. • Supporting the training and education of Alexander's Care Team. 	 <p>Priority 2</p> <p>To maintain and build on relationships with colleagues and other organisations</p> <p>The priority will be achieved by:</p> <ul style="list-style-type: none"> • Working in partnership with CCN teams. • Further developing the proposal for a Managed Clinical Network. • To promote children's palliative care across Berkshire and into surrounding counties. 	 <p>Priority 3</p> <p>To ensure meaningful engagement with commissioners</p> <p>The priority will be achieved by:</p> <ul style="list-style-type: none"> • Building on relationships with CCGs. • Engaging with ICS/ICB.
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2.7 Additional quality indicators

In the absence of nationally agreed indicators for children's palliative care, ADCHS monitors:

- Complaints and concerns.
- Incidents and accidents.
- Family Reported Outcome Measures (FROMs).



97% of families said that Alexander Devine always has a positive impact on their family's life.

Part 3 Review of Quality Performance

ADCHS processes a range of quality assurance activities to determine standards of care including data collection, audit and user feedback. Quality of care is assessed and monitored in the following areas: patient safety, effectiveness and experience.

Progress of 2020/21 priorities for improvement

- **To improve availability and access of services**

We have continued to extend services offering choice to families in place of care. We have provided end of life care in the hospice and step down for children from hospital to home. We have developed the family support programme and held our first Time of Remembrance. In addition, we have started a parents' group to provide a social and network opportunity for parents.

- **To strengthen collaborative working**

We work closely with the children's community nurses across Berkshire to support children and families in the community.

Providing quality end of life care requires an integrated approach and we are engaged in ongoing discussions to develop a managed clinical network for the region.

- **To maintain the skills and competence of our staff**

We have completed a competency review of all care staff and established an annual training programme to support statutory and mandatory training and development of clinical skills. The appointment of a Practice Educator has provided valuable clinical skills training for staff and development of staff competence and confidence.

3.1 Patient safety

Patient safety is of paramount importance, and we ensure a range of activities are undertaken to protect children and staff.

These include:

- Monitoring our risks and incidents.
- Maintaining staff knowledge and skills.
- Monitoring of clinical alerts.

Risks and incidents 2021/22

ADCHS has a positive and proactive approach to risk and incident reporting and management. All staff are encouraged to engage with risk and incident reporting in the context of a learning culture. Incidents are categorised and analysed on an annual basis for patterns and trends. Learning from incidents directly informs service improvement.

Safeguarding reports 0

There have been no safeguarding reports in this period.

IPC notifications 0

There have been no IPC notifications in this period.

Clinical risk assessments are undertaken for all children receiving care.

Analysis of incidents 2021/22

Patterns and trends	No.	Comments and further information	Learning and actions
Medicines	7	2 potential errors. 5 errors without harm.	<ul style="list-style-type: none"> To revisit process of administration and transcribing. To review storage of medicines.
Clinical care	3	Administration of oxygen. Dislodged gastrostomy. A child suffering a seizure in the hydrotherapy pool.	<ul style="list-style-type: none"> Review of oxygen risk assessment. Awareness of gastrostomy and feeding tubes on moving. Review of PEEPs.
Safeguarding	2	2 incidents related to challenging behaviour of a child.	<ul style="list-style-type: none"> To review holding and restraint policies and the management of challenging behaviour.
Health and safety / equipment	6	Incidents related to equipment.	<ul style="list-style-type: none"> To ensure safe use and maintenance of all equipment.
Administrative (Care)	1	1 GDPR concern.	<ul style="list-style-type: none"> Review of consent process.
Trips and falls	2	Child fell in playground. Child fell to the floor following absent episode.	<ul style="list-style-type: none"> To ensure safety of children when using outdoor equipment. Review of safety and management of children with seizures.

Staff knowledge and skills

ADCHS has invested in the learning and development of our staff to ensure competence and confidence in practice. Staff participate in mandatory training and specific skills development. In addition to internal training, staff are also supported to undertake single training days or workshops to extend their learning.

Number of staff completing mandatory training and courses

Topic	Number of staff required to complete	Completed	%
Fire	22	22	100%
Moving and handling	22	22	100%
Safeguarding	22	22	100%
Infection Prevention and Control	22	22	100%
Paediatric intermediate life support	22	22	100%
Medicines	22	21	95%
Record keeping	22	21	95%
Health and safety	22	22	100%
Equality and diversity	22	22	100%
Consent	22	22	100%
Trachy/Vent	18	18	100%

ADCHS also provided external training and presented at regional and national conferences.

Additional training courses for staff have included:

- End of life care.
- Catheterisation.

3.2 Effectiveness

A key priority for ADCHS is the delivery of effective care. Clinical effectiveness is not just about monitoring and measuring care or identifying risks. It is also about being proactive to identify and manage improvement to further develop the service. All these areas of clinical effectiveness are incorporated into our Clinical Governance Framework.

We maintain clinical effectiveness through:

- A rigorous quality improvement plan.
- The regular review of action from audits.
- Supporting effective leadership across the organisation.
- Maintaining networks of communication and joint working with other organisations and agencies.

3.3 Patient experience

The monitoring of compliments and complaints is central to ADCHS, to how we learn and develop the service. Complaints are formally investigated and discussed at Clinical committee, SMT and with the Board of Trustees.

We received one complaint in the last period.

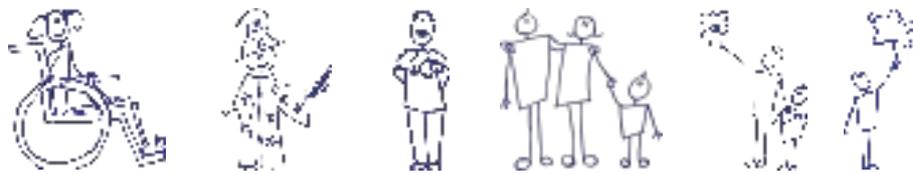
Comments and compliments are captured in various ways, with a particular focus on gaining parents' perspective on their own outcome measures (FROMs – Family Reported Outcome Measures). These are used to support individual care and to inform service development.

3.4 Lead commissioners

ADCHS provides a service across Berkshire. This Quality Account has been sent to the Clinical Commissioning Groups for West Berkshire and Frimley to provide opportunity for comment and statement.



**Alexander
Devine**
Children's Hospice
Service



Reaching out to **every** child
and family that needs us

www.alexanderdevine.org



Reg. Charity No 1118947

