Alexander Devine Children's Hospice Service





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Accountability statement

This annual Quality Account for Alexander Devine Children's Hospice Service (ADCHS) is compiled from data April 2023 - March 2024. 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 Founder and CEO
Andrew Rice Director of Finance

Warren King Director of HR and Wellbeing

Anne Bajorek Director of Fundraising

Julie Hughes Lead for Quality and Governance

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 Accounts are 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 ICB and the Care Quality Commission.

Part 1 Statement on quality

1.1 Statement of assurance from the CEO



On behalf of the Trustees and Senior Management Team I am pleased to present the annual Alexander Devine Children's Hospice Service (ADCHS) Quality Account for the year ended March 31st 2024.

For the Third Sector as a whole, it has proven to be another challenging year. With hard work, determination, commitment, and a philosophy that follows our values and culture, yet again the team at Alexander Devine has risen to every challenge and obstacle placed in front of them and I am extremely proud of all that has been achieved by our staff team, volunteers, supporters, and donors. Thus enabling us to support 203 families.

Referrals have increased by 30% with over a third of new referrals receiving endof-life care. In the last year there has been a 62% increase in the children we have supported at end-of-life.

Whilst recruitment challenges remain, we have extended our service providing more inpatient day care, hydrotherapy sessions, physiotherapy, play sessions, family support and overnight respite.

Our ambition remains to increase capacity to reach more children and families and respond to the increasing demand for care. Over the next year our attention continues to focus on financial sustainability to grow the service and meet our strategic aims.

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 ADCHS.

Fiona Devine

Fiona Devine Chief Executive and Founder June 2024

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. The growing team and partnership working has enabled us to offer flexible and responsive end-of-life care.



Alexander Devine

Our vision and aims

We deliver palliative care to children and families through a 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 in partnership with the NHS, local authorities, and other services in delivering our care.

Our mission

Reaching out to every child and family who needs us

Our values



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 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 (ADCHS) provides palliative and end-of-life care to children and young people with a life-limiting or life-threatening condition aged 0 - 19.

We care for children with a wide range of different conditions and our staff are skilled to meet the individual and complex needs of each individual child. The support we provide extends to the whole family from diagnosis, at end-of-life through to bereavement.

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



babies, children, young people and their families supported across Berkshire and surrounding counties during 2023/24



We are currently supporting 203 families, including 80 bereaved families.

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 17% of the total income we need to deliver our children's hospice service.



hours of care delivered

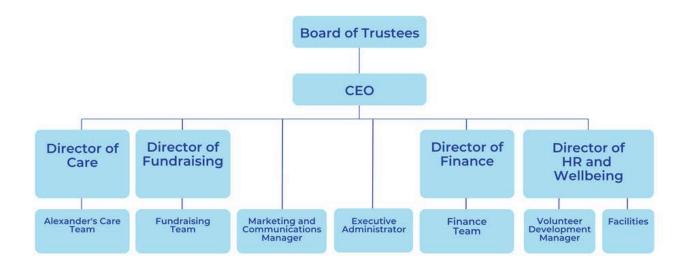


family events including sibling days, fun days and remembrance events



families had access to our specialist care for the first time

Our organisation structure



1.3 Introduction to the Quality Account

This Quality Account is the ADCHS 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 we care for.

It will also show that we regularly scrutinise the service we provide with a view to learning and improvement 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

The organisation continues to grow and develop reaching out to more children and their families.

In the last year we have invested further in the workforce and extended the service offer. There have been some notable achievements:

- Our caseload has continued to increase with **56 referrals** in the last year, and we have successfully delivered on all aspects of service.
- We have maintained all areas of quality and governance, which is integral to the
 development of the service. We have established further policies and standard
 operating procedures to underpin best practice including the implementation of
 the PSIRF (Patient Safety Incident Response Framework).
- We have delivered more end-of-life care both in the hospice and community.
- There have been some significant appointments to drive forward our strategic aims including a Transition Lead and the appointment of a Level 3 Consultant. The medical post has enhanced care delivery and provided greater opportunity for partnership working.
- The appointment last year of a physiotherapist and development of a physiotherapy service has been highly valued by families.
- We have further developed the digital platform, data and technology including the implementation of Vantage (data management solutions). We are laying the foundations for improved digital technology to improve the services we offer.
- We continue to invest in our staff through training, professional development and supervision.
- The development of the Managed Clinical Network has progressed with an operational model to underpin service delivery and targets to support a pilot in the next 12 months.
- We have contributed widely to regional and national networks to support improvement in children's palliative care.

2.2 Data reporting

The service collects data to measure outcomes and impact.



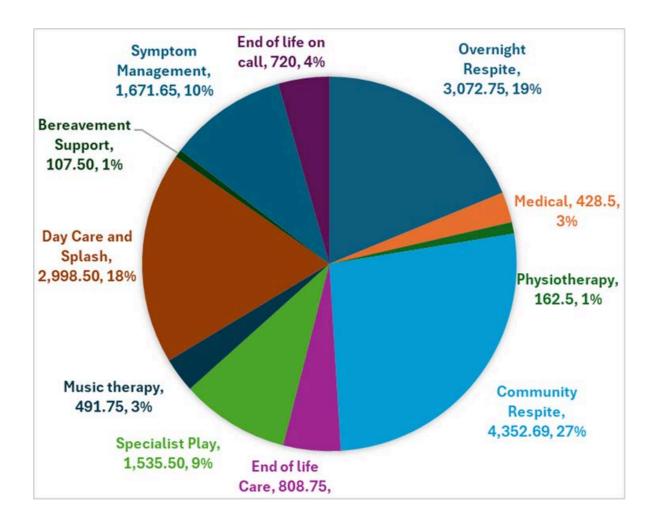




Care delivered

Service area	Number of children using each service area in 2022/23
Community respite	74
Day care	67
Overnight respite	37
End of life care in the community and in the hospice	13
Bereavement suite	5
Play specialist support	22
Music therapy	16
Sibling support	37
Physiotherapy	50
Family support/counselling	27

Care hours delivered



Total care hours delivered: 16,350.09

Note: data includes contact time with children and families and excludes admin, travel and training.

2.3 Participation in national audits

During the period 2023/24, no national clinical audits and no confidential enquiries covered NHS services provided by ADCHS.

The national clinical audits and national confidential enquiries that ADCHS was eligible to participate in during 2022/23 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 **20** local audits in 2023/24.

Summary of audit findings:

Audit undertaken	Actions required	Outcome and impact following actions
Medicine charts	 All transcriptions must be signed off by a doctor/pharmacist in a timely way Revised standard operating procedure (SOP) and policy & share changes with care staff Ensure children's weights are taken and recorded Accurate detail to be recorded on front of chart 	To ensure safe standards of medicine administration and compliance with regulation and policy To re-audit in 6 months
Security toolkit	 Maintaining effective management and administration to ensure sustainable operational practice To ensure we listen and respond to the needs of individual families Maintaining accurate communication to ensure collaborative working across services To promote shared documentation 	To maintain compliance with data security standards

Audit undertaken	Actions required	Outcome and impact following actions
Debriefs	 Maintaining effective management and administration to ensure sustainable operational practice To ensure we listen and respond to the needs of individual families Maintaining accurate communication to ensure collaborative working across services To promote shared documentation 	To maintain opportunities for debrief following the death of a child
Risk assessments	 To ensure all appropriate risk assessments are complete and in date Risk assessments to be reviewed and signed off annually Accurate index sheet to be completed To re-audit annually 	All children have current and accurate risk assessments and staff are aware of their responsibility in managing risk assessments for all children
Epilepsy seizure plan	 To ensure most recent seizure plan is incorporated in care plan Accurate descriptions of seizure presentation and what to do If an external seizure plan exists, the AD plan is not needed and should be removed To ensure seizure medication is correctly transcribed and matches seizure plan To re-audit in 12 months 	Safe seizure management
ReSPECT (Frimley PEoLC)	To ensure conversations are held with families about what matters most to them	Accurate recording of ReSPECT

Audit undertaken	Actions required	Outcome and impact following actions
Competency	 To ensure compliance with competency reviews To ensure annual reviews use the recent version 	All staff to maintain competence in clinical care as appropriate
Statutory and mandatory training (care team)	 Identified areas of training to be incorporated in to training programme 	All staff are compliant with statutory and mandatory training requirements
S11 (Safeguarding, External audit)	 Specific supervision for the safeguarding lead Level 4 training for the safeguarding lead 	The designated lead for safeguarding is qualified and supported in the role
Infection Prevention and Control (External audit)	 To display a poster outlining the process for inoculation injury/splash To ensure accurate records of environmental cleaning schedules Regular mattress cover cleaning That all rooms are free from clutter and inappropriate items Correct disposal of gloves Aprons to be stored in containers Review of sink and pipe covering All sinks are free from limescale All hand towels are wall mounted and hand cream is available in dispensers Sharps bins to be sealed and dated when full To cover vacuum cleaners 	To maintain compliance with all regulatory requirements for infection control

Audit undertaken	Actions required	Outcome and impact following actions
Lone Worker	 Ensuring lone working induction and training is undertaken with all new members of staff Lone working training update for all staff following audit. Immediate reminder to all staff and volunteers of their responsibility to be familiar with policies and procedures Send information to members of staff about location of panic alarms and what happens when they are triggered. Ensure buddy system is restarted by members of staff attending lone visits 	All staff to be aware of and follow lone working practice
Front Sheet of care plans	 To ensure all front sheets are completed accurately and in full To review whether front sheets are meaningful as part of the move to Electronic healthcare records (EHCR) 	
Respiratory	Focus on ensuring appropriate risk assessments across the organisation	All staff to be aware of and compliant with health and safety measure. To ensure the organisation is compliant with health and safety regulations
Health and Safety (External Audit)	 Focus on ensuring appropriate risk assessments across the organisation 	All staff to be aware of and compliant with health and safety measure. To ensure the organisation is compliant with health and safety regulations
Controlled Drugs	 First audit to review processes in place to manage Controlled Drugs 	To re-audit in 6 months

Audit undertaken	Actions required	Outcome and impact following actions
Incidents	 31 incidents in 2023 with the following actions identified: To review and understand the purpose and reporting of incidents to appropriate personnel and clinical groups To ensure appropriate learning from incidents is identified, shared and implemented and outcomes reported and that the process is completed To ensure specific actions are followed through and communicated effectively across the team As the team grows to maintain standards of incident reporting and just culture of learning from incidents To review incident form and implement Vantage Module for incident reporting 	To maintain oversight of learning from audits and integrate into improvement plan to ensure quality care
Oxygen	 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. 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 or consultant. The source of evidence, care plan and MAR chart should all match To re-audit in 12 months 	To ensure all staff are trained in oxygen delivery and maintain safe Oxygen practice

Audit undertaken	Actions required	Outcome and impact following actions
Communication	 Look into which communication tools can be used within Alexander Devine to support CYP needs Make a business plan for the potential of having the widget programme which will enable the creation of Symbols, Buttons, PECS, Easy reads, social stories, and adaptable care plans. As well as any staff training to increase confidence when communicating with children using Augmentative and alternative communication (AAC) or to support children to use AAC if this would suit their needs. To update any communication equipment in house and have it readily available for children visiting the hospice. To support children case by case if they require any extra support with communication To adapt communication care plan to give a full insight to that child's communication needs and how to use any aids they have in place either at home or school 	To understand the communication needs of the children and young people and ensure the processes and tools are embedded in practice to support this
Referral Process	 Ensure all data is entered into The Care Database Document reasons for delay or no contact To re-audit in 6 months 	To understand the communication needs of the children and young people and ensure the processes and tools are embedded in practice to support this
Caseload Review	Review of caseload to ensure all children and young people accepted and receiving the service meet the eligibility criteria for specialist palliative care.	That the service maintains its aims and purpose.

2.4 Stakeholder views

Children and families

We regularly gain feedback from families and encourage them to share their own outcome measures. In March 2024 we sought feedback on families' experience of the service. 18 parents responded to the survey.



"I can't isolate just one thing or person, but I just want to share how much we appreciate all the support, kindness and genuine care we receive from you all. You are integral in a journey we never expected to take and I don't know how we would navigate it without your support. Thank you all"





"More of the things you already offer. I know it's staffdependent, but in an ideal world there would be more respite, more splash sessions, more music therapy etc. Support with getting ready after splash sessions - some staff offer help, others don't."

External agencies and organisations

ADCHS works consistently with other services and organisations and has received positive feedback from stakeholders relating to the service.

Stakeholders said:



Thank you for the support that your team provided to our patient who died at home on Saturday morning. The joint working enabled her to die at home as her parents wishes, and although there were challenges along the way as there always are, the teams worked well together. We would not be able to do this without collaborative working and your expertise.

Students said:

The team were all very welcoming. They took time to show me around and made me feel very welcome and part of the team for the day. The children who came for a day session were all so lovely and a pleasure to look after/care for. I feel that you must feel very privileged to be part of these children's lives and have fun with them







I just wanted to email to thank you for making the time for me to have a shadow day yesterday. I had such a great experience and it definitely confirmed that I would really like to do some hospice work in the future.

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 2023/24 that were recruited during that period to participate in research approved by a Research Ethics Committee was nil.

ADCHS continues to support the CPOS study at Kings College London. Our role is to identify children and families as potential participants and to introduce them to the study.

The ADCHS Clinical Governance Committee gave consent to participate in 4 other research studies exploring parent and staff experiences of children's palliative care.

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

The number of patients receiving NHS services provided or subcontracted by ADCHS in 2023/24 that were recruited during that period to participate in research approved by a Research Ethics Committee was nil.

ADCHS continues to support the CPOS study at Kings College London. Our role is to identify children and families as potential participants and to introduce them to the studv.

The ADCHS Clinical Governance Committee gave consent to participate in 4 other research studies exploring parent and staff experiences of children's palliative care.

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 2023/24 by the Audit Commission.

Data quality

ADCHS has attained the standards required in the NHS Data Security and Protection Toolkit 2023.

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 considerations and learning in the last year have been:

- In depth discussions to ensure sustainable workforce capacity and capability
- The challenges of accessing medicines
- How to best manage debriefs for staff in relation to support, learning and improvements in care
- Cross organisational discussions to improve pathways of care for children after death

2.6 Priorities for improvement 2024/25

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
- Analysis of our risks and incidents
- Feedback from stakeholders through our annual satisfaction survey and through our Family Reported Outcome Measures (FROM's)



Priority 1

To address health inequalities to ensure families have access to the service they need.

The priority will be achieved by:

- To engage with families, children and young people to better understand their perspective
- To develop our family support services and the family support programme
- To enhance the work with our multifaith communities



Priority 2

To invest in data and technology to ensure we have the right information to inform service development.

The priority will be achieved by:

- To review the operation of The Care Database and management of data
- To implement Vantage across the organisation
- To link with the Southeast Digital Network forum



Priority 3

To strengthen positive working relationships with colleagues across our Network.

The priority will be achieved by:

- To enhance partnership working with NHS colleagues
- To support the implementation of the Managed Clinical Network

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).



I don't think the team at Alexander Devine will ever know the extent to which they make my life so much easier. They are all truly amazing and I don't know what I would do without them. Sarah, Franké's Mum

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 2022/23 priorities for improvement

- To further extend our service offer to reach more children and families
- By growing the workforce, we have been able to increase our service provision across all settings, community, day care, inpatient and in reach to hospital. The team have worked together to prioritise end-of-life care where staff are required to respond rapidly and flexibly. This is achieved with a high standard of skill and compassion.
- To develop a stronger medical model for Alexander Devine and across Berkshire We have appointed a level 3 consultant in children's palliative care in partnership with the local NHS Trust. This new appointment has strengthened both the collaboration with the NHS and network of medical professionals. This new role has enhanced the symptom management service supporting children and young people with complex needs.
- To ensure a comprehensive transition pathway to adult services

The appointment of a transition lead has enabled further development of the transition pathway. We have engaged a young person as an advocate and representative to achieve this work. The team have worked closely with adult colleagues to ensure consistent and coherent care for young people.

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 2023/24

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 2023/24

Patterns and trends	Number	Comments / further information	Learning and actions
Medicines	11	The majority of incidents were related to prescription errors and reconciliation / transcribing errors. Most were intercepted with 2 administration errors (one without harm, one with harm)	 To review process of administration and transcribing For all medicines incidents to be discussed at medicines management and learning identified and implemented
Clinical care	4	Themes of respiratory and enteral care	To maintain staff competence and confidence in all areas of respiratory care
Safeguarding	1	Communication supporting a placement student	To ensure effective avenues of communication with universities
Health and safety / equipment	5	Minor incidents related to equipment and maintenance Workforce incident	To ensure safe use and maintenance of all equipment
Administrative (Care)	4	Records management	To ensure robust administrative processes, trained staff and adherence to principles of GDPR
Trips and falls	6	Minor incidents with minor injury	 To maintain effective reporting and risk assessment processes

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	Percentage
Fire Safety	31	30 (1 on mat leave)	97%
Moving and handling	31	31	100%
Safeguarding	31 Level 3 1 Level 2	30 (1 new) 1 (1 new)	97%
Infection prevention and control	31	30 (1 mat leave)	97%
Paediatric basic life support	31	29(1 mat leave, 1 new)	93%
Medicines	26	24 (1 mat leave, 1 new)	92%
Information governance	31	19	61%
Health and safety	31	31	100%
Equality and diversity	31	29 (1 mat leave)	93%

Topic	Number of staff required to complete	Completed	Percentage
Mental capacity and Dols	30	29	97%
GDPR	31	30 (1 mat leave)	97%
Lone working	31	30(1 new)	97%
Risk management	31	29 (1 mat leave, 1 new)	93%
Conflict resolution	31	31	100%

Additional training courses for staff have included:

- Long term ventilation
- Epilepsy
- Advanced communication skills

Of note one member of staff has completed the Nursing Associate training.

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

Members of staff have written for publication.

Bennett HE, Duke S, Richardson A Parent experience of advance care planning: reconstructing meaning – grounded theory. BMJ Support Palliative Care 2023 0:1–11. doi:10.1136/spcare-2023-004348

Student Placements

We have engaged with universities and supported 16 student placements.

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.
- In the past year we have implemented the new Patient Safety Incident Framework (PSIRF) with an identified action plan to ensure it is embedded in practice

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, Senior Management Team and with the Board of Trustees.

We have received 2 complaint/concern in the last year which related to issues around communication. As a result of these incidents, we have reviewed processes for admission and supported staff in learning and handling of conflict management.

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. ADCHS has received 54 recorded compliments throughout the year from families and external professionals.

3.4 Lead commissioners

ADCHS provides a service across Berkshire. This Quality Account has been sent to the Integrated Care Boards for BOB (Buckinghamshire, Oxfordshire and Berkshire West) and Frimley to provide the opportunity for comment and statement.





Reaching out to every child and family that needs us

www.alexanderdevine.org



Reg. Charity No 1118947



