Alexander Devine Children's Hospice Service



QUALITY ACCOUNT 2022/23

> 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 2022 and March 2023. 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
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 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 Integrated Care Board 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 2023.

In 2022 we marked a significant milestone as a charity by reaching our 15 year anniversary. It gave us the opportunity to reflect on all that has been achieved and to plan for our future growth in response to the increasing demand for our services.

Fiona Devine, CEO and Co-Founder se

Over the course of the year, our charity has experienced steady growth and expansion in all aspects of service delivery in order to provide the best possible care and support.

The expert clinical care we provide has been further underpinned by the appointment of a Practice Educator. It has driven a full review of training for care staff to ensure we sustain a high level of competence and skills.

In extending the work we do to provide emotional and practical support for families, we have expanded our Family support team and, amongst other things, introduced regular parent groups to help facilitate families to connect with each other. We continue to strengthen our relationships with local faith leaders from across our community and we are working closely with families and professionals to establish a comprehensive transition pathway for young people in our care that will need adult services.

Our partnerships with our local Integrated Care Boards have helped us to continue to invest in our children's hospice service. However, we remain heavily reliant on our local community for their ongoing support. The friendship and commitment shown by local residents and businesses is deeply appreciated and the vital work we do would not be possible without them.



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



I look forward to the ongoing development of our children's hospice service.

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 2023



In the last 12 months, we supported

165+

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.

Our vision and 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 in partnership with the NHS, local authorities, and other services in delivering our care.



Alexander Devine

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 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 a wide range of different conditions and our staff are skilled to meet the individual and complex needs of each child. The support we provide extends to the whole family from diagnosis through to bereavement. With more than 1,200 children with life-limiting conditions across Berkshire our service and support are 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:



babies, children, young people and their families supported across Berkshire and surrounding counties during 2022/23



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.



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 we care for.

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

The charity continues to grow and develop reaching out to more children and their families. We have invested in care delivery to support quality and safe care to improve the experience and outcome for children, young people and their families 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, physiotherapist, family support worker, counsellors, pharmacist and doctors. The team is also supported by care volunteers.

Of note our achievements this year include:



Successful growth of our Alexander's Care Team with the recruitment of Alexander's Nurses, Alexander's Carers, Practice Educator and Family Support Worker.



An increase in referrals and growing caseload of children, young people and their families.



We have supported the first child for compassionate extubation at the hospice.

We provided more symptom management and end-of-life care to children and their families both in the community and in 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.



Care delivered

Service area	Number of children using each service area in 2022/23
Community respite and Day care	132
Symptom management	76
Overnight respite	27
Inpatient end of life	8
Bereavement suite	1
Specialist play	52
Music therapy	42
Sibling support	23
Counselling	18 parents



Total hours Care hours: 17,456

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

2.3 Participation in national audits

During the period 2022/23, 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 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 **25** local audits in 2022/23.

Summary of audit findings:

Audit undertaken	Actions required	Outcome and impact following actions
MAR charts	 To ensure accurate completion of charts including allergies, updated weight and photo 	Medicines group to monitor and review continued regular audit
Security toolkit	 To sustain vigilance regarding data security To explore procurement for penetration testing 	To maintain compliance with data security standards
Debriefs	 How to manage confidential information sharing To further develop relationships with oncology services and to promote early referral To strengthen collaborative working between and across services and agencies 	To enable learning to improve end of life care

Audit undertaken	Actions required	Outcome and impact following actions
S11	 Royal Borough Windsor Maidenhead (RBWM) Safeguarding partnership to ensure Alexander Devine's organisations details are provided to the WAM Local Authority Designated Officer (LADO) and add to the distribution list for any safeguarding updates/virtual training events 	To maintain standards and compliance with safeguarding practice
Review of children requiring double up visits	• Nearly 50% of children on the caseload requiring a second member of staff to support a community visit. Reasons for 2 staff include; personal care, moving and handling, more than one affected child, safeguarding, social support	Established criteria and rationale developed to support allocation of care and staffing
Risk assessments	 77 sets of care plans reviewed to determine completion of risk assessments 90% of risk assessments complete To develop risk assessment for gastrostomy 	To ensure accurate completion of risk assessments for safe care
Medicines	 To maintain accurate up to date information and prescriptions 	To comply with safe medicines management
Lone working	 For all staff to be responsible for understanding principles of lone working practice To restart the buddy system Training for staff To review SOP 	To ensure safe working practice for all staff

Audit undertaken	Actions required	Outcome and impact following actions
Respiratory	 To maintain accurate care plans To ensure correct version of care plans is used To develop a front sheet All care plans should be supported with a photo A separate oxygen audit to be completed to maintain safety checks 	To ensure high quality respiratory care and compliance with evidence-based practice
Died before accepted	 To monitor and review timely referral to the service 	To ensure timely access to palliative and end of life care
Travel	• To monitor and review expenditure and hours for travel	To ensure cost effectiveness of the service
Front sheet	 For all outstanding front sheets to be completed To ensure accurate information and confirm with families To complete all boxes To reaudit annually 	To maintain standards of record keeping
Cross reference of incidents to child's notes	 To ensure accurate reporting of identified child and ref no for audit purposes on the incident form All incidents reported in child's notes and to include ref no All health and safety incidents reported to Estates 	To ensure accurate reporting and recording of incidents
Epilepsy	 To create an AD epilepsy care plan for children who do not have a specific plan To develop an epilepsy SOP for safe practice to ensure all medicines transcribed accurately match those on the plan 	To maintain standards of safe practice for epilepsy

Audit undertaken	Actions required	Outcome and impact following actions
Checklists	 Reminder to care team staff that the checklists need completing on a daily basis, even if there is no day care/overnight respite. To determine if a signature is required Reminder to care team staff that the hydrotherapy checklist needs completing on every hydrotherapy session. Re-audit in 6 months 	Completion of checklists and maintain accurate records
IPC	• Compliant across most sections with only 7 non-compliant items including splashback at kitchen sink, and hand cream to be wall mounted and management of ant infestation	To ensure compliance with IPC standards and maintain safe IPC practice
Controlled drugs storage	 Patients own CD's require new page per drug When returning medicines to patient the balance should read Zero CD book to be kept in CD cupboard do not need to record midazolam as CD or Oramorph 	To maintain compliance with standards for CD storage
Ethnicity, faith and language	• To ensure accurate recording of faith, language and ethnicity on referral form to introduce a 'My faith' care plan as part of 'all about me'	To maintain individualised person- centred care
АСР	 Different versions of ACP - to be consistent with using most current version To ensure we have system in place for up- to-date copies Regular attendance at ACP clinic 	To maintain accurate ACP for all children that require them

Audit undertaken	Actions required	Outcome and impact following actions
Oxygen prescribed on Medicine Administration Record (MAR) chart	 All children that require Oxygen have it prescribed /transcribed on their MAR chart All Oxygen care plans to be in date and include detailed information regarding oxygen delivery, which matches the MAR chart To obtain a source of evidence to support prescription 	Accurate records for Oxygen prescription
Risks and incidents 2022	 To ensure appropriate learning from incidents is identified, shared and implemented To ensure specific actions are followed through and communicated effectively across the team As the team grows to maintain standards of incident reporting and open culture of learning from incidents 	To maintain accurate documentation and processes
Referral process	 30 files reviewed to measure standards and key performance indicators To record all contact / correspondence regarding referral and to improve initial contact with families following acceptance to the service 	All families to receive timely care following acceptance to the service
After school visits	 To gather data of the number of children receiving after school visits - 23 	To monitor and review access to after school visits against other services received

Audit undertaken	Actions required	Outcome and impact following actions
Record keeping	 20 sets of notes measured against standards for record keeping - to revisit risk and record keeping training To accurately record entries including time and to sign against errors made 	To maintain safe record keeping
Training	 To have one training database that has all training on, an attendance training register must be done at all training, so completion of the database can be updated asap following the training. The registers could be given to admin for uploading. To review the statutory and mandatory training requirements for all staff To follow up the process and reporting with iHasco A comparison of iHasco with another learning platform Completion of outstanding training To ensure all staff are aware of which training is required and when. The induction and learning handbook will be updated and sent to all staff To implement the new training programme over the course of 2023 	All staff complete the required mandatory training Records are complete A clear educational strategy for the organisation Access and delivery of required training on an annual basis

2.4 Stakeholder views

Children and families

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



We are so grateful to Alexander Devine for the amazing support you offer our daughter and family! Everyone is so welcoming and atmosphere so positive and friendly. Thank you so very much

External agencies and organisations

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

Stakeholders have said:



I would like to extend my gratitude and appreciation for all that you do for children and their families at the hospice. Your dedication and commitment to providing the highest level of care is truly commendable and inspiring. Students have said:



99

The team made sure I was always supported and given great opportunities when I could, allowed me to be my best at all times.

2.5 Mandatory statements / outcomes relating to NHS quality improvements

Participation in research

The number of patients receiving NHS services provided or subcontracted by Alexander Devine Children's Hospice Service (ADCHS) in 2022/23 that were recruited during that period to participate in research approved by a Research Ethics Committee was **nil**.

ADCHS has been accepted as a site for the King's College London CPOS study. Our role is to identify children and families as potential participants and to introduce them to the study.

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 2022/23 by the Audit Commission.

Data quality

ADCHS has attained the standards required in the NHS Data Security and Protection Toolkit 2022.

Learning from deaths

ADCHS supports children at the end of life. We work in partnership with the local community children's nursing 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 support from the ADCHS Clinical Nurse Specialists and Doctor, we can provide symptom management and advance care plans for all patients.

In the last year we have supported 17 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:

- 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 the use of shared documents.
- To ensure consistency in staff competence in particular in relation to medicines administration in the community.

2.6 Priorities for improvement 2023/24

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).



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).



88% 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 2021/22 priorities for improvement

• To extend and develop the workforce

By growing the workforce, we have been able to extend the service offer to provide greater choice to families across community and inpatient services. The appointment of a Practice Educator has enabled a full review of training for care staff, and we have developed a comprehensive annual training programme. This has ensured we sustain the competence and skills of staff.

• To maintain and build on relationships with colleagues and other organisations We have worked in partnership with our CCN colleagues and have further developed shared documentation and operational policies for practice. We have progressed the work of the Managed Clinical Network and have appointed a project manager to lead this service development.

• To ensure meaningful engagement with commissioners

We have continued to work collaboratively with colleagues and contributed to local and national Networks to promote children's palliative care. In particular, to ensure the voice of children and families at the wider palliative and end of life care (PEoLC) forums within the Integrated Care Boards (ICB).

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 2022/23

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 2022/23

Patterns and trends	Number	Comments / further information	Learning and actions
Medicines	16	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	5	Gastrostomy, seizure and respiratory incidents	 Review seizure protocols Record of disconnecting and reconnecting gastrostomy tubes Review of patient safety reporting and risk process
Safeguarding	0		
Health and safety / equipment	4	Major incidents related to equipment	 To ensure safe use and maintenance of all equipment
Administrative (Care)	3	Review of data processing	 Understanding of data breach processes
Trips and falls	2		 To maintain comprehensive care plans

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.

Торіс	Number of staff required to complete	Completed	Percentage
Fire	29	27 (2 on mat leave)	93%
Fire evacuation	27	25 (2 on mat leave)	93%
Moving and handling	29	28	97%
Safeguarding	5 Level 2	4 (1 new)	80%
	28 Level 3	23 (1 mat leave and 4 new)	82%
Infection prevention and control	29	27 (1 mat leave)	93%
Paediatric basic life support	29	22 (1 mat leave, 3 new)	76%
Medicines	26	22 (2 mat leave, 2 new)	85%
Information governance	29	17 (2 new)	59%
Health and safety	29	28 (1 new)	9 7 %
Equality and diversity	29	20 (1 new)	69 %

Number of staff completing mandatory training and courses

Торіс	Number of staff required to complete	Completed	Percentage
Mental capacity and Dols	28	28	100%
CDPR	29	26 (1 new, 1 mat leave)	90%
Lone working	29	27 (1 mat leave)	93%
Risk management	29	28 (1 mat leave)	97%
Conflict resolution	29	24	83%

Additional training courses for staff have included:

- Long term ventilation
- Epilepsy
- Advanced communication skills
- Loss and grief

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. BMY supportive and palliative care (2022) doi: 10.1136/bmjspcare-2022-003544

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 no complaints 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 Integrated Care Boards for BOB (Buckinghamshire, Oxfordshire and Berkshire West) and Frimley to provide the opportunity for comment and statement.

