

Alexander Devine Children's Hospice Service



QUALITY ACCOUNT
2019/2020



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 2019 and March 2020. 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.

John Devine	ADCHS Co-founder and Chair of Trustees
Fiona Devine	Co-founder and CEO
Helen Bennett	Director of Care
Andrew Rice	Director of Finance
Warren King	Director of HR and Wellbeing
Harjit Bola	Fundraising Manager
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 CCGs and the Care Quality Commission.

Part 1 Statement on quality

1.1 Statement of assurance from the CEO

I am delighted to present the annual Alexander Devine Children's Hospice Service (ADCHS) Quality Account for the year ended March 31st 2020.

On behalf of the Board of Trustees and Senior Management Team at ADCHS, I would like to thank all our staff and volunteers for their commitment and achievements over the past year. Our thanks is even more pertinent now than ever before, given the extraordinary times we found ourselves in.



Our service is free of charge to families and includes community care, day care within our purpose built hospice, symptom management, end of life care, bereavement support, sibling support and a range of therapies comprising of hydrotherapy, music therapy and counselling. The quality, safety and outcomes for children and families remains of paramount importance to ADCHS. The Trustees and Senior Management Team continue to provide quality assurance and oversight on all matters relating to quality care.

In these unparalleled times of Covid-19 we know that the financial challenges we face are and will continue to be immense. Our funding opportunities have been significantly reduced and the only certainty is the uncertain. The immediate impact has been the cancellation of most of our fundraising events and activities. Our normal income streams from community and corporate fundraising have also been greatly impacted.

With the rising demand for our services and care needs becoming ever more complex thanks to medical advances, it has resulted in a requirement for greater staffing levels and expertise. One of the ways we have addressed this is through the development of our Clinical Nurse Specialist service over the past year. It has been hugely beneficial for our families and well received by our colleagues in the health care sector. In order to reach out to more children and families, which is one of our identified priorities, we have also had a successful recruitment drive to grow our Alexander's Care team. This is something we are proud to have achieved especially as there is a recognised national shortage of nurses.

We are entirely grateful for the support of our local communities and our partnership with the statutory sector and we know in the coming year how important this localised support is going to be.

Over the next year our focus will be on:

- Extending our care service
- Developing quality assessment and symptom management as part of our core service.
- Maintaining the skills and competence of our staff
- Identifying new funding opportunities

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
Chief Executive and Co-founder

July 2020

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).

It is 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. It is required to register with the Care Quality Commission and the current registration status is Good.

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 its service to offer community and day care.



Our 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 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 through to bereavement. With more than 600 children with life-limiting conditions across Berkshire our service and support is vital.

We work closely with our NHS colleagues within an integrated model. Our Alexander's Care Team works closely with the Children's Community Nursing team to ensure families have knowledge and access to our service in a timely way. Our model also supports positive and valuable communication between all those involved in the care of the child.

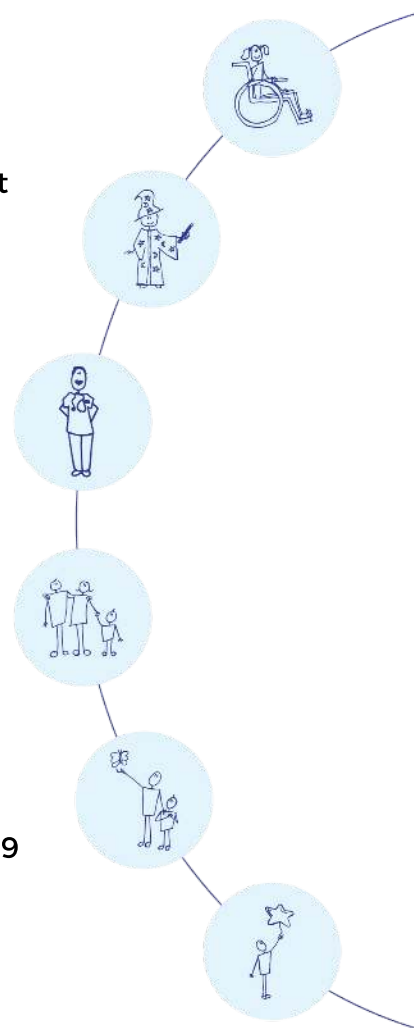
During 2019 - 2020, ADCHS provided services to around 129 children and young people and their families from across Berkshire.

For children who meet our eligibility criteria we provide:

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

Care is delivered in the community, in families own homes and schools, within hospitals and as part of our day care service at the hospice.

All services delivered by ADCHS are free at point of delivery. They are funded through a combination of fundraising activity and NHS England. Funding received from statutory sources amounts to 4.5% of the total income. These arrangements mean that all services delivered by us are only partly funded by the NHS.



1.3 Introduction to our Quality Account

This Quality Account is 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 treat. 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 organisation 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.

In particular:



We have increased our caseload of children to

129

(including 28 bereaved families) providing ongoing home care support



We continue to deliver end of life care in partnership with our NHS colleagues, demonstrating joint working and offering choice to families



We have continued to expand our day care services including hydrotherapy



We have commenced a clinical nurse specialist service focused on the provision of advance clinical assessment and symptom management

2.2 Data

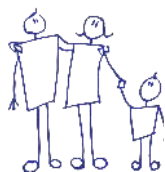
(Reporting on children 0-15 and 16 or over)

The service collects data to measure outcomes and impact.



27

Number of referrals in the past 12 months



129

Caseload, including 28 bereaved families



4

Discharges

Care delivered	Number of hours 2019/2020
Direct community care hours delivered (exluding travel, admin and training)	4,443
Day Care	2,790
Hydrotherapy	598
Clinical nurse specialist support	566
Play specialist support	1,455

2.3 Audit

(Reporting on children 0-15 and 16 or over)

During the period 2019/20 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 2019/20 are as follows: NONE

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

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 11 local audits in 2019/20.

Summary of audit findings:

Audit undertaken	Actions required	Outcome following actions
Drug charts	<ul style="list-style-type: none">To ensure accuracy and completion of transcription on all drug charts	To maintain a regular programme of audits for medicines management every three months
Fast track referrals	<ul style="list-style-type: none">To ensure accurate records and inclusion of dates of correspondence	To be able to measure standards of response
IPC	<ul style="list-style-type: none">To maintain good standards of IPC	To ensure compliance of IPC regulations
Declined referrals	<ul style="list-style-type: none">To record reasons for decline	To be able to better understand requests for support
Referrals process	<ul style="list-style-type: none">Accurate recording of dates of correspondence	To maintain standards of timely communication with professionals and families
Travel	<ul style="list-style-type: none">To determine travel costs and hours spent travelling as a baseline for future service delivery	To better understand all elements of service delivery and hidden costs

Audit undertaken	Actions required	Outcome following actions
Training	<ul style="list-style-type: none"> To ensure compliance of mandatory training 	To ensure appropriate access to training including iHASCO and face to face
Risks and incidents 2019	<ul style="list-style-type: none"> To ensure risk matrix is completed for every incident To review evidence of appropriate reporting of incidents to relevant committees To review appropriate escalation of incidents to risk register 	To maintain accurate documentation and processes with ongoing review
Baseline observations recorded	<ul style="list-style-type: none"> To ensure baseline observations are completed as near to acceptance to the service as appropriate 	To maintain accurate baseline observations
Advance care plans	<ul style="list-style-type: none"> To gather all missing advance care plans 	To re-audit in a month
Re audit of advance care plans and symptom management plans	<ul style="list-style-type: none"> To ensure all advance care plans are reviewed and up to date and filed electronically and a hard copy in the child's notes 	To work with the coordinator for advance care plans to ensure timely reviews

2.4 Stakeholder views

Children and families

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



”

For most of her life, the Alexander Devine team has been there not just K, but the whole family.

I don't think I can put into words what they mean to me and the difference they make to my family. They give us the extra support that we need. They are always there when I need them, even during our frequent hospital visits the team would come and give me a break and be there with her.



”

I don't know what we would have done without having Alexander Devine's nurses to help us. These angels helped to take so much of our stress away. Not only advising how to take care of her but working with Consultants, GP, Physios and pharmacies. So many things I was struggling with, but they helped in so many ways to resolve things. I am so grateful from the bottom of my heart and can't thank them enough. They care with their heart and soul and make the 'Devine' difference in people's lives.



”

I feel so honoured to know you. You do such a marvellous job, please pass onto your manager the feedback that you are a real asset to the hospice and all the time, effort and work you do for those children who are unwell and continue to support the families is priceless.

External agencies and organisations

ADCHS works consistently with other services and organisations and has received positive feedback from healthcare professionals relating to our Alexander's Care Team.

”

Thank you so much for inviting us to the Multi-Faith Open Day this afternoon. The children's hospice service is truly impressive and it was an extremely valuable meeting.

”

Thank you so much for a really inspiring evening yesterday. It felt a real privilege to hear the story of the hospice and to see around. You are certainly doing amazing things.

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 2019/20 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 CQC in this period.

Clinical coding error rate

ADCHS was not subject to the Payment by Results clinical coding audit during 2018/2019 by the Audit Commission

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 are able to provide symptom management and advance care plans for all patients.

In the last year we have supported six 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 learning in the last year has been:

- To ensure we facilitate and provide opportunity for debriefs following the death of a child
- To review and monitor opportunities for bereavement support

HR and whistleblowing

ADCHS employs a Director of Human Resources and Wellbeing who supports all issues related to staff management and our workplace culture. This appointment has been significant in contributing greatly to the overall charity direction. He is responsible for HR Policies and procedures and is able to provide impartial support on issues related to HR.

We have a 'Whistleblowing Policy' that details how staff can raise concerns with their manager, a member of the Senior Management Team or with the Chief Executive. The Policy states that staff raising concerns will be treated confidentially where practicable and without fear of repercussions. Concerns may also be raised anonymously. The Whistleblowing Policy was approved by Trustees in September 2015 and most recently reviewed in April 2019.

ADCHS will not tolerate victimisation, harassment, bullying or any other detrimental treatment of any worker who has made a disclosure under this Policy. Complaints about such behaviour will be dealt with under the Disciplinary Procedure. Any concerns raised will be thoroughly investigated and appropriate action will be taken. Feedback will be provided at the conclusion of the process to the person raising the concern.

2.6 Priorities for improvement 2020

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)

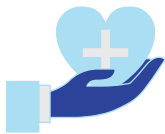
Priority 1 To develop quality assessment and symptom management



The priority will be achieved by:

- Consolidating the CNS service
- Improving operational practice of symptom management plans and advance care planning for families
- Holding quarterly MDT meetings

Priority 2 To ensure effective implementation of a medical model for the service



The priority will be achieved by:

- Establishing partnership working and secure working relationships with medical colleagues
- Establishing a contract for pharmacy service

Priority 3 To ensure we reach out to all the diverse populations across Berkshire and surrounding counties offering a fair and equitable service



The priority will be achieved by:

- Strengthening networks with multi faith communities
- Continuing to network with professionals, organisations and families to raise awareness of our service
- Working with fundraising and communications teams to strengthen communication to families and supporters

2.7 Additional quality indicators

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

- Complaints and concerns
- Incidents and accidents
- Family reported outcome measures (FROMs)

Part 3 Review of Quality Performance

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

Risks and incidents 2019

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.

There were zero (0) resuscitation or notifiable controlled drug incidents and zero (0) notifiable clinical incidents during 2019/2020.

Analysis of incidents 2019/20

Patterns and Trends	No	Comments / further information	Learning / actions
Medicines	1	1 error without harm	<ul style="list-style-type: none"> • More time to be allocated to double check medicines charts • A review of admission process
Clinical care	1	Communication and support of staff in the community	<ul style="list-style-type: none"> • To consider support of staff and how they escalate concerns
Safeguarding	1	Relating to reporting of bruising and reporting processes	<ul style="list-style-type: none"> • An important reminder for all staff to deliver sensitive care in regards to moving and handling of children with complex needs and to accurately record and report changes to care • All forms should be signed and dated to ensure we maintain an accurate chronology of events
Health and safety	5	<p>2 IPC</p> <p>2 GDPR concerns</p> <p>1 staff accident / injury</p>	<ul style="list-style-type: none"> • To develop a procedure to address the actions when a member of staff or visitor have been in contact with families prior to recognition of having an infectious disease • Addendum made to the IPC policy / SOP • PPE to be used when showering children to include footwear • Extra care to be taken when sending out information with identifiable information, to ensure that potentially confidential information is not seen • Accurate recording of personal information • Accurate reporting and investigation
Administrative (Care)	1	Transport issue	<ul style="list-style-type: none"> • Review of administration procedures for children's transport
Equipment	1	Failure of hoist	<ul style="list-style-type: none"> • Appropriate reporting and maintenance of equipment

Staff knowledge and skills

ADCHS has invested in the learning and development of 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.

Topic	Number of staff required to complete	Completed	Compliance %
Medicines	15	15	100%
Moving and handling	15	15	100%
Safeguarding	15	14	93%
IPC	15	15	100%
Paediatric intermediate life support	15	10	66% Training delayed due to Covid-19
Medicines	12	12	100%
Record keeping	15	13	86%
Health and safety	15	15	100%
Equality and diversity	15	15	100%
Consent	15	12	85%
Trachy/Vent	12	11	91%

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

Additional training courses for staff have included:

- Advanced assessment and symptom management
- Advanced communication skills
- Children's palliative care

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 by:

- 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 Trustees.

We received zero 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 Clinical Commissioning Groups for West Berkshire and Frimley to provide opportunity for comment and statement.



**Alexander
Devine**
Children's Hospice
Service



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and family that needs us

www.alexanderdevine.org



Reg. Charity No 1118947