



## Alexander Devine Children's Hospice Service Quality Accounts (2018)



### Mission Statement

'Reaching out to every child and their family'

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## **Accountability Statement**

This annual Quality Account for Alexander Devine Children's Hospice Service (ADCHS) is compiled from data April 2018 – March 2019. 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

Claire Coldicott – Director of Fundraising

Warren King – Director of HR and Wellbeing

Julie Hughes – Lead for Quality and Governance

## **Introduction**

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 CCG's and the Care Quality Commission.

## **Part 1 – Statement on Quality**

### **1.1 Statement of Assurance from the CEO – a statement summarising the quality of our services provided**

I am delighted to present the annual Alexander Devine Children's Hospice Service (ADCHS) Quality Account for the year ended March 31<sup>st</sup> 2019.

On behalf of myself and the Board of Trustees, I would like to thank all of our staff and volunteers for their achievements over the past year.

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.

The hospice has continued to provide specialist palliative care and quality respite care to more children and families and remains financially sound, thanks to generous support from our local communities and our partnerships with the statutory sector.

We have achieved most of our planned priorities over the past year however the challenge of recruiting to nursing posts has affected our capacity to extend our service delivery. The national shortage of children's nurses continues to impact on our ability to provide as much care as we would like and has impacted on outcomes for families. The reduction in NHS children's community and continuing care has all affected outcomes for families.

In the coming year our focus is on:

- Extending our care service
- To develop quality assessment and symptom management as part of our core service.
- To maintain the skills and competence of our staff

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

May 2019

## **1.2 Welcome to Alexander Devine**

Alexander Devine Children's Hospice Service (ADCHS) is a registered charity: number 1118947 and company limited by guarantee: number 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 our service to offer community and day care.

### **Introduction to the Quality accounts**

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.

### **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 Alexanders Nurse works directly in 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 2018 – 19 ADCHS provided services to children and young people and their families from across Berkshire.

For children who meet our eligibility criteria we provide:

- Respite Care
- End of life care
- Symptom management
- Family support for all family members before and into bereavement
- Specialist play

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

All services delivered by Alexander Devine 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 2.5% of the total income. These arrangements mean that all services delivered by us are only partly funded by the NHS.

## **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 121 (including 22 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 opened the hospice and are providing day care services including hydrotherapy

- We have started our volunteer counselling programme and launched our care volunteer programme

## **2.2 Data reporting on children 0-15 and 16 or over**

The service collects data to measure outcomes and impact.

No of referrals in past 12 months – 27

Caseload – 121 of which 22 are bereaved families

Discharges – 2

Direct care hours delivered – 3450 hours

Play contact visits – 722

Day care visits -217 (from June 2018)

## **2.3 Participation in National Audits**

During the period 2018/19 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 2018 - 19 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 continually to improve the services we provide. The process ensures we monitor and measure our aims and objectives outlined in our strategic and operational plans.

#### Local Audits

ADCHS has a rolling programme of local audits and the organisation completed

12 local audits in 2018 -19.

Summary of audit findings:

<b>Audit undertaken</b>	<b>Actions required</b>	<b>Outcome following actions</b>
Drug Chart	<ul style="list-style-type: none"> <li>• Ensure accuracy and completion of transcription on all drug charts;</li> <li>• To improve communication with CCN regarding completing 2 drug charts for CCN records and AD records;</li> <li>• To ensure accuracy of PRN medication prescriptions</li> </ul>	To maintain a regular programme of audits for medicines management; to re-audit in 3 months
Referral Process	<ul style="list-style-type: none"> <li>• Recording of date on referral form</li> <li>• Recording of correspondence and medical letters;</li> <li>• To improve contact with families following initial referral;</li> <li>• to improve response time of initial assessment following clinical committee; document reasons for delay</li> </ul>	Continued attention to the standards set for the referral process to ensure a timely and positive experience for families
Consent forms	<ul style="list-style-type: none"> <li>• To ensure all consent forms are completed in appropriate time frame; are updated annually; to document why a form is missing and actions taken</li> </ul>	To maintain compliance with new GDPR
Care notes	<ul style="list-style-type: none"> <li>• To ensure all staff are aware of their responsibility for effective record keeping and maintaining standards of record keeping</li> </ul>	To maintain accurate and timely record keeping
Drug charts (Re-audit)	<ul style="list-style-type: none"> <li>• To ensure every drug chart has the child's photo and recent weight</li> </ul>	Improved measures demonstrated from Audit undertaken in July; to re-audit photos in 3 months
Safeguarding S11	<ul style="list-style-type: none"> <li>• Comprehensive audit using the guidance from LSCB</li> <li>• Secure communication and set up NHS email;</li> </ul>	To ensure ongoing safety of children, family and staff

	<ul style="list-style-type: none"> <li>To ensure staff awareness of reporting process</li> </ul>	
Competency review	<ul style="list-style-type: none"> <li>Review will inform the training programme for 2019 to support core skills and confidence of staff;</li> <li>To ensure regular clinical updates;</li> <li>To demonstrate evidence of up to date documentation and verification of competence</li> </ul>	To invest in training of staff to ensure knowledge and skills
Risks and incidents 2018	<ul style="list-style-type: none"> <li>Particular attention to transcribing and prescribing</li> <li>To ensure accurate safeguarding procedures and knowledge of reporting process</li> <li>To ensure risk matrix is completed</li> <li>To identify learning from actions for each incident</li> </ul>	To maintain an open culture of reporting incidents and a robust process for investigating with identified actions and learning
Advance care plans and symptom management plans	<ul style="list-style-type: none"> <li>To ensure all ACP's are reviewed and up to date and filed electronically and a hard copy in the child's notes</li> </ul>	To maintain accurate documentation and processes with advance care planning documentation
FROM's	<ul style="list-style-type: none"> <li>To complete initial assessment for every new referral including parents expectations and outcomes</li> </ul>	To continue to collate expectations and outcomes to inform service development
Health and Safety	<ul style="list-style-type: none"> <li>To remind all staff of their responsibility to undertake the ihasco H&amp;S training and to review and maintain all processes of H&amp;S</li> </ul>	To ensure all staff are familiar with and abide by the H & S policy
Competency review	<ul style="list-style-type: none"> <li>Attention to the theory and practical sign off for competencies</li> </ul>	To maintain up to date documentation

## 2.4 Stakeholder views – What others say about us

### External Agencies and organisations

ADCHS works consistently with other services and organisations and has received positive feedback from health care professionals relating to our care team.

*'I just wanted to thank you all for being such great colleagues to work with, and how supportive you are to the children and families'.* (Nurse colleague)

### Children and families

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

One family shared feedback:

*'I just wanted to send an e-mail to say a huge thank you to the Alexander Devine team for the support we have had over the last couple of months. We have had a particularly challenging few months and without the support of the Alexander Devine team, we would have struggled even more. It made such a huge difference being able to have some respite, support in the hospital setting and day care service. Having nurses who completely understand him and are experienced in working with him makes such an enormous difference.'*

*All of the Alexander Devine team are so brilliant with him. They are great at keeping him clinically and physically safe, whilst also ensuring he has a brilliant time. He has had a tough six months and there have been points where he has been very frightened and confused, with lots of hospital stays, so it is lovely to see him have such a great time.'*

## **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 2018/19 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

Alexander Devine Children's Hospice Service 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 Doctor we are able to provide symptom management and advance care plans for all patients.

In the last year we have supported 6 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 better procedures and training in place regarding the care of the body in the community.
- Improved MDT collaborative working about transporting a child following death.

### HR and whistleblowing

In the past year ADCHS have employed a Director of Human Resources and Well being 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.

Alexander Devine Children's Hospice Service 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 2019/20**

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 (FROM's)

### **Priority 1 Extending our care service**

The priority will be achieved by

- Reaching out to all of the diverse populations across Berkshire
- Positive working relationships with all Berkshire's NHS Foundation Trusts.
- Meaningful engagement with CCG's across Berkshire.

### **Priority 2 To develop quality assessment and symptom management as part of our core service.**

The priority will be achieved by:

- The appointment of a clinical nurse specialist
- Building relationships with colleagues to deliver symptom management and end of life care

- For all children to have a symptom management plan when needed

**Priority 3** To maintain the skills and competence of our staff

The priority will be achieved by:

- Investing in the mandatory training and clinical skills programme
- Supporting staff with protected time to engage in professional development
- Rolling out specific clinical skills development of tracheostomy and ventilation care

**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 (FROM's)

### 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.

#### 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 2018

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 2018/19

Patterns and Trends		Comments / further information	Learning / actions
Medicines	3	2 Error without harm 1 no harm	<ul style="list-style-type: none"> <li>• Supporting parents with accurate prescription and administration of medicines</li> <li>• To ensure best practice (and knowledge) in the principles of medicines management for nurses</li> </ul>

<b>Clinical Care</b>	<b>2</b>	2 clinical incidents – 1 relating to the transporting of a poorly child by staff and the 2 <sup>nd</sup> regarding to a delayed feed	<ul style="list-style-type: none"> <li>• Introduction of PEWs to support assessment and decision making</li> </ul>
<b>Safeguarding</b>	<b>2</b>	Relating to reporting of bruising and reporting processes	<ul style="list-style-type: none"> <li>• Review of our safeguarding procedures in particular in relation to bruising protocols</li> <li>• To ensure accurate and timely reporting</li> </ul>
<b>Accidents (Slips, trips and falls)</b>	<b>2</b>	No Injury's sustained	<ul style="list-style-type: none"> <li>• Knowledge of all staff in relation to reporting and recording accidents</li> </ul>
<b>Key learning and recommendations</b>			
<ol style="list-style-type: none"> <li>1. Continued attention to medicines management in particular transcribing and prescribing</li> <li>2. To ensure accurate Safeguarding procedures and knowledge of reporting process</li> <li>3. To ensure Risk matrix is completed for every incident</li> <li>4. To identify learning from actions for each incident</li> </ol>			

### 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.

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

### **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 have 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.