



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 is compiled from data April 2017 – March 2018. 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 Chair of Trustees

Fiona Devine – CEO

Andrew Rice – Director of Finance

Claire Coldicott – Director of Fundraising

Helen Bennett – Director of Care

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

I am delighted to present Alexander Devine Children's Hospice Service first Quality Account.

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. Despite the current economic climate, the hospice has continued to provide specialist palliative 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.

Since the start of the service ADCHS has had a culture of continuous quality improvement in which opportunities to identify risk and improve care delivery are robustly acted on. The safety and care experience for children and families is our utmost concern and our governance structures ensure we attend to all areas of quality.

The Care Quality Commission have assessed the service as Good and that we are fully compliant with national standards of care.

We continually strive to develop care services and in the past year we have provided ongoing care to children and families across Berkshire. We have invested in the new Hospice building and our priorities for 2018 are to extend service delivery to be able to offer day care and inpatient services.

Fiona Devine
Chief Executive and Co Founder
May 2018

1.2 Welcome to Alexander Devine

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. It currently offers community support to children with a life limiting condition. The hospice building is due to open in the summer of 2018 and will provide day care and inpatient services, this will offer further choice to families. At the heart of our service we aim to provide quality family centred care.

1.3 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 people 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 limited or life threatened 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 2017 – 18 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.

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% 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 109 (including 25 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 built the new hospice and it is equipped and fit for purpose

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 – 109 of which 25 are bereaved families

Discharges – 1

Direct care hours delivered – 3010.95

Play contact visits – 461

2.3 Clinical Audit

During the period ADCHS participated in no (0%) national clinical audits and no (0%) confidential enquiries of the national clinical audits and national confidential enquiries it was eligible to participate in.

The national clinical audits and national confidential enquiries that ADCHS was eligible to participate in during 2017 - 18 are as follows: NONE

2.3.1 Local and In house Audit

ADCHS has an annual audit programme to ensure that the organisation strives continually to improve the services we provide. The process enables opportunities for learning and service development.

Local Audits

The organisation completed the baseline assessment for NICE Guidance End of life care for children and Infants.

In House Audits

The reports of 5 local clinical audits were reviewed by ADCHS in 2017 -18 and the following actions taken.

- **Blended diets care planning and risk assessment documentation**

Action taken: To add a section on the risk assessment to cover allergies and cultural/religious dietary preferences. To consider whether we can get a copy of dietitian letters/nutrition plans where appropriate.

- **Respiratory care documentation**

Action taken: To record the level of respiratory care.

To review the tracheostomy and ventilation care plans to include specific detail. To develop a humidification care plan. To ensure types of tape are recorded in the care plan. To ensure size of mask is recorded. To ensure all children have observation charts as required. To record extra settings and alarm settings. To ensure all children have benchmark observations so we are aware of their normal parameters. To develop clinical risk form for Ventilatory care. To develop clinical risk forms for Tracheostomy care. To ensure Mandatory training in place for respiratory care. To review current children and care plans and introduce risk assessments by end of February. To re audit in 6 months following the introduction of new care plans & risk

assessment and ensure regular ongoing audits as part of the audit programme. The development of a respiratory care policy and SOP.

- **Risks and Incidents**

Action taken: Continued attention to medicines management in particular transcribing and prescribing. To maintain good working relationships with effective communication between other services and families. To ensure effective care planning and risk assessment for all relevant areas of clinical care.

- **Medicines Management, compliance of photo and weight**

Action taken: Not all medicines charts have a photograph or weight of the child – all staff were actioned to ensure every child's medicines chart has an up to date photo and current weight.

- **Initial assessment and FROM's form**

Action taken: To complete initial assessment and FROM's for every new referral accepted to the caseload. To re- audit in 6 months. Where the referral is for play a Home Risk Assessment must still be carried out.

2.4 Stakeholder views – What others say about us

CQC

We are required to register our services with the Care Quality Commission (CQC). Our inspection report in February 2017 resulted in an overall rating of Good.

The CQC stated:

'We saw children and young people received care and support in a personalised way. Complex medical needs were managed well by staff who were trained to deliver specialised care and support. Children and young people said they felt safe with staff.'

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.

A message from the local school nurse following a visit from our play specialist.

I just wanted to say a huge Thankyou for being at her medical yesterday, she is clearly so relaxed in your company and distracting with the Ipad was so helpful.

This was the first time I have been in a medical with her and she has been able to talk to the Dr and say where the pain is and what it is like.

Invaluable!

Everyone involved with her has nothing but praise for the work you are doing with this lovely young lady, you are making such a difference and I have no doubt you being there allowed her to feel comfortable enough to talk. Thank you

Children and families

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

One family shared feedback:

'You are a star, thank you so much for all your care and support. Words can't describe how much we appreciate what you do'

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 2017/18 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.

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.

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 maintain effective communication between all those involved in the care of a child at the end of life.
- To ensure each child has an up to date Symptom management plan and any changes are shared in a timely way.
- The value of regular MDT meetings focused on the individual child to support care of the child and family.
- Engaging with the CDOP process through representation at the LSCB regarding explained but unexpected deaths.

2.6 Priorities for improvement 2018 – 19 - identified achievements for coming year

The three key priorities have been informed by:

- Our strategic aims and objectives
- Our annual programme of Audit and learning from recommendations and actions

Priority 1 Ensure quality of care and the needs of children are met safely by competent and skilled staff

The priority will be achieved by:

- Maintaining a robust audit programme to improve quality care
- To review the competence framework to ensure it meets the needs of staff and the complex needs of children on the caseload
- Ensure the continued competence of staff so they are skilled and confident to support the complexity of care required
- Identify new areas of knowledge and skill required to care for children and their families

Priority 2 Improved risk assessment to ensure a consistent approach and robust management of risk

The priority will be achieved by:

- Ensuring all policies and procedures are accurate and provide information that is meaningful to support best practice
- To ensure all children have appropriate clinical risk assessments to manage their care
- To maintain a robust risk register and learn from identified actions

Priority 3 Development of the service by extending to day care and inpatient services

The priority will be achieved by:

- To gain approval from CQC for our extended registration
- To develop systems to support the opening of day care
- To offer a programme of activities for children and families

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:

Analysis of Risks and Incidents 2017

Patterns and Trends		Comments / further information	Learning / actions
Medicines	3	2 Error without harm 1 Intercepted error	Attention to accurate communication in care planning and assessment Attention to accurate transcribing/prescribing
Clinical Care	4	Two clinical incidents regarding respiratory care prompted a comprehensive review of care plans and risk assessments A further 2 clinical incidents related to the care of enteral nutrition and equipment	Three audits were undertaken to review respiratory care plans and risks assessments. This supported a significant development and learning opportunity to ensure effective care. To ensure care plans are up to date and maintain good standards of incident reporting to ensure continual evaluation of and improvements in care.
Key learning and recommendations			
<ol style="list-style-type: none"> 1. Continued attention to medicines management in particular transcribing and prescribing 2. To maintain good working relationships with effective communication between other services and families 3. To ensure effective care planning and risk assessment for all relevant areas of clinical care 			

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

Staff participate in a range of training and education activities to ensure they are skilled and competent to meet the individual care needs of the child. There is an annual training programme that covers mandatory training and clinical skills development.

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:

- 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.
- Involvement in wider clinical projects – the development of the Long Term Ventilation pathway

3.3 Patient Experience

Compliments Complaints and Concerns

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 1 complaint in this period. This related to communication approach. A full investigation was undertaken the complaint was not upheld. The investigation however led to refreshed focus on effective communication with parents.

Comments and compliments are also captured 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.
