

# Alexander Devine Children's Hospice Service



QUALITY ACCOUNT  
2020/21



Reaching out to every child  
and family that needs us

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# Accountability statement

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This annual Quality Account for Alexander Devine Children's Hospice Service (ADCHS) is compiled from data between April 2020 and March 2021. 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	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	Director of Fundraising
Julie Hughes	Lead for Quality and Governance

# Quality Account statement

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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 Clinical Commissioning Groups 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 2021.

I would like to acknowledge the unprecedented times we find ourselves in and the impact and challenges the pandemic has had upon the families we support, staff, volunteers and our supporters.

In this period of time we have adapted our services to reflect the needs of the children that we care for, in the safest possible way and to ensure continued quality of care. We have

also been responsive to the needs of the charity, providing good leadership to safeguard our sustainability.

None of this would have been possible without the support of the Board of Trustees, Senior Management Team, the whole staff group at ADCHS, our volunteers and supporters.

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.

We have been incredibly proud to maintain our service throughout the pandemic and know how much this has meant to our families through the feedback they have given to us.

We have continued to provide specialist palliative care and quality respite care to more children and families than ever before and remain financially sound, thanks to generous support from our local communities and our partnerships with the statutory sector.



**100% of families told us that of the adapted care provision they experienced during the pandemic was either very helpful or helpful to them**



Despite COVID-19 we have achieved our planned opening of overnight respite at the hospice, having successfully completed a pilot programme.

We appreciate the hard work ahead but are determined to grow upon our successes and to continue the development of our service for the benefit of the extraordinary children for whom we care. The exceptional and dedicated team at ADCHS, along with our wonderful volunteers and supporters will be instrumental in helping us to achieve these objectives.

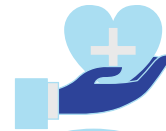
Over the next year our focus will be on the financial stability of the charity and our three key care priorities:



To improve availability and access of our services



To strengthen collaborative working across our region



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**

**June 2021**



We have continued to provide specialist palliative care and quality respite care to more children and families than ever before

## 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 our current registration status 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 8 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 a hospice 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, and now offers Community, Day care and Overnight respite.

### Our vision & 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 surrounding counties that will give children and families a choice of care and support from a skilled and dedicated team. We work closely in partnership with the NHS, local authorities and other services in delivering our care.

### Our mission

**Reaching out to every child and family who needs us, offering support and care from people who understand**

# Our values



## **Determined**

And resolute in our service to to all those that need us.



## **Empowering**

To enable whoever comes into contact with us, the power and courage to make decisions, ask questions or simply to be.



## **Valuing others**

We value you and each other, because we are all unique and special in our own way.



## **Integrity**

To be consistent in our ethos and values, principles and actions. To always behave and hold the integrity of our charity as core.



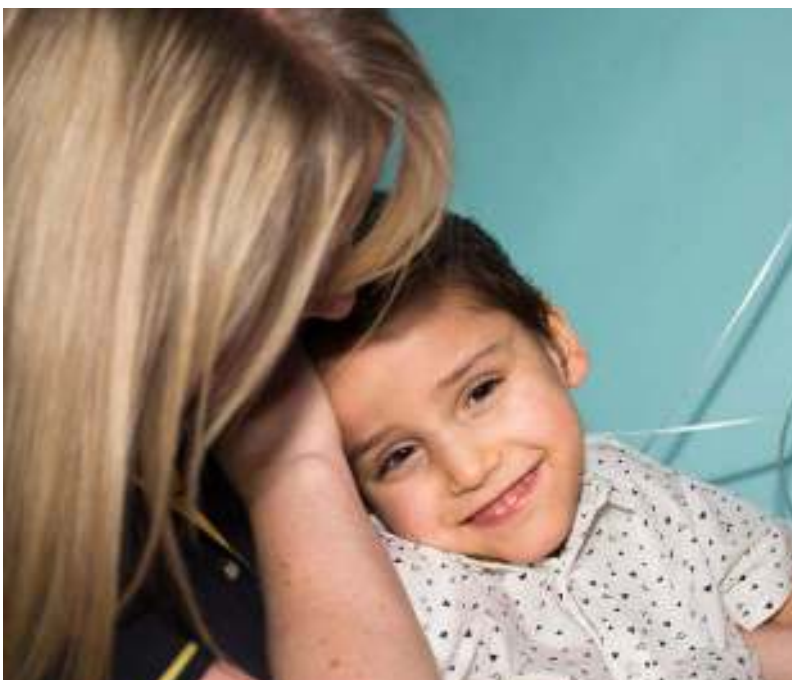
## **Nurture**

To provide an environment of protection, support, growth and encouragement.



## **Empathy**

To know that we will provide a place of safety for everyone to express their feelings, thoughts and emotions, without judgement.



The child is at the heart of everything we do at Alexander Devine Children's Hospice Service



# Our service

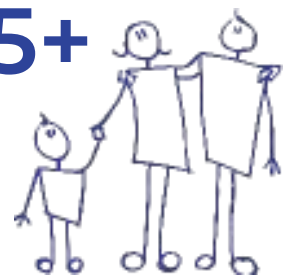
Alexander Devine Children's Hospice Service (ADCHS) provides palliative and end of life care to children and young people with a life-limiting or life-threatening condition aged 0 - 19. We care for a wide range of different conditions and our staff are skilled to meet the individual and complex needs of each individual child. The support we provide extends to the whole family from diagnosis through to bereavement. With more than 1,200 children with life-limiting conditions across Berkshire our service and support is 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:

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

# 135+



children, young people and families supported across Berkshire and surrounding counties during 2020/21

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 20% of the total income we need to deliver our children's hospice service.



We provide Day care and Overnight respite service at our hospice as well as delivering care across our community in a family's home, in schools and within hospitals.



## 1.3 Introduction to the 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 support.

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 increased our caseload of children to 135 (including 32 bereaved families) providing ongoing home care support.



We have continued to expand our Day care services including hydrotherapy.



We continue to consolidate our Clinical Nurse Specialist service to offer specialist assessment and symptom management.



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



We have commenced Overnight respite through a pilot phased opening.



We have secured commissioned funds with our local Clinical Commissioning Group that has resulted in contracted medical and pharmacy services.



We continue to work with our faith communities to strengthen relationships with the diverse populations across Berkshire.



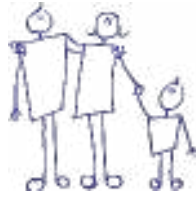
We have invested in specialist palliative care delivery to support quality and safe care in order to improve the experience and outcome for children, young people and their families.

## 2.2 Data reporting

We collect data to measure outcomes and impact.



**27**  
referrals in the  
past 12  
months



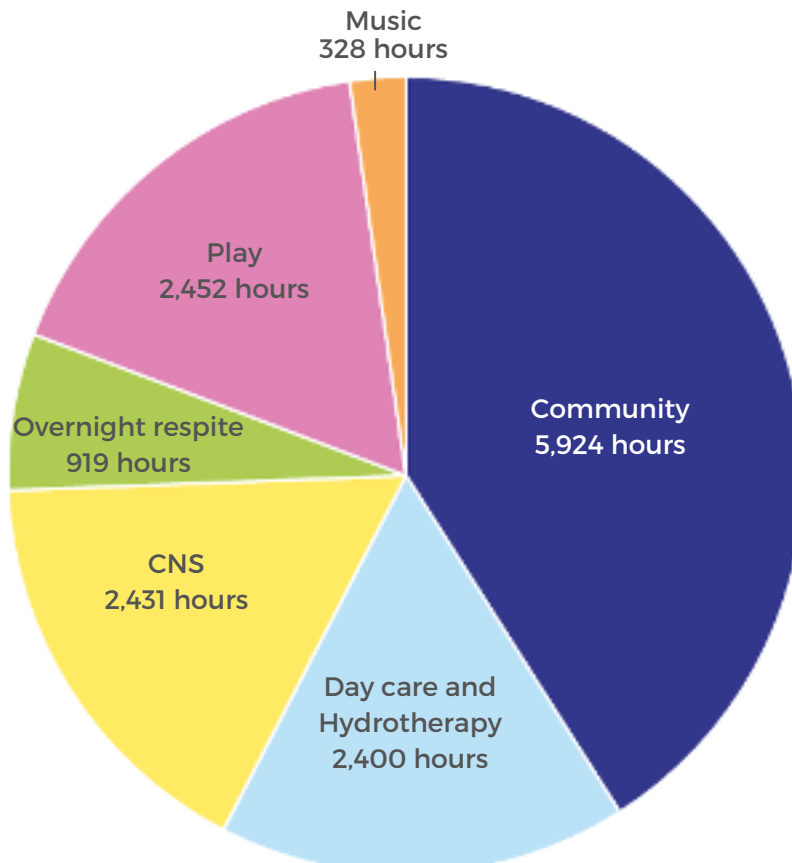
**135**  
Caseload,  
including 32  
bereaved families



**2**  
Discharges

### Care delivered

Service	Number of children using each service area in 2020/21
Community	117
Day care (closed for 3 months because of COVID-19)	56
Clinical Nurse Specialist (CNS) service	81
Overnight hospice respite (6 months from October 2020)	15
Play	59
Music	16



## 2.3 Participation in national audits

During the period 2020/21 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 2020/21 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 **16** local audits in 2020/21.

Summary of audit findings:

<b>Audit undertaken</b>	<b>Actions required</b>	<b>Outcome and impact following actions</b>
<b>Ongoing monitoring of PPE practice and stock</b>	Ongoing review of practice and availability of equipment	To ensure safe COVID-19 working practice
<b>Demographics</b>	To ensure appropriate and relevant data collection	To improve understanding of population we serve
<b>Drug chart photos</b>	To maintain standards for ensuring photos are taken for medicine chart	To ensure safe medicines administration
<b>Consent / Family Reported Outcome Measures (FROMs)</b>	To ensure all consent forms are completed, remain in date and are reviewed annually  To ensure names and DOB are included on all forms and that forms are signed	To maintain requirements for GDPR
<b>Ventilation, Tracheostomy and AIRVO</b>	To review care plans to ensure accurate information for delivering care	To ensure safe clinical practice
<b>Safeguarding</b>	Mid-term Pan Berkshire Safeguarding Children's Board, to evidence actions completed following initial audit	To progress actions to improve safeguarding and ensure compliance
<b>Advance Care Plan (ACP) East</b>	To ensure effective transition to new version 4 forms	To enable ongoing ACP conversations with parents

<b>Audit undertaken</b>	<b>Actions required</b>	<b>Outcome and impact following actions</b>
<b>Advance Care Plan (ACP) West</b>	A number of different forms being used across the West, to support congruence and transition to new form	To enable ongoing ACP conversations with parents
<b>Drug chart photos - re audit</b>	To continue to monitor	To ensure safe medicines administration
<b>Drug charts</b>	81 children reviewed of which: <ul style="list-style-type: none"> <li>• 69% current charts</li> <li>• 31% inactive service users or children awaiting initial assessment</li> </ul>	To ensure safe medicines administration
<b>Infection Prevention and Control (IPC)</b>	Large yellow bins should be lockable. Infectious waste storage area should be lockable  To consider new policies and procedures implemented to support a Covid safe service compliant with CQC guidance	To ensure safe management of healthcare waste  To ensure safe, effective IPC processes for the delivery of care during the pandemic
<b>Risks and Incidents 2020</b>	To ensure appropriate learning from incidents is identified, shared and implemented  Specific actions following medicines incident led to a review of medicines management processes and training for staff  To maintain standards of incident reporting and open culture of learning as the team grows	To maintain accurate documentation and processes
<b>Referrals process</b>	Recording date and signature  More accurate record keeping  Referral process training at induction	To maintain standards
<b>Risk assessments</b>	Knowing who is responsible for completing risk assessments for individual children  To record reason if unable to update  To update and re-audit	Accurate risk assessments to ensure safe care
<b>Record keeping</b>	To print initials and professional designation  To agree a list of abbreviations acceptable  To determine requirements for timed entries	To ensure accurate and timely record keeping
<b>Competency of staff</b>	To ensure appropriate training and development opportunities to support increased confidence  Findings to inform professional development programme	To ensure competence and confidence of staff

## 2.4 Stakeholder views

### Children and families

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

In 2020/21, our families told us:



”

*The support from Alexander Devine has been exceptionally helpful this year especially the specialist nursing practitioners. Thank you.*

”

*Alexander Devine provides a wonderful environment in which, not only our child but the whole family can relax and enjoy spending time together, doing fantastic activities arranged by the team.*



”

*We love your thoughtful and resourceful approach for home and hospice day care, putting the emphasis on creative, fun and exciting activities rather than 'care' which is excellently delivered in the background!*



## 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.

”

*Your team were  
FAB*



”

*You are always  
there for families  
and it is great to  
work with you*

## 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 2020/21 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 Care Quality Commission in this period.

### Clinical coding error rate

ADCHS was not subject to the Payment by Results clinical coding audit during 2020/21 by the Audit Commission.

### Learning from deaths

ADCHS supports children at the end of life. We work in partnership with the local children's community nurse (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 Clinical Nurse Specialists and Doctor we are able to provide symptom management and advance care plans for all patients.

In the last year we have supported ten children at the end of life. All deaths are reported to the child death overview panel (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:




- How to manage confidential information sharing
- To further develop relationships with oncology services to promote earlier referral
- To strengthen collaborative working between and across services and agencies

## 2.6 Priorities for improvement 2021/22

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)

 <p><b>Priority 1</b></p> <p><b>To improve availability and access to Community, Day care and Overnight respite</b></p> <p>The priority will be achieved by:</p> <ul style="list-style-type: none"><li>• Monitoring and reviewing all care activity</li><li>• Ensuring effective user engagement</li><li>• Growing and strengthening the care volunteer programme</li></ul>	 <p><b>Priority 2</b></p> <p><b>To strengthen positive working relationships with NHS colleagues</b></p> <p>The priority will be achieved by:</p> <ul style="list-style-type: none"><li>• Working in partnership with children's community nurse teams</li><li>• Promoting and developing awareness of our service with GPs</li></ul>	 <p><b>Priority 3</b></p> <p><b>To support the professional development of staff to maintain skills and competence and enhance confidence in practice</b></p> <p>The priority will be achieved by:</p> <ul style="list-style-type: none"><li>• Investing in the mandatory training programme</li><li>• Ensuring access to specific skills training</li><li>• Supporting a robust mentorship model</li><li>• Reviewing competence and confidence through a skills audit</li></ul>
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## 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)



**97% of our families rated  
their overall experience of our service as  
excellent or very good**

# 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 2020

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

All staff are encouraged to engage with risk and incident reporting in the context of a learning culture



## Analysis of incidents 2020/21

Patterns and trends	No.	Comments and further information	Learning and actions
<b>Medicines</b>	4	2 potential errors 2 errors without harm	<ul style="list-style-type: none"> <li>To revisit reconciliation and transcribing processes</li> <li>Further training for staff</li> </ul>
<b>Clinical care</b>	2	Dislodged gastrostomy  Seizure in hydrotherapy pool	<ul style="list-style-type: none"> <li>Awareness of gastrostomy and feeding tubes on moving</li> <li>Maintaining safety procedures for hydrotherapy and splash sessions</li> </ul>
<b>Safeguarding</b>	2	1 safety of staff in community  1 relating to reports of marking and bruising to a child following respite	<ul style="list-style-type: none"> <li>To review lone working practice</li> <li>To ensure all comments and concerns from parents are dealt with promptly and sensitively</li> </ul>
<b>Health and safety</b>	1	IPC legionella	<ul style="list-style-type: none"> <li>Further water testing and increased flushing</li> </ul>
<b>Administrative (Care)</b>	1	GDPR concerns transport issue	<ul style="list-style-type: none"> <li>Extra care to be taken when leaving doorstep deliveries that these are left at the correct address and to ensure that potentially confidential information is not seen</li> </ul>
<b>Trips and falls</b>	1	Child fell in playground	<ul style="list-style-type: none"> <li>To ensure safety of children when using outdoor equipment</li> </ul>

## Staff knowledge and skills

We have 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.

There is a mentorship model in ADCHS to support new and junior staff members to develop competence and confidence in clinical care.

## Number of staff completing mandatory training and courses

Topic	Number of staff required to complete	Completed	Compliance %
Fire	18	14	77%
Moving and handling	18	11	61%
Safeguarding	18	18	100%
Infection Prevention and Control	18	18	100%
Paediatric intermediate life support	18	18	100%
Medicines	16	16	100%
Record keeping	18	15	83%
Health and safety	18	18	100%
Equality and diversity	18	18	100%
Consent	18	13	72%
Trachy/Vent	14	14	100%

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

Additional training courses for staff have included:

- Advanced assessment and symptom management
- Dietician update

## 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 zero complaints in the last period.

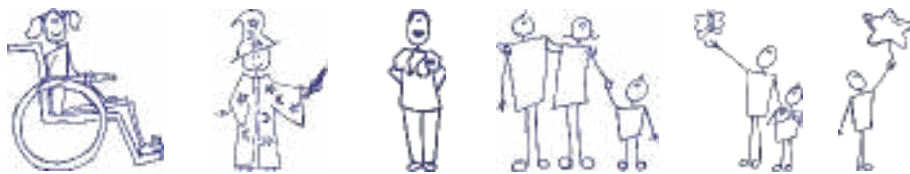
Comments and compliments are captured in various ways, with a particular focus on gaining parents perspective on their own outcome measures (FROMs – Family Reported Outcome Measures). These are used to support individual care and to inform service development.

## 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](http://www.alexanderdevine.org)



Reg. Charity No 1118947

