children's hospice SOUTH WEST

Quality Account 2018/2019

Making the most of short and precious lives across the South West

www.chsw.org.uk

Registered Charity No. 1003314

Contents

Introduction

This Annual Quality Account for Children's Hospice South West is compiled from data for the period 1 April 2018 to 31 March 2019.

This Report has been produced by the Director of Care.

Part 1

Statement of assurance from the Chairman of the Board of Trustees and the Chief Executive

This is our fifth Annual Quality Account. On behalf of the Board of Trustees and Senior Management Team at Children's Hospice South West (CHSW), I would like to thank all our staff and volunteers for their diligence and excellent achievements over the past year.

Chairman's Report

This year we have been able to provide more help to sick children and their families than ever before, as well as improving the range of services offered. We have invested widely in staff training, clinical services and in care management in order to meet the needs and ensure the safety and high quality of care to the families we serve with very complex medical needs.

The scenario of increased medical and nursing complexity for those children and young people we care for will gather pace as the boundaries of the care the State can offer reduce and as medical advances are made.

It is therefore pleasing to see that processes for assuring care quality are firmly embedded in CHSW and that quality is being regularly measured with some outcomes which give much satisfaction and enabled the Board to have confidence in the assurance process and approve this document.

I confirm, therefore, that I am assured in regard to the quality of care being offered by CHSW and the processes used to ensure that both now and in the future the high quality of service being offered will be maintained.

Furthermore, it is worthy of note that CHSW's financial situation is healthy and that this supports the quality agenda. The quality of the service CHSW offers is illustrated by the following quotes from families:

"The only place, other than with close family, who I totally trust to look after my four year old son. I can leave him for short respite breaks in the knowledge that all his needs, including medical and emotional, will be met by the kind, caring and highly professional staff who look after him."

"Every preconception I had of what a hospice was going to look like could not have been further from the truth. This is a remarkable facility which enables families to have so much fun and happiness at such a challenging time. The thought and consideration into every ergonomic and aesthetic aspect is astounding and what I expected to be a harsh and clinical environment is full of warmth, calm and love."

David Turner
Chairman of Trustees

Chief Executive's Report

In 2017/2018 the Charity launched a new Strategic Plan setting ambitions for the next five years. The plan says what we want to achieve in response to the changing environment in which we work, in summary the key points are:

- The number of children with complex clinical and nursing needs is steadily increasing so we need to ensure that our Care Teams both in terms of skills and numbers reflect this. In particular we need to sustain and improve nurse recruitment in a market where supply is a problem.
- We want to continually develop care services which are externally facing and responsive to the needs of children and their families.
- In order to achieve these objectives we need to increase our income and ensure that everyone in the region has heard of the charity and knows what it does.

Financial sustainability is an important cornerstone in being able to assure high levels of service quality and it is pleasing to note that thanks to the generosity of thousands of people we are very fortunate to be in a comfortable financial position.

Our main aim is to deliver excellence in all we do and to be able to evidence this. The Quality Account and the outcomes of measuring service quality assure me that the organisation is in a good place to achieve current and future ambitions outlined above. Thus, we face the future with confidence.

The ethos of the Charity remains undimmed, placing children and families at the centre of all we do.

Eddie Farwell MBE
Co-Founder and Chief Executive

Director of Care's Report

As Director of Care I am privileged to lead the teams at all three hospices who have embraced the quality agenda this year and this is demonstrated in the improved resulted and outcomes. Our biggest achievement is the progress made with listening and engaging families which is something which we will build upon for the year ahead.

It has been a busy and demanding year for the team who continue to keep children and families in the centre of everything we do. I look forward to the year ahead and delivering the objectives we have set to ensure our services remain sustainable, responsive and of the highest quality.

Allison Ryder
Director of Care

Part 2: Priorities for service quality improvement and statements of assurance from the Board

2.1 Priorities for service quality improvement 2018/2019

2.1.1 Quality within the organisation

At the heart of care and services we provide at CHSW is our vision which is to provide exceptional care to the children and families who access our children's hospices. We have a well-deserved reputation for high quality, child and family centred care and a determination to place the children and families we care for at the centre of our decision making and service planning. Performance against this aim is monitored and reviewed on a regular basis not only at Board level but throughout the organisation. The following tables set out our achievements on the priorities set in the last financial year and look forward to the priorities for clinical quality improvements in the coming financial year, why they have been identified and how they will be achieved, monitored and reported. They span the three key areas of Patient Safety, Clinical Effectiveness and Patient Experience.

2.1.2 Achievements on priorities for 2018/2019

Priority area	Achievements to date
Safety	
1 Safeguarding Children and Young People • Improve training and compliance • Launch Speaking Up • Organisational values and behaviours	**We have achieved this target** • Training Compliance has increased across all three hospices (see section 3.2.3.3). • We have a lead in place as Freedom to Speak Up (FTSU) Guardian, supported by a Trustee and a team of champions, who have received special training, representing the whole of the organisation and there has been an organisational wide awareness campaign. • We continue to embed and raise awareness of our organisational values and behaviours which were updated in January 2018 and circulated this year to the whole organisation and discussed at team meetings. **Outcomes and Impact on children and young people:** We recognise that children are at risk of abuse and harm. We also recognise and are aware of the inappropriate behaviours and cultures which have been allowed to develop in other major charities, and that as a charity providing services to children, we are a potential target for perpetrators both directly within care and in fundraising. Children and families have a right to expect us to prioritise safety, safeguarding and embed a culture of trust and respect in our values and behaviours. Having a culture where safeguarding values and behaviours are embedded, clearly setting out expected behaviours, alongside an open approach where staff are encouraged to share any concerns helps us ensure we provide an environment where they can feel safe and be treated with dignity and respect.

Priority area	Achievements to date
Safety	
2 Information Governance • Compliance with IG Toolkit (now Data Security and Protection Toolkit) • Steering Group • Cyber security	**We have a achieved this target.** • We have achieved Level 2 compliance with the IG Toolkit. • The Steering Group meets on a regular basis and now also has a General Data Protection Regulation (GDPR) subgroup. • Cyber security has been given a high priority with organisation wide awareness training and independent testing of our systems, which has shown our IT systems are robust. • Care staff have achieved 99% compliance with IG training through e-LfH. **Outcomes and Impact on children and young people:** We recognise that children and families need to know their information is kept safe and won't be shared without permission or an appropriate 'need to do so'. Equally, families who use our systems need assurance that we are doing everything possible to protect the organisation from cyber crime. Children and young people have assurance through national accredited tools like the IG Toolkit, that CHSW takes information governance seriously and we have systems in place to ensure we meet the standards required. This will provide confidence that their confidentiality and information is held appropriately and safely.
Clinical effectiveness	
1 Improved monitoring of audit data and effectiveness • Activity data • Quality leads to review audits • Repeating of audits where improvement required • Improved audit compliance	**We have achieved this target.** • Activity data has been reviewed and changes made to improve confidence and assurance. See section 3.2.3.3. • The Board reviews care KPIs. • Each base has a Quality Lead at Senior Team Leader and Carer Level. • Audits have been reviewed at clinical governance with improvement in compliance demonstrated in most areas. • Audits have been repeated where compliance has been a concern. • The quality leads for each site meet on a regular basis to review progress and ensure consistency across the organisation. **Outcomes and impact on children and young people:** We recognise the expert parent and child/young person and the importance of an individualised approach to care. Children and families need to have trust in the care which we provide and see evidence that we monitor the care we provide. Children and young people can be assured that standards are closely monitored at CHSW and the care they receive through the hospice is of a high standard. Through more accurate bed night monitoring, we can inform strategic planning ensuring that services remain sustainable and accessible for the future.

Priority area	Achievements to date
Clinical effectiveness	
2 To ensure we have a programme of learning and development for staff • Clear standards for mandatory training • Compliance monitoring • Review of the competency framework • Training for carers • Increased training including online solutions	**We have achieved this target.** • Mandatory training has been reviewed, new standards set and a new compliance monitoring system in place. • Competencies have been reviewed and a new framework set out with the first competencies (ventilation and medication) rolled out to the team. • Carers have been supported to undertake the Care Certificate. • All care staff now utilise e-LfH the NHS training portal. **Outcomes and impact on children and young people:** We recognise for children and families with complex/palliative care needs, having confidence in the staff is essential, if they are able to trust our team to care for their child and take a break. Children and young people can be assured that the staff who work with them are up to date with current practice and confident that those providing clinical care are competent and confident and will benefit from staff retention enabling them to build relationships.
Patient experience	
1 Feedback from children and families • Engage with families and children effectively • To ensure 'child's voice' is captured • Increase variety of feedback	**We have achieved this target.** • We have held engagement events for families this started with sessions specifically around bereavement and building on from that we have had wider events with current families at LH and CF. We learnt this year the importance of good clear communication with families after hearing families concerns about a treasure seeker post at LH being ended due to external funding. Building on this we now have a programme of three events at each house planned for the year ahead and a newsletter to try and improve our communication with families. Holding these engagement events has significantly improved the way we engage and listen to families. • We have increased the methods of feedback which include electronic systems where children can write feedback and score us using a star system, the token system which changes theme every three months at LH, which children particularly engage with and feedback boards using the 'you said we did' approach ensuring families can see how we acted on their feedback. See section 3.2.5.1. **Outcomes and impact on children and young people:** We recognise services we deliver need to meet the needs of children and families, the importance of listening to families and also including them in service design and developments. Children and families who use our services feel confident to talk to us and share their views, they need to see that the suggestions they make are listened to and changes made to adapt and respond. Examples of this can be seen in section 3.2.5.

Priority area	Achievements to date
Patient experience	
2 To develop externally facing responsive services • To increase in reach to external organisations • To increase day visits • To ensure referrals are appropriate and children have choices about the service they access	**We have achieved this target.** • We have a joint nurse post with Bristol Royal Hospital for Children (BRHC) which is new this year. • Our Medical Director at CF works one day per week at BRHC in the Palliative Care Team. • We have supported a rotational nurse between BRHC, Jessie May and CF this was the first year these nurses came to base and worked as part of the Care Team and was very successful. • We have built successful links with Plymouth neonatal unit who have visited LH this year and worked with us to improve referrals. • We hold professionals' days to enable other professionals to visit and engage with the hospice including educational opportunities. • Day visits have increased across all three sites to access a range of services including music therapy, hydrotherapy and family choices. • We audit referrals and test for consistency across the three bases. **Outcomes and Impact on children and young people:** Families with children who have limiting illnesses work with many providers and we understand they need us to work jointly towards seamless service provision. This ensures families get to hear about our services enabling them to make informed choices about using our services. Our links with neonatal units has resulted in more babies being referred enabling families to build family memories outside of the hospital environment, which we know has been valued by families and professionals. We know children and families have welcomed seeing hospice staff in other environments, for example during hospital stays, and it has made a real difference overcoming the fears of engaging with a hospice and an example can be seen below: During the early part of the summer we had learned that the child had been admitted to BRHC. It was during this stay that they had managed to have a conversation with our hospice doctor, during one of her outreach days in the hospital, we later learnt from the family this hospital contact was key to helping them developing trust in the hospice.

2.1.3 Priorities for 2019 to 2020

We recognise the value of the work undertaken last year and this year the leadership team want to build upon these building blocks. In addition, we recognise the ambition is high so have reduced the number of targets to ensure they are afforded the right level of resource.

Priority area	Outcomes	How priority will be achieved	How progress will be monitored
Safety			
1 To publish and embed a new medicine policy to strengthen administration and reduce incidents	New policy will be published There will be reduced number of medication incidents	• Complete rewrite of the medicine policy • Staff feedback • Review of teaching and competencies	Clinical governance
2 To review our infection control/cleaning procedures	A new policy will be published There will be new cleaning schedules in place There will be a new audit template to reflect the cleaning schedules	• The infection control group will lead on this work and implement across all three sites	Clinical governance
Clinical effectiveness			
1 To improve the quality of the Clinical Data we hold	There will be quarterly reports from each base to the Director of Care Each current data set will be reviewed for accuracy and appropriateness A project plan will be in place for a new care database	• By reviewing data sets • Accurate quarterly reporting • Two year plan to improve the Clinical Database	Activity reports Care sub committee

Priority area	Outcomes	How priority will be achieved	How progress will be monitored
Patient experience			
1 Increase the amount of service user feedback and engagement at each site	Family engagement events will have been achieved at each site The amount of feedback will have increased at each base Clear themes for feedback will have been achieved We will have a clear process for capturing the voice of the child	• Embedding the work started at LH across all three sites • Increasing the data captured. • Increase the ways we engage with children and families	Clinical governance
2 To reduce the number of cancellations by the hospices	The number of cancellations by CHSW will have reduced A review of the service model will have been presented to the Board	• Operating a new model of bookings • Get feedback from families • Review of service model	Activity reports

2.2 Statements of assurance from the Board

This section includes statements which all providers must include as part of their quality account. Some statements are less applicable to providers of specialist palliative care, such as CHSW; where this is the case a brief explanation is included.

2.2.1 Review of services (this includes services provided to the NHS during 2018/2019)

CHSW has reviewed all the data available to us on the quality of care in these services.

CHSW is a regional service and provides hospice care to children and families who live in the South West of England. This includes Cornwall and the Isles of Scilly; Devon, Plymouth and Torbay; Somerset; North Somerset; Bristol; Bath and North East Somerset; South Gloucestershire and West Wiltshire. We have three hospices; Little Bridge House (LBH) in Devon, Charlton Farm (CF) in North Somerset and Little Harbour (LH) in Cornwall, (please click on the individual hospice names for links to more information and videos).

CHSW exists to make the most of short and precious lives and puts children and families at the centre of all we do. Our vision is to be fit for the future by continuing to:

- To provide the highest level of care, clinical expertise and enrichment opportunities for children who are expected to die in childhood
- Continue to provide holistic care which meets the needs of all family members
- Ensure our services remain relevant and are sustainable into the future

We provide hospice care for children with life-limiting conditions and their whole family across the South West. These services are offered on referral from the NHS, Social Services, direct family referral and other organisations and individuals. Our services include:

- Respite care
- Day visits
- Symptom control and emergency admissions
- Palliative care
- End of life care
- Bereavement care
- Sibling services
- Music therapy

All our bases have accommodation for the child and family and we encourage families to access our services as a family unit, and 74% of our children come with families members, usually parents and siblings. We offer a supported, relaxed environment where children with life-limiting conditions and their families can take a short break away from home to recharge their batteries in a homely, warm and welcoming environment. At CHSW we believe in 'Time to Care' and as a standard provide every child with one to one care giving families confidence to take a break from care duties and concentrate on being a family. In the main we provide respite, the chance for families to get away from it all. As a responsive service we offer choice and some families choose to just visit us of for day care and this aspect of care is especially helpful for new referrals or where there is anxiety or increased need for support between overnight stays.

All families have access to a sibling service, music therapy, hydrotherapy, soft play, sensory room and play, arts and crafts and each hospice has been located in a tranquil setting with quiet reflective space, sensory gardens and specialist play equipment. Most of our families will receive services from us for up to 10 years although, as we reach out to more families, we are increasingly able to offer our service to children and families who sadly have a much shorter journey. When children need it we offer emergency care, symptom control and end of life care in a peaceful and comfortable setting. Our support for families is ongoing with bereavement support available including care of their child after death and ongoing bereavement support for parents and siblings.

2.2.2 Funding of services

From the income generated from the contracting of services to the NHS in 2018/2019, 100% of this has been spent by CHSW in providing those NHS services.

Services provided by CHSW are funded through a combination of fundraised income/voluntary donations and contributions from public sector bodies (health and social care). Where a public sector contribution is made, this is only ever a partial contribution towards the cost of a child/young persons' care at the hospice. During 2018/2019 CHSW has continued to be in receipt of an NHS England Children's Hospice Grant and has NHS local commissioning agreements with the following Clinical Commissioning Groups (CCGs):

Clinical Commissioning Group (CCG)	Number of children supported (cumulative)	Number of children supported at the end of period (31 March 2019)
North East Somerset (BANES, Bath and North East Somerset)	23	23
Bristol (BNSSG, Bristol, North Somerset and South Gloucester)	149	137
Wiltshire	25	23
Kernow (Cornwall and Isles of Scilly)	96	87
NEW Devon (North, East and West Devon)	146	128
South Devon and Torbay	45	37
Somerset	79	66
NHS Local Commissioning groups where there is currently no agreement in place and children out of area	3	2
Total number of children supported	**566**	**503**

As can be seen in the previous table there has been significant fluctuation throughout the year in our four biggest CCGs in terms of the numbers of children supported (Bristol, NEW Devon, Kernow and Somerset) this is based on the

cumulative number of children supported and those being supported at the end of the financial year. More information is in the referrals section of this report.

For the year 2018/2019* CCG contributions to care at full cost recovery represented just 10% of the total expenditure on care services, with a further 9% coming from the NHS England Children's Hospice Grant.

CHSW actively engages in constructive dialogue with all our commissioners about quality of care, models of care, sustainability of services and added value of service provision.

Increasingly our services are being used to support more complex cases, and support hospital avoidance or early discharge and our expert nursing and medical skills to manage symptom control and end of life care. This requires a more intensive support package and frequently longer stays than we have previously experienced.

As a provider we have never sought an uplift in NHS funding since it was agreed in 2010 but in order for us to remain sustainable and relevant all CCG contributors have been asked to review their funding in line with these changes and economic growth.

*Figures accurate as of April 2019 prior to completion of auditing.

2.2.3 Goals agreed with commissioners

Use of CQUIN Payment Framework

During 2018/2019 CHSW's income was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework. However, CHSW works closely with commissioners and provides quality data on a quarterly basis.

2.2.4 Participation in clinical audits

2.2.4.1 National audit

During 2018/2019 CHSW did not meet the criteria to participate in the national clinical audit and national confidential enquiries.

2.2.4.2 Local and in-house clinical audits

CHSW has an annual audit, review and tabled reports programme which ensures that, as an organisation, we are continually improving the care and clinical services we provide.

Other audits are performed and disseminated across the organisation in other ways. It does, however, provide a focus on some of the areas which need to be audited in line with our regular reporting mechanisms to those that commission our services.

During 2018/2019 a full schedule of audits and reviews were undertaken as part of the annual clinical governance and quality programme. The schedule can be seen in appendix 1 and are commented on in detail in part 3 of this report.

2.2.5 Commitment to research and education

The number of children/young people receiving services (funded by the NHS) provided or subcontracted by CHSW in 2018/2019 who were recruited during this period to participate in research approved by a research ethics committee was zero. This statement refers to research approved by a research ethics committee within the National Research Ethics Service; CHSW is not aware of any of its patients who were involved in any such research.

CHSW demonstrates a strong commitment to research and innovation and has engaged in and collaborated with a number of projects. These include:

2.2.5.1 MyQuality: My Quality of Life Assessment tool

We have continued to make available the internet based quality of life assessment tool for children and parents to use. This tool can be used by families to identify the things that are difficult for them and to rate how they feel about those issues on a regular basis. This information can be fed back electronically to the nurses and doctors of their choice so that care can be adapted to meet the child's changing needs. A doctor with whom we are communicating with is now further exploring the potential for MyQuality as part of a PhD at the University of the West of England. We have nominated leads to support the development of this project in each base.

2.2.5.2 Prescribing project

During 2018/2019, CHSW continued to participate in the ongoing project, which is building an electronic prescribing tool for use in symptom management for end of life care and working towards a shared prescription chart for children moving between services in the Bristol area. The project was initiated following concerns that it was difficult to access expert children's palliative care prescribing advice in several settings, such as the child's home, when needed. The project is ongoing and CHSW is involved alongside teams in BRHC and community palliative care services.

2.2.5.3 Medical input into children's hospices

During 2018/2019, CHSW continued to support a doctor and PhD student (with whom we are connected) with Bournemouth University, who has been investigating the models of Paediatric Palliative Medicine (PPM) provision utilised by children's hospices across the UK. This important study has highlighted the need for guidance regarding the way in which PPM is established and utilised by children's hospices. Her findings were presented at the Together for Short Lives conference and is looking at further areas highlighted by the study in which investigation can be continued and used to improve service provision.

2.2.5.4 Benchmark group

Our Head of Quality and Compliance continued to work with a group of Quality Leads from other Children's Hospices across the UK as part of a steering group looking at quality benchmarking measures for children's palliative care. Although in its early stages the aim is to develop an outcomes framework for children's hospice services.

The Aim of the Pilot is to explore the feasibility of establishing a common framework for capturing and assessing patient centred outcomes for children's hospice services. In so doing, it is hoped to evidence user and service development priorities in a robust and consistent way, and to provide a basis from which to assess their achievement.

The overall purposes of assessing outcomes from this pilot are:

- To improve individual care (through better understanding of individual needs and aspirations)
- To inform service development within an organisation (through a collective view and consistent approach)
- To provide an evidence base to assess the difference made by individual hospice services (for local use)

2.2.5.5 Paediatric nursing rotational post

In 2018/2019, a rotational post between BRHC, CHSW and Jessie May has become a reality with two nurses completing a community and hospice placement. The post consists of a 12 months secondment at the BRHC followed by a year in CHSW (children and young people's hospice) and Jessie May (community outreach service for children and young people with life-limiting conditions). The aim of the post is to be able to support the joint working of three organisations and to support staff to develop skills and knowledge in all areas of palliative care having in depth insight into the journey of families and the care they receive in different settings. It is hoped that these nurses will remain in the South West sharing and retaining their skills for local children.

Evaluations from current rotational nurse are being undertaken by the UWE Bristol. These will help us measure the impact of the programme and inform improvements for the next cohort. Disappointingly, because Jessie May recruited one of the participating nurses, the full rotation cycle was not possible in the first year. We are hopeful that in the second year, both nurses will rotate as planned to gain the full value of this project.

2.2.5.6 Palliative care modules with UWE Bristol

As part of the partnership working, a module has been developed entitled 'Enhancing Practice in Palliative Care for Children and Young People'. This module has been designed in collaboration with practice partners in children's palliative care. The aim is to offer a course to professionals working with children and families with palliative care needs in any setting, that:

- Values and builds existing knowledge and experience
- Explores the key issues facing children's palliative care
- Develops academic skills and confidence
- Creates a supportive space in which sensitive issues can be discussed
- Encourages individuals to share ideas to take back into practice

This is a dynamic and exciting new learning opportunity and we are pleased to see CHSW staff delivering training on this course.

2.2.5.7 Colours of Life

A doctor with whom we are connected is undertaking a review of the CHSW Colours of Life, which is a tool developed by CHSW to measure and grade a child's journey, helping hospices identify the most vulnerable children. This tool is now well established, and this project will provide insight into how it is being used and its usefulness.

2.2.5.8 Blended diet

A CHSW nurse at LBH has been leading on the development of blended diets for a number of years. She is recognised in the field as a leading expert demonstrated by the requests for advice, policy development and development of care practice, this includes advice requests from NHS Trusts, hospices and presenting at conferences and supporting learning events. This project is a key part of listening to children and families, who want to try and normalise care thus enriching the lives of children.

2.2.6 What others say about us

2.2.6.1 Care Quality Commission (CQC)

CHSW is required to register all three hospice sites with the CQC and its current registration status is unconditional. CHSW does not have any conditions on registration. The CQC has not taken any enforcement action against the hospice during 2018/2019 (click on the site name below for link to full report).

Hospice	Overall	Safe	Effective	Caring	Responsive	Well led
Little Bridge House (LBH)	Good	Good	Good	Outstanding	Good	Good
Charlton Farm (CF)	Good	Good	Good	Good	Good	Good
Little Harbour (LH)	Good	Good	Good	Good	Good	Good

CQC on LBH: Positive caring relationships were developed with children and their families. We observed that staff were very caring and compassionate towards children and their families. They made sure children were content, comfortable and having fun wherever possible. Staff showed concern and responded quickly and calmly when children where unsettled or upset. Staff were highly motivated and developed caring and supportive relationships with children and their families.

CQC on CF: People told us staff were kind and compassionate. They felt staff had a shared vision of providing care which was of the highest quality. The provider supported staff to achieve this through an extensive training programme and support from colleagues and line managers.

CQC on LH: During the inspection we saw parents were relaxed and comfortable talking with staff and managers. There was a friendly atmosphere with staff and families being visibly pleased to see each other. All of the parents we spoke with felt they were involved, consulted and their views and opinions were listened to. None of the parents we spoke with had anything negative to say about the service they received they only had praise.

Parents told us they felt their children were safe in the hospice. One parent said,

> "I trust the staff here, they know my son and me very well. I know that they will look after him so I can rest. I trust them completely."

There was a positive culture in the service, the management team provided strong leadership and led by example. All of the staff were highly motivated and keen to ensure the care needs of the families they were supporting were met. Every member of staff we spoke with was very open and proud of the service they provide.

2.2.6.2 Users' experiences

We are proud of the exceptional feedback we get from children and families and ensuring that we enrich the lives of children using our services is a key priority.

> "I would give anything not to need the support provided by Charlton Farm. But as we do, I would say that all the staff, fundraisers and volunteers are our miracle. You are the light on our dark days, you have given us memories we would not have had the opportunity to make, as well as the chance to recharge. No matter what has happened or is happening with other families at the time, you don't let it impact on our stay. To stay at Charlton Farm is not our right, it is a privilege. Words can never express how much you all mean to us."
> December 2018

Further feedback for families and comments from commissioners are provided in part 3 of this report.

2.2.6.3 Other providers

During this year we have had positive feedback from the teams we work with. The feedback we get has ranged from informal comments to formal letters of thanks. This year one of our priorities was to build our external relationships and this has certainly had a real impact on building relationships for the benefit of local services and our children and families. Here is a snapshot of some of the comments received giving insight into the diverse teams and organisations we work with.

> During a child death review meetings, those in attendance highlighted and praised the role of our hospice in supporting the children and their family during the last few weeks of their life and after, our responsiveness of their rapidly changing needs accommodating the whole family, was very appreciated, they thanked everyone involved.
> October 2018 and February 2019

> The Community Team part of the Multi-Disciplinary Team (MDT) involved in the care of a child with complex symptom control plan, initiated during a stay at CF. Fedback how lovely it was to see the child settled and smiling, allowing the family to have quality time, so valued and special after a tough few months and thanked for the intensive input and effort CF had put in to achieve this.
> Charlton Farm, March 2019

> "I was at the Oncology Integrated Care meeting at BRHC today, we heard some extremely positive feedback about the end of life care that your team have recently been providing at Little Harbour for X and family."
> Feedback from a CHSW attending a meeting at BRHC

> "I wanted to say thank you to everyone for all your help and care for my child. It was a real pleasure to work with you and I feel that my child got the best possible care and support."
> Email received from Consultant Paediatrician

> "Thank you for the support of Little Bridge House and the caring and approachable staff. The parents obviously think the world of you all. 'The child' sounds as if she is stable at present and the care and medication plans you have provided will be very useful. We shall hopefully pick up where you left off and provide continuity where possible."
> Email received from Children's Community Nurse

> "On behalf of Cornwall College please can we express our sincere gratitude for accommodating our student, after becoming very distressed when we told him he had to sleep at college his face lit up when we said he would be spending the night at Little Harbour Again, thank you."
> Email received from Cornwall College (student with complex needs stranded due to snow)

Student feedback:

"Thank you everyone for making my sign off placement such a fantastic one. You are all so fab and have taught me so much."

"Thank you all for an amazing experience and a fab three weeks. I have learnt a lot and you have all taught me new skills."

"Thank you to each and every one of you, you have all made each day of my placement absolutely fabulous and taught me so much and supported me to become a better nurse. You are all amazing people and I will miss working with you all every day."

2.2.7 Data quality

CHSW is not eligible to participate in the Secondary Users Service for inclusion in the hospital episode statistics which are included in the latest published data scheme.

2.2.8 Clinical coding error rate

CHSW was not subject to the Payment by Results clinical coding scheme and therefore was excluded from audit processes during 2017/2018 by the Audit Commission.

2.2.9 Information Governance Toolkit

CHSW has engaged with the GDPR and IG requirements and has achieved Level 2 in the IG Toolkit. We have all the key roles in place including a Data Protection Officer, Senior Information Risk Officer and a Caldicott Guardian. There is an organisational Information Governance Committee with a subgroup specifically responsible for GDPR. Information Governance is part of our mandatory training requirements for staff.

2.2.10 Duty of Candour/Freedom to Speak Up

CHSW has embraced the Freedom to Speak Up (FTSU) ethos which came out of the Francis Report and believe we have embedded a culture where staff are encouraged to share learning, speak up and raise concerns. We have appointed our Director of HR, to be the CHSW Guardian, and she is supported by a Trustee and a team of FTSU champions covering all three bases and departments. The champions have been supported with training and the wider workforce made aware through training at site meetings and the online e-LfH module.

Alongside this as an organisation we have:

- Adopted a clear values and behaviours framework for all staff and volunteers
- An open and transparent approach to risk and complaints being open with children, families and commissioners
- Adopted a shared learning approach to risk including the use of learning summaries which highlight the story, the impact on the child, family or service, what needs to change and what is required from the organisation and from individuals

Part 3: Review of quality performance

3.1 Hospice activity

There is no national minimum data set for children's hospices.

The following is a summary of our activity during 2018/2019.

We have sustained our region wide service through the provision of hospice care to children and families in the South West from our three hospices: Charlton Farm, Little Bridge House, and Little Harbour. The spread of our hospice sites means that one of our hospices is easily reached from the far West or East of the South West, despite the large, rural catchment area which we serve.

This has meant that more families have been able to receive much needed care and support closer to home and without the pressure of long and arduous journeys with a sick child. During 2018/2019 we were again able to care for more children and families than in previous years and in addition saw a 47% increase in emergency care requirements. This is a result of our investment in both medical care, posts shared across organisations and the work the teams have undertaken to raise awareness and build relationships with other local providers. However, this has also led to challenges and reluctantly a higher cancellation rate at CF and at LH by the hospices.

Caring for children in a local hospice not only has the benefit of making hospice care far more accessible, but it also allows the care staff in each hospice to develop closer and more effective working relationships with other services and professionals working with the families locally. This shared care approach means the children and their families receive consistent and coordinated care, rather than a fragmented approach which can leave gaps in care.

In early 2017, film clips were made available, to promote CHSW's service to both professionals and families of children with life-limiting conditions. These short films are available on the website, along with a new information sheet specifically targeted at professionals and will help address misconceptions and fears about a children's hospice and provide a clearer understanding of CHSW's and 'children's hospice' care for both professionals and children and their families. During 2018/2019 the website in its new format has demonstrated an increase in online activity. The new format makes it easier for both families and professionals to access information and resources.

3.1.1 Activity data

Caseload activity	2017/2018	2018/2019
Children supported (cumulative total)	537	566
New referrals	104	107
Referrals accepted	76	84
Referrals declined/withdrawn	26	25
% of referrals processed within the CHSW target response time of 40 working days	97%	85%
All deaths on caseload	31	36
Deaths in hospice	12	17
Discharge/deferments	21	24
Parents supported (cumulative)	989	1038
Siblings supported (cumulative)	892	941

The cumulative number of children and families supported by CHSW continues to increase steadily year on year. At the current rate of growth, it is projected by 2020 CHSW will be supporting close to 600 children and their families. However, this would lead to an unsustainable service without expanding one or more of the hospice bases to respond to the increasing capacity and demand. Therefore, in the year ahead a review of the service model is required.

Referrals: it should be noted that as referrals are continually being received, some will still be pending assessment at the start and end of a financial year. The numbers accepted and declined/withdrawn may therefore not match the total of new

referrals during a year but can be identified (in 2017/2018 there are two referrals with an outcome outstanding at year end but in 2018/2019 these two referrals can be seen in the figures).

CHSW cares for children of all ages, from newly born infants to teenagers and can continue to care for some very poorly young adults who are in the end stages of their life. The largest age group of children who use CHSW are those of primary school age, five to 11 years old. There has been a decrease in the number of young adults we support as we have built in more robust review systems at annual reviews and as our numbers increased been more robust to start transition where they no longer meet our criteria.

Children using CHSW by age group:	2016/2017	2017/2018	2018/2019
Preschool (age four years or under)	17%	20%	27%
Primary school (age five to 11 years)	39%	40%	37%
Secondary school (age 12 to 17 years)	29%	23%	28%
Young adults (over 18 years)	15%	17%	8%

The figures demonstrate activity has generally increased, the numbers of children, the numbers of referrals processed and accepted, bed nights, day visits and the number of deaths within the hospice.

Care activity	2017/2018	2018/2019	Difference
Emergency bed care nights	326	480	+154
Planned bed care nights	3,702	3,644	-58
Total number of bed nights of care	**4,028**	**4,124**	**+96**
Day care visits	115	118	+3
Starborn nights	101	109	+8
Parent/carer stay nights	4,852	5,199	+347
Siblings stay nights	3,095	3,329	+234
Total number of family stay nights	**7,947**	**8,528**	**+581**
Total stay nights	**11,975**	**12,652**	**+677**

The majority of children and families use our services for between eight to 10 years, and the value of the care received during this period is well documented. Even our families for whom the pathway is very short benefit from staying at the hospice, getting to know the team, prior to their need for emergency or end of life care. Each family is given an allocation of respite nights, so they can plan short breaks during the year. However, when children become unwell and require symptom control, or require support after a hospital admission or end of life care we provide emergency care. These stays are above the allocation of nights they receive.

Types of care

Day care CHSW has also provided 118 'day visits' for children and their families these are provided both as an introduction to the Hospice and to support children's and/or family's needs including access to specialist equipment, treatment including music therapy and social support.

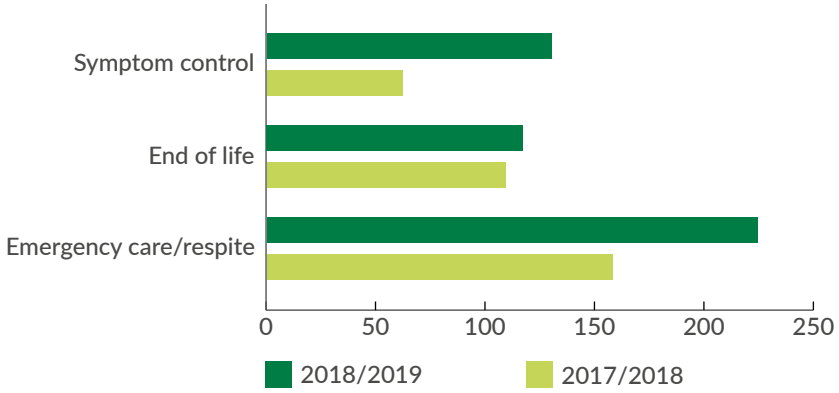
End of life care can be defined as the period of care provided just before and including death. After a child has died, we can, if the family wish, continue to care for the child and family and we call this Starborn care describing the special room where this care is provided. This care is usually offered for up to seven nights before the funeral to help a family during this particularly challenging time in a supported caring environment.

Symptom control admission are to support specialist medical and nursing expertise to help manage a child's symptoms as their condition deteriorates. Frequently these admissions support hospital discharge or admission avoidance and our cover by the medical team is essential to this provision.

Emergency respite and emergency care relate to periods where the child requires specialist support this can be due to a number of reasons including:

- The breakdown of a home care package
- Illness or crisis in the family impacting on the child
- Home adaptations
- Step down from hospital or for a break mid long-term hospital stay

Emergency care has significantly increased this year and can be broken down into different categories.



In addition to emergency care we have also seen an increase in the acuity and dependency of the children we care for. At CHSW we pride ourselves in our commitment to 'Time to Care' and always plan to have one member of staff dedicated to each child staying in the hospice. However, for some children with additional clinical or behavioural needs they can require more than one staff member to care for them safely. In order to achieve this we 'close a bed' to ensure the team had adequate resource to ensure that child has a safe and enriching stay.

Last year we closed 603 bed nights to accommodate children who require more than one member of staff to meet their needs.

Cancellations

In 2018/2019 we have seen an increase in cancellations at two of our bases (CF and LH) which directly links to the increase in emergency care. However, the level of cancellations by families remains significantly higher than cancellations by hospice.

We recognise the impact of cancelling a respite stay and have worked hard to ensure that we pre-empt decisions and give families adequate notice of cancellation and improve our communications with an open and honest approach. We also ensure that all cancellation decisions are made at senior level ensuring a fair and equitable approach.

In 2019/2020 we are piloting at CF and LH a new allocations and bookings systems with the aim to improve patient flow and reduce the number and impact of cancellations. In addition, we plan to work with families to see if we can reduce the number of family cancellations experienced particularly at LBH.

How did we use resources?

In 2018/2019 we had a total of 4,124 bed nights not including other activity with a KPI to achieve 75% of occupancy including bed nights and activity. Bed nights + activity is measured against a target of 5,495 funded and staffed bed nights per year.

Activity included are those where children and families receiving direct care: day visits, respite care, emergency care, starborn nights and family bereavement stays. We know there is some activity we currently do not capture, including home visits.

For 2018/2019 the activity figure (nights, day visits, Starborn and family overnight bereavement visits) is 4,416. This equals 81% of activity against an internal KPI of 75%.

However, when you add to that activities where resources were directly being used to deliver care, including clinical dependency (603) and events (teenage weekends and bereavement events (111) this figure increases 5,090 = 93% which demonstrates highly effective and efficient use of resources.

3.1.2 We delivered high quality care to children and their families.

We undertake several user satisfaction surveys and collect qualitative feedback from users of our hospices which show that children and families are highly satisfied with the care they receive at our hospices. These include a child friendly electronic platform (NPT- Orovia), comment cards, specific electronic and paper based questionnaires and surveys, focus groups and collecting comments from thank you letters, cards and emails. The following quotes are from families using the service:

Little Bridge House

"An ultrasound scan shows our worst fears realised and her tumour has returned. It has all happened over days. Our consultant thinks Little Bridge House will be the best option for us as a family. We arrive at 1.00pm. We spend a week here making wonderful memories. We then spend a week at home before returning for another week. We were fed, children entertained and cleaned for. We also had the opportunity to make foot and handprints and casts. We spent time cuddling our child and also time at the beach. It gave us time to rest and keep energy levels up ready for our little girl's final night. The staff were amazing and looked after everything. She passed surrounded by mum and dad and sisters and brother. The next few days we spent with staff organising the funeral and spending time with our child. We know when we leave we will still have their support. Our time here, although, difficult, will be looked on fondly. Thank you Little Bridge House, every single person here has been amazing."

"Just to say thank you so much for the reports, and also to your wonderful care team who made it possible for our family to have an excellent break this week. Our daughter's care was excellent and we were so relaxed, now ready to continue with recharged batteries."

"When we first found out our daughter's condition was life-limited and threatening the thought of the hospice was really scary. I always thought this was a place for end of life care where poorly children spent their final days. How I was so wrong."

"Little Bridge House is a magical place and filled with enough love and entertainment the kids never want to come home. It's not just about end of life care but helping families to lift some of the strains from home life and the opportunity to spend time as a family. We have been going for 18 months now and haven't looked back."

"This week I was able to take my other two children out whilst our daughter was in the care of the hospice team. I felt guilty but it was a fantastic day completely worry free. I am able to spend much needed time with all my girls and husband without worrying about the cooking and cleaning and washing. We have film and games nights. We spend time in the hydrotherapy pool as a whole family and we have fun, lots of it."

"We don't have to worry about where our daughter is she's 1:1 the whole time. I can fully engage in conversations with others and spend 1:1 time with my girls. My eldest daughter learnt to ride a bike without stabilizers this week! It only took her half an hour but it was half an hour where she had my full attention."

"Little Bridge House is an incredible place, we are so lucky to have them. I have come home with a clear head, more strength to fight the next few months and I can't wait to go back."

Charlton Farm

"Huge thank you to everyone at Charlton Farm for an amazing supportive visit. I turned up feeling very strung out and frazzled, leaving feeling rejuvenated, energetic and like I have my personality back. You are and amazing group of people with sun beams coming out of your faces."

Little Harbour

"Our little girl has again been offered top quality care by each and every one of the team. Staff have picked up even the smallest change in her presentation."

"Yes my child had all they needed and more. The staff are amazing. The weekend stay was special and created some incredible mother's day memories."

"My child's needs are brilliantly met and staff are very creative in coming up with new ideas."

"Our room was excellently presented, a range of snacks and drinks were available in the kitchen on the parents floor."

"There is still a stigma about why a child would be referred to a Hospice, can't express enough how different the environment is to what most people expect it to be."

"I just wanted to let you know how much I appreciated all of your hard work yesterday with the girls and helping them to understand their feelings and love for their sister. If you could pass on my thanks to the Sibling Team."

"We would like to say a massive thank you to all the staff at Little Harbour for their support over the past few years. In particular, we are incredibly grateful for the expert care our daughter had in the last few weeks. Forever grateful."

3.1.3 We enriched the lives of children and families

At CHSW, we are absolutely committed to making the most of short and precious lives and the care offered at each of our hospices is not simply about medical and nursing care for sick children, but enriching the lives of children and their families. Each of those days are filled with a wide range of exciting activities to ensure children and families do not simply get a rest but also enjoy fun filled opportunities which enrich each day and allow families to enjoy quality time together. We hear the benefit from families who by coming to our environment can do everyday things which are rarely achievable 'being able to sit in the garden' and need support to remember 'how to enjoy family time'.

At each of our hospices children and their families can enjoy themselves in our art therapy rooms, soft play facility, sensory rooms, hydrotherapy pools and family activity rooms, complete with an up to date suite of computers, computer games and a wide range of music instruments to support everything from an in-house rock concert to music therapy. Outside the gardens are a place to explore full of exciting opportunities for outdoor play but also quiet reflective spaces drawing on the beauty of the natural surroundings.

All members of the Care Team work in small contact groups, two to three members of the team working with up to 16 children and families to provide telephone and contact support between visits. They would also aim to give some continuity and consistency of care for a child's visit to the hospice. These 'Contacts' continue with Bereavement support for a family following the death of a child. 2018/2019 has seen the introduction of a new Head of Family support with one of the primary goals in this role being a review of the family support services to improve the consistency and quality of the services we provide.

3.1.4 Music therapy

The Music Therapist at each site is able to provide therapy to children at all points of their palliative care journey, music is a powerful tool and it utilised in many ways. Music therapy can be enjoyed on a one to one or group level and sensory, musical stories are very popular. Equally for the more energetic, our staff and even the local farm animals have enjoyed special concerts starring our very own rock stars.

Children with complex needs can engage and respond to music when their other forms of communication are limited. It can be used to reduce stress, anxiety and is helpful to both the children we care for and their siblings and parents. Importantly, it can be a communication tool and build self-esteem and confidence.

Observation of a Care Team member of a shy, vulnerable little boy with a low self-esteem.

They played me the song and I grinned as he sang his heart out, something I had rarely seen, I could see the pride in his eyes and beaming from his face. He had written the words to a Christmas song with the help of the music therapist. The words expressed the importance of true Christmas spirit.

"Christmas, it's a time to give. Christmas, doesn't matter where you live."

He then shocked us all by wanting to perform his masterpiece in front of an audience, something I would have never thought he would do. We planned. I will lead bell ringer, our Music Therapist would sing the verse and he would come in at the chorus, strumming the guitar throughout.

He made tickets, some personalised for staff who he knew and for family members. I could see his eyes light up and his cheeks blush as more and more of the Fundraising Team wanted to be part of the audience.

The time had come. He was very nervous and at points I didn't think he would go through with the performance, but as more people came and sat down to watch, the realisation that they were there to support him had sunk in.

1,2,3,4 ... We began and he became louder and more confident. He played the final strum on his guitar and the applause filled the house. I have never seen him look so pleased with himself and confident that he was able to perform his own work in front of a crowd.

Dry eyes were limited as the staff congratulated him and left with a festive feeling in their hearts.

In recognition of the importance and benefit of music therapy we have increased our provision this year and this has been very popular with children and families.

3.1.5 We enriched the lives of brothers and sisters

Brothers and sisters are inevitably affected when there is a child with a life-limiting condition in the family. When parents have to juggle the demands of caring for a very sick child, it is often brothers and sisters who have to take second place. Our sibling service is very important, this was reflected by parents at one of our parent engagement events who said a trusted person for their well child to talk to was just as essential as the care of the child referred. At each hospice we have a Sibling Team who dedicate their time to brothers and sisters, providing a wide range of fun and adventurous activities also providing them with emotional support. At our hospices, we find that bringing together children and young people who find themselves 'in the same boat' has proved very powerful.

The Sibling Team put on a range of 'in-house' activities and 'out of house' trips for brothers and sisters when they are staying at the hospice and during school holiday's they also run themed activity weeks which are very popular and give a supported space to be with other children who understand to explore thoughts and feelings. Not only can the children relax and enjoy the fun activities which are offered, which is frequently difficult for them to do at home. They also gain tremendous support from talking together and finding that the problems and concerns they have are shared by others.

This year there has been visits to the cinema, trips to the zoo, the Eden Project and aquarium, local play and activity centres are all enjoyed.

CF is fortunate to have woodland alongside the hospice so woodland treasure hunts, den and dam building can also be great fun activities. CF continues to enjoy shows and activities offered to us from the egg theatre in Bath through our Children & the Arts partnership which is in its third year.

The relationships built provide a strong foundation for support to the whole family. They will work with the family in helping to prepare a sibling through pre-bereavement work; at the time of death of their brother or sister and as part of the bereavement support for the family.

The Sibling Team will work with the children following the death of their brother or sister, giving them time to talk about their feelings, and opportunity to share, record and save special memories. This may be through play, craft activities, journals and often by creating a 'Memory Box' which the child can add to gradually over the first few days, then take home and continue to use over the weeks and months to come.

A member of the Sibling Team will often be asked by the family to attend the child's funeral and will be alongside the siblings to continue support on that day.

From Teenage Bereavement Weekend LBH:

> "There's other people who have experienced similar things and it's nice to talk."
>
> "Don't have to pretend."
>
> "Coming here is like a break from the stress of reality."
>
> "Coming to LBH feels like a hug."
>
> "Feels like a second home."

3.1.6 We responded to increasingly complex needs in the children we care for

Advances in medicine and health care technology have improved the supportive care available to children with life-limiting conditions. This development is welcomed because it has helped children to live for longer, but they require increasingly complex care and treatment regimes to sustain life. This means that the children who come to our hospices need to be cared for by expert carers, nurses and doctors who are very competent practitioners. It also means that the children are very dependent for their care and some may need more staff than usual. We know that the numbers of nights when a child is staying within CHSW who needs two members of staff to safely meet their care needs is growing and this year reached 603 nights.

To help us better respond to the clinical and nursing needs of the very sick children we care for, we also employ Children's Palliative Care Medical Staff including Paediatricians. Building on the success of having one of our doctors based at CF we have increased our medical provision at LH this complements our model with our Medical Director supporting the team from LBH.

In addition, emergency care for end of life and symptom control has significantly increased particularly at CF and LH. We continue to work with other local providers to ensure care is seamless, that families are given choices and most importantly that expertise is delivered in the South West across organisations.

3.1.7 We helped make a real difference in end of life care

We believe that bereavement care starts at the point the child is diagnosed with a life-limiting condition and so we try to respond to and care for those facing the awful reality of their child's untimely death. This includes offering support and professional friendship throughout their child's stay.

The care provided at end of life is holistic and considers all the needs of both the child and their family. It ranges from providing expert medical and nursing care, to ensure the child is kept comfortable and free of distressing symptoms; to explaining what to expect and how to cope with this; to thinking about what is important to the child and family at the time of death and how we can help with this. This bereavement support continues well after the actual death of the child and in some circumstances, this extends for many years.

We are committed to being responsive and working collaboratively. An example of this can be seen when following the news that their daughter was now receiving palliative care only this family knew that they wanted to spend time receiving the care and support given both here at LBH, and at home with support from the palliative care/community team and Oncology Team at the Royal Devon and Exeter Hospital. They desperately wanted to maintain elements of their 'normal' lives for the benefit of their other children by spending time in their family home.

> "We knew we needed to support the family to the very best of our ability and this required a flexible approach and regular and thorough communication with the other teams involved. There were some logistical difficulties along the way, but we did succeed in supporting this family in the manner they wanted. For the staff at LBH, this experience gave us professional opportunities to give training and support to new members of the team around the clinical aspects of end of life care, for example anticipatory symptom control plans to be used at home and within the hospice. As challenges arose, we were able to engage in 'in the moment training' for our team leaders, for example finding the most effective means of communication between ourselves and the other professionals involved. As we met together for debriefs, we were able to gather feedback and from this we developed a communication tool which now supports the provision of seamless care between our services."

On average, most children and families who use CHSW hospices use our service for eight to 10 years. This means that the child and family develop a close relationship with the Care Team, especially those who are named as their 'contacts'.

For this reason, after their child's death it is the same care staff who provide bereavement support to the family, for as long as the family feel they need it. Bereavement care is tailored to the needs and wishes of the family and many attend our annual 'Remembering Day' or 'Bereavement Weekends' at each hospice.

There are thriving support groups for hospice users which are an integral part of the bereavement care offered, with parents who access these groups drawing great comfort from the friendship and support of other parents who understand what they are going through.

There is a growing demand for bereavement care at each of our hospices and the emotional pressure experienced by members of our Care Teams who work so closely with children and families facing loss is considerable. We have invested in developing a service level agreement at each of our hospices for the delivery of psychology support, supervision and training for our staff by qualified psychologists. This has been very well received by staff and is now integrated fully into our staff support measures.

> Compliment given by bereaved parents reflecting back to the time their little boy spent in Starborn:
> They expressed how they felt they were 'swooped up' by staff and 'it immediately felt so right'. They felt the time they spent here allowed them to be themselves without being watched or judged. They felt if they had stayed at home they would have had to behave in a way that others would expect.

Each year the opportunity is offered for a group of the bereaved teenage siblings to attend an outdoor activity residential weekend. We have found that this weekend has contributed to promoting the confidence of the siblings and that friendships are developed with others in similar circumstances. Feedback has reflected the value to the siblings of being able to share their experiences both with the team and with their peers, and to be spending time with others who are facing the same emotional journey.

A tailored siblings' day at Hauser and Wirth art gallery, the siblings who attended enjoyed a day being with other bereaved siblings. Some new friendships were forged and the Sibling Team attended to maintain that continuity of support. Enabling the children to open up and feel able to chat freely to the staff and each other while doing art activities which they then took home and talked to their parents about. For many of the bereaved siblings these are the only opportunities that they have to meet other children in a similar position as them. Their feedback has noted that this is one aspect which they hold important and special.

Further events this year included a picnic for bereaved families which was held off-site to enable families who are not ready to come back to the hospice the opportunity to meet others and see staff again without the pressure of being at the place their child died.

3.2 Quality metrics/quality markers

3.2.1 Quality at the heart of care

At CHSW we feel very strongly about providing a service which is of exceptional quality and places children and families first. We are committed to making the most of short and precious lives and the care offered is not simply about medical and nursing care for sick children, but enriching the lives of children and their families we do this through our commitment to 'Time to Care' ensuring every child has one to one care and ensuring children and families remain at the centre of everything we do. In order to deliver this, it is essential we listen to children and families and that we assure ourselves that the care we deliver meets the standards we expect. When there are challenges, we learn from them in an open and transparent way ensuring we are responsive and effective in our response.

3.2.2 Quality assurance activities

This part of the report outlines a range of Quality Assurance (QA) activities to determine standards of care being delivered at CHSW. This includes the views of users of the service, however, although we recognise the importance of understanding user views we are also acutely aware, given the difficult circumstances faced by the children and families and that they will use our services on average for seven years, of not over burdening or fatiguing an already over researched/audited group. Therefore, it is important that we use a wide range of quality assurance activities which vary year on year to encourage ongoing participation by users.

CHSW is required to report to NHS commissioners on the quality of its services via the NHS Standard Contract. This however varies between each CCG group, so a quality schedule has been devised to cover not only the Key Performance Indicators (KPIs) which the CCGs require but also those that are of use to CHSW as an organisation in the assessment, evaluation and development of services provided.

We have systems in place to monitor quality, safety and effectiveness this include:

- Clinical governance meetings
- Information governance committee
- Weekly risk meeting attended by the Senior Care Management Team (SCMT)
- The use of a reflective tool for all care staff to respond to incidents
- The use of learning summaries shared across all three bases to learn from incidents
- An electronic database and risk system

The QA activities that CHSW has been engaged in as part of this organisational wide approach to monitoring and auditing of service quality and provision is conducted around three main areas:

Patient safety and clinical effectiveness

- Infection control audit suite of 18 audits including hand hygiene observed practice audit
- Documentation audit including Medicine Administration Record audit (MAR)
- Controlled Drugs (CDs) and accountable officer audit
- Moving and handling audit
- End of life care plan audit
- Departure letter content audit
- AINMs report
- Complaints report
- Medicine incident report
- Safeguarding report
- Emergency transfer report
- In-house death and difficult symptom control report
- Resuscitation events report

Management and administration

- Policy and procedure version control audit
- Departure letter process audit
- Referrals audit
- Training and education report

User experience and satisfaction

- Orovia audit (friends and family test)
- Patient satisfaction audits
- Family engagement events

As well as these, other QA activities include:

- CQC inspection report summary (external)
- Provider visit (Trustees) report summary (internal)
- Commissioner visits (external)
- Submissions to NHS England for employed Doctors for accreditation and revalidation purposes (external)
- Regular KPI and activity reporting to commissioner's and other NHS England Bodies

3.2.3 Patient safety and clinical effectiveness

Details for some of the key audits and reports for which information is disseminated to the CCGs follows:

3.2.3.1 Accident, incident and near miss reporting (AINMs)

We have clear systems in place to manage risk and give it a high priority. There is a clear pathway from direct care to the Board in terms of reporting and we report quarterly to CCGs.

Quality objective	2017/2018	2018/2019
Number of Serious Incidents Requiring Investigation (SIRI)	3	2
Incidents requiring reporting under RIDDOR	1	4
Number of Never Events reported	0	0
Number of Falls categorised at Level 4 or above	2	0
Infection control		
Number of MRSA bacteraemia (post 48 hours)	1	0
Number of Clostridium Difficile (post 72 hours)	0	0
Needlestick/sharps injuries	1	1
Pressure ulcers Grade 2 and above		
Admitted with PU	1	2
Developed within 72 hours	2	0
Developed after 72 hours up to 72 hours post discharge	0	0
Duty of candour breaches		
Concerns raised under whistle-blowing policy	0	0
Disclosure of information about poor care which has resulted in death or serious injury	0	0
Breaches in Duty of Candour disclosure/reporting	0	0
Information governance		
IG breaches	18	45
Breaches involving CHSW information but not by CHSW	1	6

Comments

We have seen a significant increase in IG reporting but believe this is a result of training (99% compliance for online IG training achieved). When we look at the incidents nearly all of them are very low grade breaches which whilst are a concern may not be reported in other organisations they include 37 incidents where information remained within CHSW (all our staff are bound by confidentiality) but something went wrong these include misfiling in notes, records that could not immediately be located, sending information (not necessarily service user information) to the wrong printer or email.

We had two concerning incidents one where there was a different understanding between staff and parents about consent to discuss their case with Children's Services as learning from this we have reminded staff that this has to be done with clarity in the moment.

The second related to a staff member PDR which was accidentally sent to another member of staff, and individual learning has been undertaken.

We believe the high number of reports is positive and demonstrates the open and embedded nature of IG whilst we hope to improve our data screening for the year ahead to ensure things like telephone service issues are not captured.

Safeguarding incidents	2017/2018	2018/2019
Adult safeguarding incidents occurring on hospice premises: concern relates to family care (staff not involved in incident)	0	1
Adult safeguarding incidents occurring on hospice premises: staff involved in concerns raised	0	0
Adult safeguarding concerns disclosed to staff not occurring on hospice premises and no staff involvement in incident	4	4
Child safeguarding incidents occurring on hospice premises: concern relates to family care (staff not involved in incident)	4	5
Child safeguarding incidents occurring on hospice premises: staff involved in concerns raised	3	0
Child safeguarding incidents disclosed to/by staff not occurring on hospice premises and no staff involvement in incident	9	6
Total	**20**	**16**

Comments

We would not necessarily see safeguarding incidents involving family members as a negative report as the fact they have been referred for support is a positive step. In addition, the number of incidents disclosed that were not on hospice premises indicate that children and families feel able to talk to staff.

Care health and safety incidents/accidents	2017/2018	2018/2019
Child	32	28
Sibling/family	58	60
Staff/contractor	18	33
Equipment/facilities only	23	55
Total	**131**	**176**
Care near miss health and safety incidents/accidents		
Child	0	3
Sibling/family	1	2
Staff/contractor	0	0
Equipment/facilities only	4	20
Total	**5**	**25**
Clinical incidents (excluding medicines and safeguarding)		
Child	119	99
Sibling/family	17	4
Staff/contractor	48	40
Total	**184**	**143**
Near miss clinical incidents (excluding medicines and safeguarding)		
Child	5	14
Sibling/family	0	0
Staff/contractor	0	5
Total	**5**	**19**
Total incidents	**551**	**533**
Number of incidents leading to moderate to severe harm	**4**	**10**

Comments

The majority of incidents causing moderate harm did not involve children receiving care. Three were related to incidents whilst siblings were under supervision of parents and three related to adults who were unwell. One incident was reported formally as it involved a malfunction of a wheelchair which tipped over and was known to have done so before in the community. There is work to in the year ahead to ensure our moderate risks do meet the criteria.

Data relating to children with life-limiting conditions only	2017/2018	2018/2019
Total number of incidents	369	250
Number of incidents leading to moderate or severe harm	11	3
% of harm free stays	99.25%	99.73%

Comments

Two of the moderate harm incidents relate to pressure area care at end of life both were appropriately managed clinically, and further harm prevented. One related to the oxygen break on a circuit not being correctly placed and teaching has been undertaken to raise awareness again no long-term harm occurred.

Key topics learning

For all incidents and concerns we use a reflective tool that all staff complete to ensure we get a full understanding of events, context and wider influencing factors whilst at the same time encouraging staff to see incidents as learning and personal/team growth opportunities. After any incident where we feel wider learning could be shared (not necessarily linked to the severity of the incident) we produce a learning summary which is a summary of the case, any impact on the child and family, lessons learnt, and expectations for the organisation and for staff.

Examples of Learning Summaries circulated this year:

- Fire after two near miss incidents involving lights.
- Hoist safe usage and troubleshooting
- Hydrotherapy ensuring space remains safe: security
- Blood sugar monitoring: awareness of families storing different sticks in the same pots and re-calibration requirements
- Medication: reminder of expected practice.
- Care: reminder of expected practice
- Confidentiality: reminder of expected practice.

An example of how we have been responsive can be seen after the review and reintroduction of a feed chart after an increase in incidents relating to feeds. This has been successful in reducing incidents and improving documentation.

3.2.3.2 Medicine administration

Medicine administration is a very important part of the work of the hospice and a significant amount of time is invested not only in the practicalities of administration but also in the audit, review and development of safe practice and systems relating to medicine administration. The following reflect the activities for this area of patient safety and clinical effectiveness.

Medicine incidents and error reporting	2017/2018	2018/2019
Total number of medication incidents	188	148
Number of medication incidents that included CDs	81	54
% of medication incidents that included CDs	43.1%	36%

All CD incidents are reported via the South West Control Drugs Local Intelligence Networks (CDLIN) via quarterly reporting and attendance at the CDLIN meetings by the CHSW Accountable Officer for Controlled Drugs (AOCD).

All medication incidents are reviewed both locally at the hospice monthly team meetings and at the Clinical Governance meetings every other month and weekly risk management meetings which are organisation wide.

Controlled drugs audit

Audit tool	This is based on the Hospice UK audit tool	
Target	Compliance of 100% to be aimed for although benchmarked at 85%	
Result	2017/2018: 96%	2018/2019: 95%
Summary This audit is undertaken by the AOCD		
Key learning points and recommendations • Parent signatures were missed on departure compounded by a significant amount of paperwork. This has been effectively streamlined - complete • Delays to the destruction of medication, training of appropriate people carried out, so each base has good access to timely support - complete • Different schedule of CDs currently requires different paperwork which has the potential to cause confusion - this is under review		
Progress to date/planned future actions • The CHSW medication policy is currently under review and due for launch in the Summer 2019 this includes CDs		

3.2.3.3 Infection prevention and control audits and reports

Several audits are completed for infection control and reported as the 'Consolidated Infection Control Audit Results' as an annual report to the clinical governance group and also individual audits are reported back to the Care Team as part of the monthly team review agenda. On an annual basis and at the regular clinical governance meetings infection control incidents are reported as part of the overall incident reporting mechanisms.

a. Infection incident report

Quality objective	2017/2018	2018/2019
Total number of infection incidents and near misses	13	17
Number of MRSA Bacteraemia cases (post 48 hours admission)	0	0
Number of Clostridium Difficile (Post 72 hours after admission)	0	0
Number of needlestick injury incidents	0	1
% of staff who have completed annual infection prevention and control training	81%	94%

Comments

The Care Team now undertake e-LfH training and we have achieved 98% compliance at Level 1 and 90% at Level 2.

We utilise an outbreak investigation tool if we have an infection outbreak. Work has been completed with parents to ensure they understand not to come to the hospice (if avoidable) when they or a family member are unwell.

b. Hand hygiene audit

Audit tool	This is a Hospice UK audit tool which has been adapted by CHSW to include an observed practice audit tool.	
Target	Above 85% which is deemed as low risk and Green on the RAG rating	
Result	2017/2018: 90.50%	2018/2019 Overall practice: 96% Hand Hygiene: 94%$

Summary

Hand Hygiene is included here as well as in the Consolidated Results as it is a specific QA activity that is reported on within the NHS Standard Contract. This audit was reviewed and since 2015 includes both the Hospice UK tool and an observed practice tool based on the ICNA toolkits. This provides more robust evidence to measure whether practice was safe, and the provision of facilities met the required standards.

Key learning points and recommendations

In order to maintain the high standards achieved Hand Hygiene training continues to form part of the induction and mandatory annual training.

- Staff have been reminded about standards required and where necessary given individualised action plans to support progress
- One of our sinks which is dual purpose (handwashing and a ritual sink to support spiritual/religious beliefs) design fails the standard

c. Consolidated infection control audit results

Audit tool	Hospice UK Toolkit suite of audits and IPC hydrotherapy pools audit	
Target	Above 85% which is deemed as low risk and Green on the RAG rating	
Result	2017/2018: 81%	2018/2019: 88%

Summary

Following a review of infection control and prevention audits early in 2015/16 it was decided to move towards a suite of audit tools that could be reviewed against other hospice practice and took a view of standards throughout the year. As the Hospice UK Toolkit is the one being used by a number of children's hospices, we have adopted this and incorporated the IPC hydrotherapy pools audit to cover an area of concern not addressed in their suite of audits. We are pleased to see this standard increase this year.

Key learning points and recommendations

- We have infection control champions and have engaged the wider team in the audits to improve understanding and accountability
- We are reviewing our cleaning schedule which we hope will provide improved direction for the wider team

3.2.3.4 Safeguarding children and adults

As part of the requirements included within the NHS standard contract CHSW holds with CCGs across the South West is for the organisation to provide a report on our performance against 10 core safeguarding children standards. These are:

- Governance and commitment to safeguarding children
- Policy, procedures and guidelines
- Appropriate training, skills and competences
- Effective supervision and reflective practice
- Effective multi-agency working
- Reporting serious incidents
- Engaging in serious case reviews
- Safe recruitment and retention of staff
- Managing safeguarding children allegations against members of staff
- Engaging children and their families

Many of the issues above also relate to the young people in our care who fall under the adult safeguarding legislation and standards. The performance indicators and standards which are unique to adult safeguarding as covered in the NHS key performance indicators statements are:

- Prevent
- Deprivation of Liberty Safeguards (DoLS)
- Mental Capacity Act (MCA)
- Whistle-blowing
- Domestic violence and abuse
- Learning Disability (LD) are being addressed and met

The following six principles from the Care Act apply to all sectors and settings, including healthcare services and should inform the ways in which professionals and other staff work with adults:

- Empowerment: adults at risk are supported to make their own decisions
- Prevention: it is better to take action before harm occurs
- Proportionality: the least intrusive response appropriate to the risk presented
- Protection: support and representation for those in greatest need
- Partnership: local solutions through services working with their communities
- Accountability: accountability and transparency in delivering safeguarding

Both the children and adult safeguarding standards are informed by legislation and statutory guidance and evidenced from research. As part of our compliance with these standards, as an organisation, CHSW complies with all statutory/national guidance related to safeguarding children and adults. Incident reporting for this area can be seen in the AINMs reporting section 3.2.3.1.

Safeguarding training data report

Quality objective	2017/2018	2018/2019
% staff completing annual adult safeguarding Level 2* training	81%	94%
% staff completing adult safeguarding Level 3* training	69%	82%
% staff completing annual child safeguarding Level 2* training	81%	93%
% staff completing child safeguarding Level 3* training	85%	88%

Summary

*Please note the levels have now changed nationally and what was Level 2 is now Level 1 and Level 3 is now Level 2. For, clarity and comparison we agreed to change the label of the training in April 2019, but levels have been appropriately allocated.

In addition to Level 2 and 3 training all care staff receive training at induction and on an annual basis on MCA, DoLS, domestic abuse, child exploitation, FGM, human trafficking and modern slavery. These sessions are set throughout the year on the monthly team meeting days. If any staff miss the training, then the Practice Educators do catchup sessions and all staff engage with the e-Lfh modules.

This year we are pleased to report overall increased compliance for safeguarding training despite challenges, external training cancelled due to weather conditions and our review week (dedicated training week) moving to May resulting in a challenge to ensure mandatory modules were complete by the 31 March 2019.

3.2.4 Management and administration

In order to ensure the safety, effectiveness and quality of care there are a number of management and administrative systems which support the clinical and care functions of the organisation. These contribute not only to the smooth running of the service but also to the safety and clinical effectiveness of the services provided. These include Care Documentation audits and Departure Letter Audit. The results from these show that CHSW remains compliant and they have been reported on at Clinical Governance.

3.2.5 User experience and satisfaction

3.2.5.1 Compliments, complaints and concerns

The monitoring of 'Compliments, Complaints and Concerns' is central to the way in which CHSW learns from our children/young people and families about how we are performing to their expectations. Complaints are formally audited and discussed as part of our Clinical Governance and Weekly Risk Meeting agendas. We are fortunate not to have many complaints and it is inherent in the model of care offered to our children/young people and their families, which is one that is personalised and holistic, that complaints are often dealt with at the concern stage as part of our ongoing engagement with the children/young people and their families.

CHSW prides itself in the very low numbers of complaints and concerns which are raised on an annual basis. We recognise that by working so closely with the families, children and young people who use our service, over a number of years, means that we can proactively address issues that may be a future cause for concern or complaint. During 2018/2019 we had two complaints and 10 concerns raised, all were investigated as appropriate and dealt with within our complaints policy framework and timeframes. There were no consistent themes in the concerns and complaint raised and all have been resolved.

We are mindful that it is important that families feel able to raise concerns, we are open to feedback and that they do not feel in anyway potentially disadvantaged by raising a concern with us.

CHSW follows being open and duty of candour and share with parents our findings and the outcomes of any concerns they have. For all concerns we use a reflective tool which staff complete to ensure we get a full understanding of events, context and wider influencing factors whilst at the same time encouraging staff to see incidents as learning and personal/team growth opportunities. After any incident where we feel wider learning could be shared we produce a learning summary which is a summary of the case, any impact on the child and family, lessons learnt, and expectations for the organisation and for staff.

The high level of engagement we have with the children/young people and their families allows us to continually assess their needs, plan the care required and evaluate its outcomes. As such the staff are continually seeking and receiving

feedback from the children/young people and their families regarding the specifics of the care required and provided. This information has traditionally been recorded in the individual care plans and clinical records and although this remains so, we now capture and disseminate this information in a variety of ways which ensures that learning can be shared across the organisation. It was important that we could show that we were meeting our vision of 'Making the most of short and precious lives' whilst at the same time enriching the lives of the children/young people and families using our services.

3.2.5.2 Friends and family test audit

The NHS Friends and Family Test (FFT) was created to help service providers and commissioners understand whether their patients are happy with the service provided, or where improvements are needed. It is a quick and anonymous way for users to give their views after receiving care or treatment across the NHS. Here at CHSW not only do we receive some NHS funding for the care that we provide so have an obligation to participate in the FFT, but we feel that people who use our services should have the opportunity to provide real time feedback on their experience. This feedback enables us to make informed decisions about where and how improvements can be made and can be used to highlight practices which lead to good experiences for the children/young people and families who use our services.

3.2.5.2.1 National Paediatric Toolkit platform

Orovia and Family satisfaction questionnaires (Monkey Wellbeing)

CHSW continues to have the electronic system in place for families to provide feedback on services. However, despite ensuring the system is visible and increasing visibility of feedback (you said we did boards) we have had a low uptake in this method in comparison to the number of families. However, those who did use the system gave very positive feedback with 84% of feedback rating the service as Excellent/Extremely Likely to recommend the service and only 2% giving neutral feedback (lowest score for CHSW).

3.2.5.2.2 Feedback and comments

Comments and Compliments are also captured on the care data base from our social media networks, comments cards and by direct contact from families who use the service by letter, verbally and emails. Some of the comments made which are very typical of the large number we receive are shared in section 3.1.2 earlier in this quality account.

3.2.5.3 Family engagement events

In 2018 we introduced family engagement events where the Director of Care, Head of Family Support and Head of Care for each hospice facilitates a session open to parents. We have open agenda although we bring service challenges and developments for views the items covered to date include:

- Sibling service
- Parental contracts/Charter for House rules
- Bookings
- Bereavement service

From these events we have implemented the following changes based on feedback:

Uniform: staff at CF and LH now wear a CHSW polo t-shirts so parents can easily identify them as a member of the Care Team.

Team communication: we have developed a more structured approach for the contact role, which includes 'key moments' for contact with families and a photo of their contacts (including starters/leavers). In addition, a newsletter for families helping them stay connected with the hospice between visits.

Sibling service: families welcome further clarity regarding service provision and proposed a contract to ensure clear agreement regarding the responsibility for siblings during their stay. We have also set up age related facilitated groups for siblings to meet together and explore thoughts/feelings in a safe way.

Bookings: families welcome pilots to try and streamline bookings and reduce cancellations by having an emergency bed and having a gold star stay.

Bereavement: setting up a bereaved mums' group.

3.2.5.4 Token systems

LH has led on developing more interactive systems to get feedback from children and families and one key initiative has been developing a fun token system similar to systems in place in supermarkets.

We have also created a bespoke form of feedback encapsulating the CQC core values providing a safe, responsive, well led, caring and effective service to children and families.

The purpose was to find alternative methods of capturing feedback in an interactive manner. We used a colour coded token system to enable families to rate their experience as satisfactory, unsure or unsatisfactory. The themes were based on trends identified in AINMs, family feedback sessions, annual audits; documentation, infection control, medical, sibling support/activities (including music therapy), care given, and the catering service provided in-house in order to enhance and excel the quality of the service. Topics were changed throughout the year to collaborate with timely intervals families were encouraged to take between stays, to capture a broader spectrum of feedback.

An example of the questions and feedback can be seen below:

April/May:	Satisfactory	Unsure	Unsatisfactory
Sibling support/range of activities	32	0	0
Housekeeping and standard of cleanliness	36	0	0
Care Team: quality of care	34	1	0
Kitchen: quality of food	33	2	0

Additional comments box also gathers specific feedback which is then responded to examples provided below.

Feedback: could we do some of the signing paperwork before arrival day?

Action: pre-stay checklist compiled. All families phoned to discuss any changes to the care plans/medications in order to minimise the time taken at sign in.

Feedback: for their child to continue with his 'brainwave' activities during their stay.

Action: contacts informed. Adjustments made to care plan to include the brainwave activities.

3.2.5.5 Staff feedback

CHSW engaged with Birdsong to undertake an annual survey of staff with excellent results. The satisfaction survey for 2018 had in total approximately 8,000 responses from 42 hospices to benchmark ourselves against. CHSW had a good uptake of 268 responses. The results showed that in comparison to all other organisations responses our feedback for total agree comparison showed zero worse scores, 14 the same and 33 better.

Our top variances with the All Hospice Benchmark ie where our results are better, pleasingly reflect the focus of our attention this year with the Green Agenda at the top, which is a staff led initiative. Confidence in the Senior Management Team and the Board of Trustees also feature in the top 10.

Staff remain highly engaged with the work we do with 98% proud to work for CHSW and engaged with the aims of the charity. 96% enjoying the work they do and enjoying the people they work with. Staff still see us as a good employer with 84% saying they would recommend us (dropping slightly from 88% last year). The areas of improvement were around the efficiency targets we focused our attention on last year (managing poor performance; the green agenda; maximising skills and abilities to improve productivity and efficiency), with a 15% increase around the Green Agenda; and small but significant improvements in staff who feel performance is dealt with and making best use of individual ability. We also saw continued improvements around communications.

At CHSW we have a clear programme of annual PDRs and regular 121 for care staff with their line manager. Each base has access to dedicated clinical psychology time specifically for staff support and we have peer supervision in place. In addition, every year we close for staff training once a year to enable a whole team approach to learning. For the year ahead, we are strengthening our staff wellbeing strategy which has had good engagement and examples include a staff well being day held at CF. We have also opened up leadership coaching to the SCMT which has been successful in its first year.

There is a staff council with representatives from all areas of the organisation who ensure staff priorities are listened to, one example is the green agenda which has seen significant improvement.

3.2.6 Other quality assurance activity

3.2.6.1 Trustees assurance visit reports

Under Regulation 17 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Regulations 4 to 20A) CHSW is required to have systems and processes which ensure that we are able to meet other requirements of the Act and Regulations. To meet this regulation, we must have effective governance, including assurance and auditing systems or processes. These are expected to assess, monitor and drive improvement in the quality and safety of the services we provide. As part of the overall organisational strategy to meet these requirements our Trustees have a schedule of annual visits to each hospice for which the purpose and aim of the visits are to:

- Meet children and families in order to understand their experience of care and assess the standard of care being provided
- Meet staff to understand their experience working for the organisation
- To inspect the hospice using the CQC framework
- To record and report their findings
- To ensure engagement of the trustees with the service
- Assuring the CHSW Board of Trustees of the quality of the service being provided

The trustees visited all three hospices during the reporting period and used a new reporting form which follows the same format of the CQC inspections in terms of looking at the safe, effective, caring, responsive and well led domains. During these visits the trustees are looking for assurance on the full organisational working of the hospice, including the actions of departments other than care, but concentrating their report on care. Their reports are disseminated to the local team and to the Board for consideration and recommendations are made on improvements that could be made. This is a helpful inspection and feedback process and a valuable tool for the Care Teams to support continuous improvement.

3.2.6.2 Summary of the priorities identified for care:

Alongside The priorities for improvement CHSW has set for 2019/20 each house has hospice specific targets that they will be working towards. This will be monitored predominantly by the SCMT and the Quality Assurance Teams.

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Little Bridge House			
Documentation: care plans	Parent and staff feedback	Documentation working party	Documentation audits will continue twice yearly. Feedback will be gathered from staff and families
Capturing the voice of the non-verbal child to gather feedback	Staff quality report	Exploration and trial of different methods of gathering feedback including use of technology and by gaining an understanding of how similar organisations address this need	By successful collection of feedback, monitored through clinical governance
To continue to explore the families understanding and experience of the booking process and act on findings	Parent and staff feedback	More staff will be shown how to use the Orovia tool and so be able to capture more information and feedback from parents Parent engagement events	Information and feedback will be gathered around families' experiences
To ensure that audit tools used are fit for purpose	Identification of areas of the audit tools that need adapting	Working with the Head of Quality and Compliance to adapt the tools used within CHSW. This is a process that has been started by the Senior Team Leader for quality in this interim period	When audits are in progress, they are deemed to be accurately measuring all areas appropriate to LBH

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Charlton Farm			
Improve compliance standards in our documentation audits (MAR, Care Plan, Notes)	Documentation audit results	Ensure robust documentation training update is provided as part of annual training Commence poster/awareness campaign to raise awareness of the importance of compliance and the standards required Review education programme for new staff and bank staff Ensure robust auditing and re-auditing schedule is implemented by the Quality Team	Documentation audit results
Improve variety of and uptake of feedback measures available to children and families	Family feedback Friends and family test	Implementation of new feedback measure's sourced from LH Training and awareness programme for the Care Team on the importance of obtaining feedback Review and revamp feedback area and display board in the family entrance. Ensure this is routinely updated, highlighting that feedback is listened to and sharing areas of development as a result of feedback received	Family feedback and friends and family test numbers AINMs information on compliments, concerns and complaints
Develop our communication with families in between respite stays	Family engagement events	Produce and distribute a quarterly family newsletter Hold three parent engagement sessions through 2019/20 Produce a monthly bookings email to be shared with families, proving key information and updates on respite opportunities	Family feedback Review of information sent through 2019/20

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Charlton Farm			
Consistently operating a short notice/emergency bed	Family feedback Complaints Monthly Performance Report (MPR) data on cancellation rates	Ensure recruitment measures are proactive, with adverts being placed in a timely manner to ensure establishment levels remain high Review bookings monthly, ensuring one emergency bed remains staffed and open. If occupancy numbers fall or staff sickness levels or referral levels are high consider decreasing the number of planned respite Implement a system of weekly review of short notice offer, ensuring data is collected on how the bed is utilised	MPR data Review of weekly information.
Improve Challenging Behaviour (CB) expertise within the team and ensure all risk assessments are updated annually	CB audit	Source CB Care Team link via advert and ensure it is provided with project time and training. Ensure individual CB risk assessments are updated in the year ahead	CB audit

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Little Harbour			
To identify and implement a feedback tool to capture user feedback from children with communication difficulties	To set up interactive ways for gathering feedback using communication aids Orovia	Quality Team will work together to gather information from other hospices/special schools/ research and implement feedback tools	Regular meetings with the Quality Team and Care Management Team. Rotational feedback schedule which will summarise at end, to run quarterly
To improve the quality of care planning and documentation for our children/young people and raise team standards (to include End of life care planning)	Auditing and implementation of action plans Care plan champion working group	By reviewing audit data and feedback Care plan champion working group to look at what works well Engagement of families in the review of care plans and what works	Discussion of audits and action plans at clinical governance Care plan champion meetings will feed into SCMT and clinical governance
To ensure that LH is CQC inspection ready, ensuring evidence is in place to meet KLoEs	Resources and evidence to be available on inspection Collate feedback into themes/KLoEs	A clear system to be implemented so that the team can be continuously inputting evidence and actions	This to be constantly reviewed by the Care Management Team and quality leads
To review how we care for children/ young people who are resident at LH for long periods of time at End of life and the impact that this has on families and the Care Team	To work alongside external teams to build knowledge of what they can provide for families Work alongside psychologist to look at training needs for team and how we can ensure they remain resilient	Training with psychologist - resilience, difficult conversations Healthy wellbeing project for staff Working with families to maintain external relationships with professionals	Training evidence Clear documentation To produce a template/ process that will capture constant review of whether a child/young person can go home for periods or whether they need to remain at LH and then key actions we need to consider for the team and families if they remain here

3.2.6.3 Commissioner (CCG) visits

As part of the scrutiny of our service by the CCGs, who commission some of our services, visits to assure themselves as to the quality and safety of the care and services provided can be requested under the standard contract. During this reporting period none of the CCGs completed a site visit.

3.3 Statements from Commissioner and Local Scrutineer

NHS Northern Eastern and Western Devon Clinical Commissioning Group (NEW Devon CCG) and South Devon and Torbay Clinical Commissioning Group, (SDT CCG) (as of 1 April 2019 known as NHS Devon CCG) would like to thank the Children's Hospice South West (CHSW) for the opportunity to comment on its quality account for 2018/19.

CHSW is commissioned by a number of Clinical Commissioning Groups (CCGs) and the services have been developed in a way to provide equitable access to all children, young people and their families and carers that require support. We routinely seek assurance that the care provided by the hospice is safe and of high quality, that the care is effective and that the experience of the care given is a positive one.

As Commissioners we undertake quarterly review meetings with the Hospice and are confident that the 2018/19 quality account contains accurate information relating to the services provided.

The CCG recognises the challenges and experiences identified by CHSW including but not limited to; supporting the increase in demand for services in response to the changing environment, maintaining financial stability, continuing to develop and provide responsive services and reducing the number of hospice and family instigated cancellations.

We recognise the effort and energy CHSW continues to demonstrate and sustain a suite of quality services in a changing environment. With regards to this we support and welcome the review and re-design work to establish the changes needed to support our population.

The CCG were also pleased to be invited to join the recruitment process for the appointment to the position of Head of Quality, it was a robust and open process and was a pleasure to contribute to.

The Quality Account highlighted a number of positive points against key work streams for 2018/19; these include but are not limited to:

Organisational development and strategic planning: CHSW continue to develop the organisation and implement changes in a responsive way being sure to uphold their values and behaviours of the organisation and aiming to maintain high standards. Strategic planning has enabled the charity to identify clear goals and ambitions for the future to ensure the needs of the population are met.

Patient experience and engagement: We are pleased to read testimonials and quotes relating to the high quality care given at all the hospice sites. It is encouraging to see how CHSW addressed a need to increase the ways in patient feedback is sought and increasing the number of engagement events undertaken during 2018/19.

Enrichment in services: There are a great variety of services provided by CHSW and a clear dedication to understand individual needs and adapting to those for the family and the young person or sibling. Examples include: the increase in the use of music therapy and the impact this has on families and young people. We are pleased to read about the additional support and attention given to siblings giving them a support network within the hospice and beyond.

Governance and reporting: Whilst it is noted that for 2018/19 incidents reported have been rated as low level, notwithstanding, the provider has ensured that there is robust process of investigation and review in order to learn from those experiences.

Care Quality Commission (CQC) involvement: We welcome and support the provider's open and transparent communication of their involvement with the CQC during 2018/19. We would like to congratulate the provider for the positive achievement across the provider in respect to their recent CQC visit with ratings of 'Good' and 'Excellent' in all areas at all hospice locations.

Lorna Collingwood-Burke
Interim Deputy Chief Officer/Chief Nursing Officer
NHS Devon CCG

Appendix 1: Glossary of terms and definitions

Glossary of terms and definitions	
AINMs	Accident, Incident and Near Miss Reporting, this is a reporting tool which recognises that all accidents are incidents. However, the definition of an incident is wider in that it also includes dangerous occurrences and near misses. A near miss is an unplanned event which did not result in injury, illness or damage but had the potential to do so
AOCD (or CDAO)	Accountable Officer for Controlled Drugs, the 2013 regulations require healthcare organisations such as NHS Trusts and independent hospitals to appoint a Controlled Drugs Accountable Officer (CDAO) who has responsibility for all aspects of Controlled Drugs management within their organisation
BRHC	Bristol Royal Hospital for Children
CB	Challenging Behaviour
CCG	Clinical Commissioning Group are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England
CD	Controlled Drugs are prescription medicines which are controlled under the Misuse of Drugs legislation (and subsequent amendments). These medicines are called controlled medicines or controlled drugs. Examples include morphine
CDLIN	Controlled Drugs Local Intelligence Networks, a legal duty of collaboration was included in the Health Act 2006 requiring organisations to share concerns, within certain constraints, about the use of controlled drugs. Local intelligence networks were set up and led by NHS England to bring together organisations from the NHS, independent health and other responsible bodies, regulators and agencies including the General Pharmaceutical Council, NHS Protect, Prison Services and the Police Services
CEO	Chief Executive Officer is the most senior corporate officer, executive or leader in charge of managing an organisation
CHSW	Children's Hospice South West, the three hospice sites are: Little Bridge House (LBH), Charlton Farm (CF) and Little Harbour (LH)
CQC	Care Quality Commission is the independent regulator of all health and social care services in England. Its job is to make sure that care provided by hospitals, dentists, ambulances, care homes and services in people's own homes and elsewhere meets government standards of quality and safety
CQUIN	Commissioning for Quality and Innovation. The system was introduced in 2009 to make a proportioin of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified area of patient care
Cumulative	The total number calculated for the whole year
Cyber security	The body of technologies, processes and practices designed to protect networks, computers, programs and data from attack, damage or unauthorised access.
DoLS	Deprivation of Liberty Safeguards, an amendment to the Mental Capacity Act 2005. They apply in England and Wales only. The Mental Capacity Act allows restraint and restrictions to be used, but only if they are in a person's best interests
FFT	NHS Friends and Family Test, was created to help service providers and commissioners understand whether patients are happy with the service provided, or where improvements are needed. It is a quick and anonymous way to give your views after receiving care or treatment across the NHS
FGM	Female Genital Mutilation
FTSU	Freedom to Speak Up

Glossary of terms and definitions	
Gap analysis	A technique which organisations use to determine what steps need to be taken in order to move from their current state to the desired, future state. Also called need-gap analysis, needs analysis, and needs assessment. Gap analysis forces an organisation to reflect on who it is and ask who they want to be in the future
GDPR	General Data Protection Regulation, the is a legal framework which sets guidelines for the collection and processing of personal information of individuals within the European Union
ICNA	Infection Control Nurses Association
IG	Information Governance is the set of multi-disciplinary structures, policies, procedures, processes and controls implemented to manage information
IPC	Infection Prevention and Control
IT	Information Technology, the study or use of systems (especially computers and telecommunications) for storing, retrieving and sending information
KLoEs	Key Lines of Enquiries
KPIs	Key Performance Indicators
LD	Learning Development
Lifelites	Lifelites is a charity that provides specialist entertainment and educational technology packages for Children's Hospices, www.LifeLites.org
MAR	Medicine Administration Record
MCA	Mental Capacity Act
MDT	Multi-Disciplinary Team
Monkey Wellbeing	A child friendly survey produced by Monkeywellbeing.com, this is used to obtain information and valued feedback on children's and families' experiences of their care
MPR	Monthly Performance Report
MRSA	Methicillin-Resistant Staphylococcus Aureus infection is caused by a type of staph bacteria which has become resistant to many of the antibiotics used to treat ordinary staph infections.
NHS	National Health Service
NPT	National Paediatric Toolkit, a unique innovation which uses animated methodology to capture the opinions and experiences of children and young people in settings such as healthcare, education and social services
Orovia	The company who developed the software and support package for National Paediatric Toolkit
PDRs	Personal Development Reviews
PPM	Paediatric Palliative Medicine, specialised medical care for children with serious life-limiting/ life threatening illnesses. It focuses on providing relief from the symptoms, pain and stress of a serious illness, whatever the diagnosis. The goal is to improve quality of life for both the child and the family
QA	Quality Assurance
RAG	Colour rating system for incidents/risks G = Green = low risk/minor A = Amber = moderate R = Red = major/severe
RIDDOR	Reporting of Injuries, Disease and Dangerous Occurrences Regulations 2013
SCMT	Senior Care Management Team
SIRI	Serious Incident Requiring Investigation
UWE Bristol	University of the West of England

children's hospice SOUTH WEST

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Published: 27 June 2019