children's hospice SOUTH WEST

Registered Charity No. 1003314

Children's Hospice South West (CHSW)

Quality Account 2016 - 2017

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INTRODUCTION

This Annual Quality Account for Children's Hospice South West (CHSW) is compiled from data for the period 1st April 2016 to 31st March 2017. This Report has been produced by the Head of Quality and Compliance – Carole Coombs with the support of the Director of Care and CEO. It also draws information that has been gathered in the production of other annual reports for CHSW such as the Annual Safeguarding Report, Annual Accounts and Annual Report and Impact Review.

PART 1 – STATEMENT OF ASSURANCE FROM THE CHAIRMAN OF THE BOARD OF TRUSTEES AND THE CHIEF EXECUTIVE

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

Chairman's Report

2016-17 was a year marked by "celebration", "change" and continued "success" for Children's Hospice South West.

We celebrated the 25th anniversary of the charity's foundation. Many special and precious memories were brought to mind and every step of the way we were reminded of the strong bond that exists between families, supporters, volunteers and staff. This culminated in a truly wonderful and poignant Service of Thanksgiving at Exeter Cathedral in July 2016 held in the presence of our Royal Patron HRH The Duchess of Cornwall.

In the midst of this celebration there was change. Trevor Lloyd, our Chairman since the foundation of the charity in 1991 retired having led the work in a skilful, selfless and faithful way. We owe him a massive debt of gratitude and I am privileged to follow in his footsteps. In addition, our only ever Director of Care, Mandy Robbins, also retired. We thank her for her skilled and compassionate leadership throughout her 21 years leading the work of caring for families.

Celebration and change were accompanied by ongoing success for Children's Hospice South West. Continued financial security has allowed further investment in our care services in order to meet the needs of the increasing number of sick children with very complex medical and nursing needs.

This report makes encouraging reading. Thank you for whatever part you played in our success, which is perhaps best summed up by words spoken by one of our families:

"This is not a place that concentrates on death, but rather makes the most of life, however short"

David Turner

Chairman of Trustees

Chief Executive's Report

This year celebration was remarkable for its ability to inspire all associated with Children's Hospice South West to journey on with renewed energy that will ensure success for the future.

The mission of our three hospices, which link the South West together, will not change in that. Uniquely, we will continue to provide, in those places, care for every member of a family touched by the reality of their child's premature death.

All hospices were inspected by our Regulator, the Care Quality Commission, with no actions needing to be taken to improve the service. It was extremely pleasing to read the description of each service expressed in such a positive and warm manner.

What of the future, because the environment within which the Charity operates is changing?:

- the number of life limited children with complex clinical and nursing needs is steadily increasing
- the Government is redefining the boundaries of what the State can afford in health and social care, leading to some expectations not being met.
- there is a national shortage of children's nurses at a time when we need more in order to meet increasing needs.
- there is a limit to what the charity can expect to raise through voluntary income because we continue to live in uncertain economic times.

As our chairman has stated, Children's Hospice South West is well placed to face these challenges with confidence and is reviewing its Strategic Plan to take account of these challenges as well as the inevitable opportunities which will arise.

Thank you all once again for your continued support.

The Quality Account

This is the organisation's third Quality Account. The Quality Account is a means by which we are able to share information publicly about the quality of care we provide, in a format common to other providers of services to the NHS. It is an assessment of the quality of our healthcare services in the form of an annual report, demonstrating evidence of our achievements in the past year and commitment to excellence through our quality improvement priorities.

This report has been prepared jointly by the Director of Care, Head of Quality and Compliance and myself, and is endorsed by the Board.

To the best of my knowledge the information reported in this Quality Account is an accurate and fair representation of the quality of healthcare services provided by Children's Hospice South West.

Eddie Farwell MBE

Chief Executive & Co-Founder

PART 2 - PRIORITIES FOR SERVICE QUALITY IMPROVEMENT 2016/17 AND STATEMENTS OF ASSURANCE FROM THE BOARD

2.1 PRIORITIES FOR SERVICE QUALITY IMPROVEMENT 2016/17

2.1.1 Quality Within the Organisation

At the heart of care and services we provide at Children's Hospice South West 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. With this in mind 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 from 2015-16

Priority Area	Achievements to date
Safety: **1. Ongoing development of the Accident, Incident and Near Miss (AINMs) reporting system within the Care Data base**	Review of Incident reporting has become an integral part of the clinical governance agenda and has provided a significant contribution to improved safety in practice. As part of this review process the reporting of all AINMs has increased, this is not because there have necessarily been more incidents but that staff are using the system to record incidents and are more aware of the need to do this to improve the organisations safety culture. There is an established cascade of learning and actions to and from the clinical governance committee and the care teams' at all three sites via their monthly review team meetings. As we have developed our reporting and reviewing of incidents we have identified further areas of development for our AINMs system which, uniquely, is an integrated part of our Care Database. These developments will further improve our reporting systems which are an integral part of Quality Monitoring. The focus for next year will be improving on how we close the loop from individual incidents, ensuring our data is robust and information rich enabling us to assimilate themes of learning across the organisation.
2. Deprivation of Liberty Safeguards (DoLs)	CHSW has completed and implemented an organisational approach to DoLs which includes: Clear organisational leadership for DoLs (Deputy Director of Care). With champions at each base. Guidance and training for staff Embedded DoLs into work with young people over 14 years as part of transition care. In recognition of relevance for the young people accessing our service and the additional National Guidance due to published this priority will remain in place for next year as the final judgement by the law commission is still to be released.

Child and Family Experience: Further development of the National Paediatric Toolkit (NPT)/Orovia tool to monitor child and family experience	In 2016 / 17 CHSW continued to utilise the electronic resource (Orovia platform) to gain feedback from families and the response rate increased. The Head of Quality & Compliance successfully implemented the 'Monkey Survey' which enabled us to specifically target children and young people (including siblings) ensuring we continue to place the child in the centre of everything we do. The plan for the year ahead will be to ensure we continue to build on this success and increase the levels and variety of feedback we receive. In addition we want to build on how we utilise this information.
Safety and Effectiveness 1. **Information Governance:** Improve information governance (IG) throughout the organisation.	The focus on IG in 2016 / 17 has been effective and pivotal in the achievement of the significant Level 2 milestone in the IG Toolkit. This has been a significant work stream led by the IG Committee and its success a result of departments across the organisation working together. This work will be further developed in 2017 / 8 reflecting the challenges faced in cyber security and the impact of the awaited requirements set out in General Data Protection Regulation (GDPR) Compliance. Structures, processes and policies have been implemented so that CHSW achieved level 2 in the IG Toolkit by 31st March 2017.
2. Information Technology Improvements: Development of a robust IT infrastructure to support existing and future services	The IT team have successfully implemented an audit and developed a strategy for improvements. Work undertaken this year included: • Transferring all data to a secure external server, • updated IT equipment at each site and • Installation of Citrix a secure IT platform that protects the organisations information and supports satellite working. • Robust IT support for staff through IT commercial. For the year ahead there is a detailed programme of improvement planned including the updating of wireless internet, expanding the use of technology and digital information in Care and leading on cyber security.
Clinical Effectiveness **1. Practice Educators** Development of a robust clinical practice and education team to support existing and future services	During 2016/17 as part of the overall care team review the Practice Educator role was reviewed. These posts have all now been recruited into and embedded into the team. The role of the Lead Practice Educator was advertised but not successfully filled which lead to a further reflection of what the organisation needed. The importance of our external facing development was recognised building on the innovative work done at CHSW creating the rotational post collaboratively with Bristol Children's Hospital and Jessie May Trust. The development of a university module in paediatric palliative care is a key part of the innovation and reflecting this strategic development

	the post has been changed to the Head of Education & Development. For the year ahead this post will be recruited into in order to provide leadership for the existing Practice Educators and improve our external links through a strategic plan to support clinical practice and education. This role will also support our strategic vision to develop academic partnerships and increase the learning and development portfolio for our staff building on our reputation as the leading provider of children's palliative care in the south west.
2. Senior Care Team: Development of the newly appointed Senior Team Leaders for Clinical, Quality and Compliance, and Family Support/ Bereavement	Phase One of the care review introduced a new senior structure and these posts have now been recruited into. There has been positive feedback reflecting improved clinical leadership. Looking ahead for 17/18 we need to ensure we have got the structure right and ensure we maximise senior experience cover directly providing care.
3. Team Leader Role Development of the newly appointed Team Leaders	The introduction of team leaders has had a positive impact at the front of care delivery ensuring clinical leadership and introducing development opportunities for staff. At the end of this year we have evaluated the success of the new structure and in the year ahead will reflect the messages from staff are included in further staff developments.

2.1.3 Priorities for 2017-18

Priority Area	How identified as a priority	How priority will be achieved	How progress will be monitored
Safety:			
1. Deprivation of Liberty Safeguards (DoLs)	• Legislation • CQC requirement • Safeguarding • Review/ assessment of client group who need applications	• Guidance from statutory supervisory bodies has been sought and will be implemented • Policy will reflect the new guidance from the Law Society when it is published and this will be reflected in clear procedures for staff • Systems and processes will be developed to meet requirements • Training for staff	• Policy & practice Committee • Audit of Practice & Training.
2. Information Governance: To build on the success of achieving Level 2 in the IG Toolkit with a focus on cyber security and the General Data Protection Regulation (GDPR) Compliance.	• IG toolkit and Improvement plan • Publication of GDPR	• Continued compliance with IG Toolkit • IG steering group to continue to push forward the action plans for IG • Implement actions identified in the improvement plan • Gap Analysis by independent consultant • IT leadership on cyber security.	• Review by IG steering group • Annual audit of the improvement plan and actions register
Clinical Effectiveness:			
1. Improved use of technology to support care records	• Phase One of the Care Review • Strategic Plan • Family feedback • Staff feedback	• Full involvement of the Clinical Governance and Senior Care Management Team in service delivery changes • Opportunities to electronically manage data including the care plans.	• Review and audit of Care Database
2. Implementing a recruitment and retention strategy to ensure the workforce is responsive and resilient.	• Vacancy factor at each base. • National nursing shortages • Together for Short Lives report into the children's hospices nursing workforce	• Nurse Recruitment and Retention Strategy to recruit staff, retain current staff and develop staff. • Career development and progression opportunities for all staff • Operational changes .e.g. working patterns.	• Vacancy Monitoring at each base by SMT

3. To ensure our electronic information on incidents is data rich, viewed thematically and shared across the organisation.	• Quality Monitoring	• Further development of the AINMs system closing the loop on individual incidents, increasing the breath of our generated reports and reviewing themes across the organisation.	• Clinical Governance.
4. To ensure we have a programme of learning and development for staff	• Nurse Recruitment and retention strategy • Quality Monitoring	• Recruitment into Head of Education and Development • Review of competency and training framework • Development of accredited training for carers • Development of university modules in paediatric palliative care	• Care Review Phase 2 • Clinical Governance • Senior Care Management Meetings.
Patient Experience:			
1. Feedback from children and families. To increase the levels and variety of feedback we receive and strengthen the links to measuring success and influencing service developments	• CQC standards • Quality reporting	• To ensure we utilise a variety of methods to gather feedback • To improve how this information is collated and thematically reviewed • To capture the voice of the child in measuring effectiveness.	Clinical Governance.
2. Development of family support (sibling and bereavement service).	• Phase One of the Care Review • Strategic Plan	• Recruitment Head of Family Support • Time allocation for post holders to develop service • Increased bereavement support • Strategy development for the sibling service	Senior Care Management Team.

2.2 STATEMENTS OF ASSURANCE FROM THE BOARD

This section includes statements that all providers must include as part of their quality account. Some statements are less applicable to providers of specialist palliative care, such as Children's Hospice South West; where this is the case a brief explanation is included.

2.2.1 Review of Services

Children's Hospice South West (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.

Children's Hospice South West has three hospices:

- **Charlton Farm** located in Wraxall, North Somerset;
- **Little Bridge House** located near Barnstaple, North Devon;
- **Little Harbour** located near St. Austell, Cornwall.

Each of our hospices provide the same range of services, however Little Bridge House and Charlton Farm are 8 bedded hospices and Little Harbour is a slightly smaller facility with 6 beds.

At CHSW we are absolutely committed and dedicated to making the most of short and precious lives. The care offered at each of our hospices is not simply about medical and nursing care for sick children, but about enriching the lives of children and their families.

We are set up specifically to meet the needs of children with life limiting or life threatening conditions that are not expected to live into adulthood.

This means that not all children with disabilities will be eligible for children's hospice care, but all children with a life limiting or life threatening condition who are not expected to live into adulthood will be eligible – whatever their diagnosis. We care for children with a wide range of different conditions and with both physical and learning disabilities and our hospices are staffed and equipped to care for children with very complex and/or continuing health care needs.

Children's Hospice South West is able to care for children ages 0 – 21 years, although we do not accept new referrals after the age of 18, as children reach their early teens we work with the young person, their family, and other agencies to put in place transition arrangements to other services which will be more suitable for a young adult by the age of 21. Each young person is individual and we will work with them flexibly to ensure a smooth transition based on their specific needs.

The support we give extends to the whole family, into bereavement and beyond for as long as each family needs us. With more than one thousand life-limited children across the South West, our support for families is absolutely vital.

During 2016/17 Children's Hospice South West (CHSW) provided the following services to the NHS:

For Children referred to our services we provide:

- A homely, welcoming, fully accessible and age-appropriate environment.
- A large range of facilities (both play and educational) and staff skills to enrich lives to the maximum.
- A happy safe environment where children are encouraged to reach their full potential.
- Medical care from specialist doctors (and out of hours cover) 24 hours a day, 365 days a year.
- Personalised one to one holistic care during the day, resourced from and supported by a multi-disciplinary team, led by children's nurses.
- Respite breaks.
- Emergency care when the child is poorly: one of our beds in each hospice is always kept available for emergency care.
- Emergency care for symptom control or clinical assessment.
- End of life care.
- The opportunity for children and young people to discuss their own mortality and prepare for their dying and death.
- The opportunity for children to enjoy normal childhood experiences with interconnecting rooms to facilitate sleepovers and teenage weekends.

- An environment that enriches with access to music therapy, a Jacuzzi, soft play, sensory gardens, music and media facilities, and specialist outdoor play.
- Activities planned throughout their stay out based on children's interests and wishes

For parents, siblings and other family members we provide:

- Hotel standard accommodation.
- All meals during stay.
- Time to enjoy quality family time with a break from caring and the domestic routine.
- The choice to do as little or as much with their child as they wish.
- The opportunity to leave their child at the hospice whilst going away for a break.
- Time to talk and meet other families.
- Ongoing contact and support through named staff members.
- Sibling care: a dedicated team of sibling workers support well siblings during their stays and help them to cope on the journey and prepare for a future without their brother or sister.
- Bereavement care.

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

2.2.2 Funding of Services

From the income generated from the contracting of services to the NHS in 2016/17, 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 2016/17 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 (CCG's):

Clinical Commissioning Group (CCG)	**Number of Children supported**
Bath and North East Somerset (BaNES)	23
Bristol, North Somerset and South Gloucester (BNSSG)	146
Wiltshire	19
Kernow (Cornwall and Isles of Scilly)	92
New Devon (North, East and West Devon)	123
South Devon and Torbay	39
Somerset	84
NHS Local Commissioning groups where there is currently no agreement in place and children out of area	5
Cumulative Children Supported:	**531**

For the year 2016/17 Clinical Commissioning Group (CCG) contributions to care at full cost recovery represented just 12% of the total expenditure on care services, with a further 10% coming from the NHS England Children's Hospice Grant and the rest being funded from the other sources as previous listed. This ratio of funding has remained steady over the last few years.

CHSW actively engages in constructive dialogue with all of our commissioners about quality of care, models of care, sustainability of services and added value of service provision. As with other Children's Hospices where NHS contracts are in place CHSW strongly advocates for a reduction in the bureaucratic burden to one which is proportionate and appropriate.

2.2.3 Goals Agreed With Commissioners

Use of CQUIN Payment Framework

During 2016/17 CHSW's income was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework. This is because NHS funding is only ever a contribution towards the cost of care and commissioners did not consider it appropriate to include in their NHS standard contracts or grant agreements with CHSW.

2.2.4 Participation In Clinical Audits

2.2.4.1 National Audit:

During 2016/17 CHSW was ineligible to participate in the national clinical audit and national confidential enquiries. This is because there were none that related to children's specialist palliative care.

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. This is not meant as a limit to the quality activities that take place, as there are others that are performed and disseminated across the organisation in other ways. It does, however, provide a focus on some of the areas that need to be audited in line with our regular reporting mechanisms to those that commission our services.

During 2016/17 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

The number of children/young people receiving services (funded by the NHS) provided or sub-contracted by CHSW in 2016/17 that 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 that 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. During 2014 Dr Nicky Harris and a number of CHSW My Quality Champions first introduced this on-line quality of life assessment tool to 33 families using the hospices as part of a research and evaluation project to determine how successful this tool is in supporting care. The impetus for the study was that measuring outcomes and quality of life is difficult in palliative care; there are limited tools available for use with children; and there is no consensus on which tool is most appropriate.

Nicky is now further exploring the potential for MyQuality as part of a PhD at the University of the West of England. This is currently being taken through the ethics application process and we are keen to continue participation in this ongoing study with Nicky which will hopefully start later in the 2017/18 reporting period.

2.2.5.2 Aurora: Electronic Prescribing Project.

During 2016/ 2017, CHSW continued to participate in the on-going Aurora Project, which is building an electronic prescribing tool for use in symptom management for end of life care. The project was initiated following concerns that it was difficult to access expert children's palliative care prescribing advice in a number of settings, such as the child's home, when needed. The concept of the Aurora Project is based on the benefits which have already been derived from a similar electronic prescribing system used in PICU. A clinician simply has to complete a decision tree, which prompts for certain information such as the child's symptoms and other relevant clinical data, and the tool will suggest both non pharmacological interventions and also drugs which may help. If a clinician needs to prescribe a drug, they input the requested information, such as the child's weight, for the drug dose to be calculated.

The Aurora project is on-going and CHSW is involved alongside teams in Bristol Royal Hospital for Children and community palliative care services.

2.2.5.3 Seizure Management in End of Life Care:

During 2016/2017 CHSW has continued to participate in a project to explore the best approach to seizure management in end of life care. A number of people in children's palliative care services had identified challenges in seizure management at the end of a child's life and it is believed that guidance in this area will improve the care and treatment offered to children. The project team leading this work has included two CHSW paediatricians, a neurologist, and a Children's Palliative Care Consultant.

This project has now ended and the paper from it has been accepted for publication in the BMJ Supportive and Palliative Care Journal. It has also been accepted for presentation at the RCPCH national Conference in May 2017.

2.2.5.4 Medical Input Into Children's Hospices

During 2016/17 CHSW continued to support Dr Jo Frost a PhD student 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 with regard to the way in which PPM is established and utilised by children's hospices. Dr Frost has the opportunity to present her findings so far at the Together for Short Lives conference later this year.

2.2.5.5 Benchmark Group

During 2016/17 our Head of Quality and Compliance has been working 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.

At the moment there are no clear outcomes frameworks for children's hospices. The first phase of this project is to initiate a collection of outcomes as defined by families, children and young people.

This pilot project hopes to get a number of hospices collecting the same type of data for a proposed 12 month period to evaluate whether or not this type of outcome is something which both families, children and young people and hospice providers find useful.

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*).

2.2.5.6 Paediatric Nursing Rotational Post

CHSW has worked in collaboration with the University of West England, Bristol Children's Hospital and Jessie May Trust to develop rotational post for newly qualified nurses to enable them to take a three year post during which time they will get to complete their preceptor year within the Acute Hospital Environment at Bristol Children's Hospital then spend a year in a children's hospice environment (CHSW - Charlton Farm) and a year in a community paediatric palliative care team at Jessie May. This is an innovation project in paediatric palliative care nursing recognising the lack of skills and career development opportunities that are available in this field. In the year ahead we will commence formal evaluation of the experience of the nurses involved in this project.

2.2.6 What Others Say About Us

2.2.6.1 CQC

CHSW is required to register all 3 hospice sites with the Care Quality Commission (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 2016/17.

During 2016/17 a change of registered manger was made at our Little Harbour Hospice apart from this there were no other changes to our hospice registrations with CQC.

All Three of our hospices were inspected by CQC during 2016/17 and received the following ratings:

Hospice	Overall	Safe	Effective	Caring	Responsive	Well Led
Little Bridge House	Good	Good	Good	★ Outstanding	Good	Good
Charlton Farm	Good	Good	Good	Good	Good	Good
Little Harbour	Good	Good	Good	Good	Good	Good

Click on the site name above for link to full report.

The CQC reports for each hospice included the following statements which are reflective of the reports as a whole:

Little Bridge

"The children we met during the inspection had complex needs and were not able to tell us their experiences because of their complex ways of communicating. We observed how the staff interacted with the children and their families. Staff were caring and showed children and their families' kindness and compassion. Staff were very motivated and demonstrated a commitment to providing the best quality care to children, young people and their families. Children received care and support in a personalised way. Children and young people had good links and access to the healthcare support they needed during their stays at the hospice. All parents were happy with the care provided by Little Bridge House. Staff knew children well and understood their complex needs. Parents told us their children were safe in the care of Little Bridge House. Children were relaxed and comfortable with staff."

Charlton Farm

"People told us staff at Charlton Farm were kind and compassionate. They felt staff had a shared vision of providing care that was of the highest quality. The provider supported staff to achieve this through an extensive training programme and support from colleagues and line managers…... Parents felt their children were safe at Charlton Farm…… Care that was offered to children and young people was personalised and reflected their needs. The needs of children and young people were reviewed prior to every short break visit and during their stay. In this way the provider could assure themselves care was in line with current needs and wishes. Staff were knowledgeable about the children they cared for. They were able to maintain the privacy and dignity of the children and young people whilst providing care and to ensure they met their diverse needs. Staff were knowledgeable about the individual communication needs of the children and young people. Where possible, they delivered care in line with the child's wishes. Where this was not possible, staff sought consent from parents or used other measures to ensure the child's rights were protected and any decisions made were in their best interests. The provider worked sensitively with children, young people and their families to help ensure the care and wishes of a child could be realised during their life, when they became unwell and after their death. There was bereavement support that was offered to families after the death of their child. Charlton Farm provided a suitable environment for children and young people. It was clean and hygienic. There were a range of activities available within the hospice or that could be accessed in the community. The provider had responded to the differing needs of teenagers and young people and had tailored the service they offered in response."

Little Harbour

"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.

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."

2.2.6.2 User's Experiences

Further feedback for service users and comments from commissioners are provided in Part 3 of this report.

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 2016/17 by the Audit Commission.

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 2016/17

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 peninsula, 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 2016/17 we were again able to care for more children and families than in previous years.

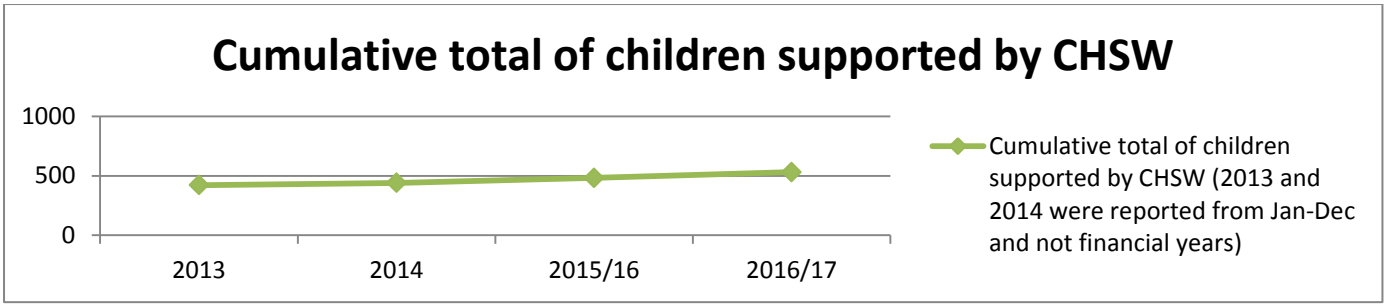
Caring for children in a local hospice not only has the benefit of making hospice care far more accessible, but it also allows the care staff in each hospice to develop closer and more effective working relationships with other services and professionals working with the families locally. This shared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

The opening of Little Harbour, with the subsequent transfer of some children and families from our other hospices, has also relieved the pressure at our other hospices, by freeing up demand at peak periods – which has meant that families have been more able to access care not just where they need it, but when they need it.

3.1.1 Activity Data

Caseload Activity	2015/16	2016/17
Children Supported (Cumulative total)	482	531
New Referrals	131	125
Referrals Accepted	97	110
Referrals Declined / Withdrawn	27	19
% of Referrals Processed within the CHSW Target Response Time	78%	93%
All Deaths on caseload	38	42
Discharge / Deferments	28	21
Families using the service (cumulative)	465	514
Families with more than one child using the service	17	17

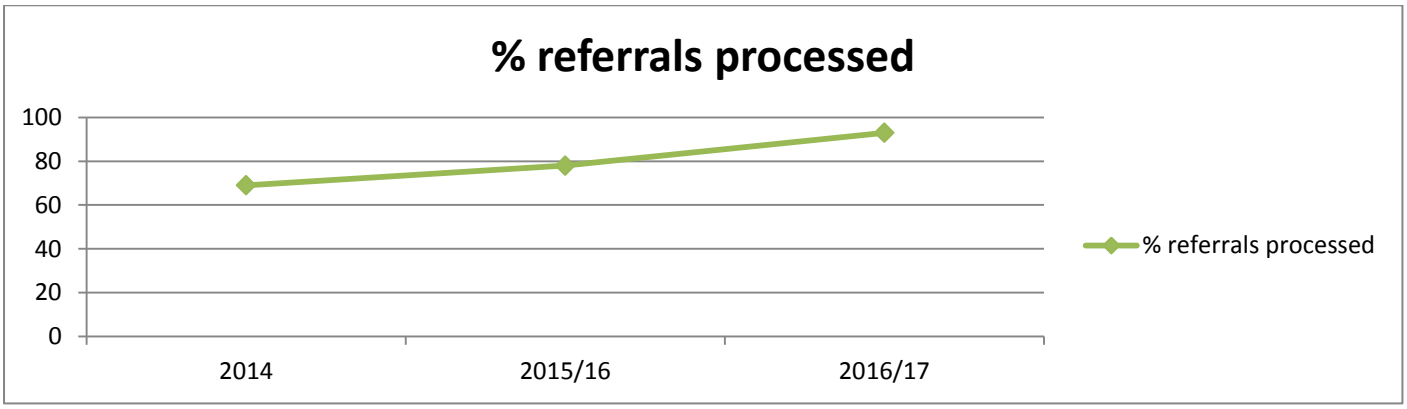
It should be noted that as referrals are continually being received, some will still be pending assessment at the start and end of a financial year. The numbers accepted and declined/withdrawn may therefore not match the total of new referrals during a year.



The Cumulative number of children supported by CHSW has increased steadily year on year by an average of 8%.

CHSW cares for children of all ages, from newly born infants to teenagers and some young adults aged up to 21, 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 Children's Hospice South West are those of Primary school age, 5 to 11 years old. There has been very little change in these ratios over the past 3 years.

Children using CHSW by age group:	2014	2015/16	2016/17
Pre-school(age 4 years or under)	18%	16%	17%
Primary school (age 5 to 11 years)	40%	40%	39%
Secondary school(age 12 to 17 years)	30%	28.5%	29%
Young adults (Over 18 years)	12%	15.5%	15%



During the course of 2016/17, 110 new referrals were accepted by CHSW a 13.4% increase on the previous year. This increasing referral demonstrates the on-going need for our services for children with life limiting conditions and their families.

What is important to note is that CHSW received 125 referrals during the year, but of the 19 children who were recorded as not accepted for hospice care, 11 of these children (58%) the reason for this was family choice rather than being declined a service. To maximise the reach of our service to children with life limiting conditions, we need to continue to raise awareness about our service and the particular group of children we care for and to address fears and anxieties amongst families about the use of a hospice.

A further 6 (32%) of the children were not accepted because they did not meet the diagnostic/assessment criteria. Whilst families recognised that it is good news that their child does not need the service of a

children's hospice, it is nonetheless disappointing for those who are not accepted that they cannot access the care and support we offer.

For these reasons, we made available new film material, to promote our service to both professionals and families of children with life limiting conditions. These short films are available on our 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 our remit for both professionals and children and their families. We are also looking at a redesign of our Website which will make it easier for both families and professionals to access information and resources. This is due to launch around the end of the Summer 2017.

Care Activity	2015/16	2016/17
Bed nights of Care Total	**4316**	**4090**
○ Emergency	302	390
○ Planned	4014	3700
Total Number of family stay nights	**9120**	**8035**
Parent/carer stay nights	5531	4854
Siblings stay nights	3589	3181
Total Stay nights	**13,436**	**12,125**

There has been an increasing demand for emergency stays in the last year. Each family is given an allocation of nights 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.

At both Little Bridge House and Little Harbour emergency stays have doubled in the last year. Emergency care by its nature is usually a stay requiring the most intensive medical and nursing support. This increase reflects the specialist nature of the provision we provide alongside the pressures on statutory services. This does have impact on the planned respite care because on occasions it can require a planned stay to be cancelled, something parents are aware of and we carefully monitor to ensure impact is minimised. This is reflected in the overall bed nights where Little Bridge House overall stays were reduced by 139 nights and Little Harbour by 253.

There is a national shortage of children's nurses in the UK and CHSW like all other organisations has seen fluctuations in staffing. During 2016/17 Little Harbours vacancy rate increased significantly which required us for a period of time to take a different approach. Safety is always a priority at CHSW so where necessary we cancelled planned respite to ensure we have been able to respond to emergency care but have also increased the number of children using the services for day visits which has helped us reach out to families who have not used our services before. A CHSW recruitment and retention strategy has been developed to ensure the impact of the national and local nurse recruitment pressures are minimised for our organisation and every opportunity is utilised to develop and strengthen our workforce.

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

We undertake a number of 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 e-mails. The following quotes are taken from a number of these collection methods:

- *"This has been our first stay and it has been fantastic. We were slightly apprehensive but we have felt so welcome and so refreshed. The staff have been brilliant with our disabled child and the sibling workers have been excellent. Our non-disabled child wishes she lived here! We feel like we have had chance to recharge our batteries for the first time in years and just enjoy being a family. Thank-you to everyone!"*

- *"It's a happy place for the children and families to stay. Really nice accommodation and surroundings."*

- *"The staff at Little Bridge made our stay very welcoming, looked after P well, Kind and caring accommodated all our needs"*

- *" Kept the children motivated and entertained really well"*

- *" We wouldn't have gotten through the tough times without Charlton Farm & CHSW"*

- *"I love staying at Charlton Farm and I've been coming here for almost 10'years now. You have helped my little sister through the bad times and without you I don't think she would be alive without you. Thank you"*

- *"Made to feel so welcome, nothing too much trouble, everybody so friendly and caring, both to E, myself, M and J. Always feel safe and so well cared for"*

- *"Looked after our son well. Gave him lots of 1 to 1 attention and care. Provided a good range of activities to keep him occupied and a varied selection of things to do. Our son loves coming to Little Harbour."*

3.1.3 We enriched the lives of children and families

At Children's Hospice South West 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.

During 2016/17 we offered over 12,000 bed nights care for children and their family members at our three hospices. 90% of these stays were for respite care with the remaining 10% being for emergency and/or end of life care.

Each of those days was 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.

At each of our hospices children and their families can enjoy themselves in our Messy Play rooms, soft play rooms, sensory rooms, Jacuzzis, and family activity rooms – complete with an up to date suite of

computers and computer games. Outside the gardens are full of exciting opportunities for outdoor play and all of our hospices have a wide range of family friendly destinations on their doorstep for trips and outings.

3.1.4 Enriching the lives of brothers and sisters

Healthy 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 to us. 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 and 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. Not only can the children relax and enjoy the fun activities which are offered, (and for many siblings these are activities they cannot join in with at home because of the needs of the life limited child at home) but they gain tremendous support from talking together and finding that the problems and concerns they have are shared by others.

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 holidays they also run themed activity weeks which are very popular.

3.1.5 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 regimens to sustain life. This means that the children who come to our hospices need to be cared for by expert 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.

We take the education of our staff very seriously as we know how important it is that the children are cared for by compassionate and competent staff. We employ Practice Educators at all our hospices to support the training and development of our Care Teams and to ensure they have the necessary skills and knowledge to care for the children safely and competently. The Practice Educators plan and deliver a comprehensive induction programme for all new staff which takes place during the first month of their employment. Throughout the year, all staff are provided with regular dedicated time for training and access to a wide ranging programme of training coordinated by the Practice Educators.

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 Paediatricians. These doctors are expected to support the clinical learning of all care and medical staff, both within CHSW and externally. During 2016/17 there has been a change in the medical team we have recently been successful in recruiting a new Medical Director at Charlton Farm at Level 3 who is currently working towards level 4. This prompt successful recruitment, in the current climate, is a reflection of how highly the work of CHSW is held by potential employees.

The senior care staff at each hospice continue to build strong relationships with the Community teams and maintain the schedule of regular monthly meetings. At CHSW we are very committed to building up the relationships with other professionals and sharing best practice as a consequence of this we have run a number of educational events and professional open days at each of our hospice sites.

We have also received compliments from other professionals who refer into our service which highlight the appreciation of the type of multidisciplinary collaboration which we try to achieve in providing the level of care and support to our children/young people and their families and carers.

Some of the comments that have been included:

- *"We just wanted to thank you all for being so accommodating and supportive to our team whilst YP was at Little Harbour for symptom management. They all loved their shifts and spoke very highly of all the staff. Thank you for everything you do you are all very special"* **Stay at Home Team**

- *"I have been really grateful for input and discussion in recent days from J, M and C, and wish to thank E and everyone at Charlton Farm for taking J at such short notice and for their very compassionate care last night."* **BMT Consultant**

- *"CDOP would like to commend Children's Hospice South West of the end of life care provided for this child and to thank you for your continued support and input into the child death review process."* **Letter from Child Death Overview Panel Sept. '16.**

- *"To All the Staff at LBH, Thank you all for the past 10 weeks. I have really enjoyed my time and feel very lucky to have worked with such lovely people and amazing children."* **Student Nurse**

- *"I'm writing to firstly say how impressed we were when we worked alongside you concerning the funeral of EM. The care and attention shown was phenomenal and seeing you all in action was both touching and humane. It's often the case that people tell me that they do not know how I do what I do, but I can honestly say the same to all of you. You truly are all special, special people."* **Bereavement Services Officer, James Brothers Funeral Directors**

3.1.6 We helped make a real difference in end of life care.

Bereavement Support	**2015/16**	**2016/17**
Number of bereaved families with whom we currently have contact	**281**	**306**
Total number of Bereaved families	484	528
Number of families using "Starborn"	26	45
Number of nights "Starborn" used	148	145
Total Hours spent on all activities supporting bereaved families (In house pre and post funeral care, visiting, supporting those on visit to hospice, bereavement events and sibling bereavement support)	7671 hours (320 days)	8655 (361 days)

We believe that bereavement care starts at the point your 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.

The care provided at end of life is holistic and takes into account 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 year we have also seen an increase in children requiring complex end of life care with long admissions requiring significant expertise to manage symptoms.

Despite overall care nights decreasing the number of children and families using Starborn after death has significantly increased this year reflecting the increase in emergency stays and the specialist care we provide. At CHSW we constantly strive to improve the care we can provide, particularly at the end of life, our mantra being: 'sadly, we only get one chance to get this absolutely right'.

3.1.7 We stayed alongside families, offering support and friendship, throughout their child's life and after death.

Facts and Figures 2014	2013	2014	2015/16	2016/17
Numbers of children who died	35	33	38	42

Sadly the number of bereaved parents being actively supported by Children's Hospice South West has been steadily growing and during 2016/17 we provided bereavement support to more parents and brothers and sisters than ever before. There are currently 528 bereaved families known to CHSW and 306 of these are still receiving active bereavement support.

On average, most children and families who use CHSW hospices use our service for 6 - 7 years. This means that the child and family develop a close relationship with care team staff, 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 return to our annual 'Remembering Day' or 'Bereavement Weekend' at each hospice.

There are also 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 all 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 by qualified psychologists. This has been very well received by staff and is now integrated fully into our staff support measures.

We now have a Senior Team Leaders (Family Support/Bereavement) for all 3 of our hospices and aim to appoint a full time Head of Family Support Services for CHSW early in the next reporting period. The Senior Team Leaders work with all CHSW care staff to enhance and improve the psycho/social and bereavement care available to families.

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.

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 in order 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 (KPI's) which the CCG's require but also those that are of use to CHSW as an organisation in the assessment, evaluation and development of services provided. The audits and reports generated as part of this schedule are shared at the Clinical Governance Meetings. Appendix 1 shows the Clinical Audit Programme that was used for the Clinical Governance Committee discussions in 2016/17. 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 3 main areas:

- Patient Safety and Clinical Effectiveness
- Management and Administration
- User Experience and Satisfaction

During the reporting period, this included:

- **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 and Accountable Officer Audit
  - Moving and Handling Audit
  - End of Life Care Plan Audit
  - Departure Letter Content Audit
  - AINM's 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

As well as these other QA activities include:

- CQC inspection report summary (External)
- Provider Visit (Trustees) report summary (Internal)
- Commissioner Visits (external)

Details for some of the key audits and reports for which information is disseminated to the CCG's follows.

3.2.3 Patient Safety and Clinical Effectiveness

A key priority for CHSW is the delivery of excellent, safe care. Patient Safety and Clinical Effectiveness is not just about monitoring and measuring care given or identifying risks after an incident has occurred. It is also about the proactive identification and management of risks and the systems being in place to introduce changes and make improvements when they are needed and monitoring of the changes to make sure they are both beneficial and sustainable. Both the proactive and reactive measures taken to improve patient safety and clinical effectiveness are incorporated into our Clinical Governance Framework through a schedule of audit, reporting, sharing of experience, learning and monitoring of progress. CHSW takes patient safety and clinical effectiveness extremely seriously and systems have been developed to support continuous improvement in all areas of service provision.

3.2.3.1 Accident Incident and Near Miss Reporting (AINMs)

AINMs Report		
Quality Objective	**Data 2015/16**	**Data 2016/17**
Number of SIRI's	0	0
Incidents requiring reporting under RIDDOR	1	4
Number of Never Events reported	0	0
Number of Falls categorised at level 4 or above	0	0
Infection Control		
Number of MRSA bacteraemia (post 48hrs)	0	0
Number of Clostridium Difficille (post 72hrs)	0	0
Needlestick / Sharps injuries	1	2
Pressure Ulcers grade 2 and above		
Admitted with PU	2	1
Developed within 72 hours	2	4
Developed after 72 hrs up to 72hrs post discharge	0	0
Duty of Candour Breaches		
Concerns raised under whistleblowing policy	0	0
Disclosure of information about poor care that has resulted in death or serious injury	0	0
Breaches in Duty of Candour disclosure/reporting	0	0

Information Governance		
Breaches by CHSW	2	11
Breaches involving CHSW information but not by CHSW	3	3
Comment: The increase in reporting is linked to increased awareness following training.		
Safeguarding Incidents		
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
child safeguarding incidents occurring on hospice premises: concern relates to family care (staff not involved in incident)	0	5
child 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.	1	0
child safeguarding incidents disclosed to staff not occurring on hospice premises and no staff involvement in incident.	5	2
Comment: There were no safeguarding incidents relating to staff. All safeguarding incidents identified appropriately referred to Children's Services.		
Care Health and Safety Incidents /Accidents		
Child	48	24
Sibling / Family	53	73
Staff/ Contractor	26	23
Equipment/facilities only	9	27
Care Near Miss Health and Safety Incidents /Accidents		
Child	4	2
Sibling / Family	1	2
Staff/ Contractor	2	0
Equipment/facilities only	4	4

Clinical Incidents (exc. Medicines)		
Child	154	146
Sibling / Family	0	6
Staff/ Contractor	0	20
Near Miss Clinical Incidents (exc. Medicines)		
Child	14	7
Sibling / Family	0	0
Staff/ Contractor	0	1
Total Incidents and Accidents	**332**	**370**
Data relating to Affected Children only		
Total Number of incidents	164	183
Number of Incidents leading to Moderate or Severe Harm	3	4*

*It is noted that all four incidents categorised a moderate or severe harm were influenced by external factors.

1 Medication error prescribed in the community (not by CHSW) and identified when the child arrived at hospice.
2 Fracture which was not conclusively dated and the cause unable to be identified in a child with fragile bones (fully investigated).
3 Child admitted post-surgery with a pressure sore on admission which continued to deteriorate.
4 Child contracted chicken pox which has a long incubation period and very likely contracted in the community prior to arrival (other children unwell at a family event), the illness identified during child's stay. Care was provided but the child declined and required hospitalisation and high dependency care.

Total Number of full Stays for affected children	1523	1525
Incident affected stays (Adjusted for stays were more than 1 incident happened in stay)	(NR)	179
% of Harm Free stays	99.81%	99.74%
% of Incident Free Stays	92.06%	88.27%

For 2016/17 Safeguarding, Infection Control, Information Governance, Duty of Candour Breaches, Falls and Medicine Incidents / Near Misses have been included in these totals but are also individually addressed later.

Complaints and Emergency Transfers have not been included but are discussed later.

AINMs Report	
Summary	
All risk as reviewed within the individual teams and the CHSW Clinical Governance Committee ensures oversight across the three bases and monitor learning from events. This year we have seen an increase in the number of incidents reported. However, this was a predicted increase and reflects awareness and training with the Care team regarding recognising and capturing risks and incidents. One key theme from clinical incidents relates to lifting and handling therefore this has been a topic for scrutiny and a focus for learning.	
Key Topics Learning	
Findings	**Action Plans / Progress**
There have been a number of incidents which have had an element of issues to do with "Moving and Handling".	• Organisational Review of Moving and Handling documentation for child/young person • Moving & Handling group have developed new care plan for this, introducing a traffic light system, pictures, risk assessments for each child • Documentation to detail which staff move & handle children within daily diary • Review and rewriting of the Manual handling policy and procedure has been started to make it a more usable document reflecting good practice. • The development of a resource and training portfolio for each hospice site which will include current best practice guidance.
Information Governance AINMs have increased. This is in part due to the increased awareness of the team to this type of incident because of the training that has been undertaken and an associated acknowledgement that reporting is important in finding out the reasons for this type of incident. The majority of these incidents have been around paper based notes and not electronic formats.	• Systems are being looked at to improve the manual filling and filing of notes with the future potential towards digital integration of clinical notes and point of care recording. • As incidents arise these are been used as an opportunity to remind staff of the importance of IG in team meetings. • An organisation wide session has also been provided at site meetings during Q3 and for care at the annual review training sessions.

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 are a reflection of the activities for this area of patient safety and clinical effectiveness.

a. Medicine Incidents and Error Reporting

	2015/16	Q1	Q2	Q3	Q4	Year End 2016/17
Number of CHSW medication Incidents that cause harm	**0**	0	0	0	0	**0**
Number of external medication Incidents identified by CHSW that cause harm	**0**	1	0	0	0	**1**
Total Number of medication incidents	**71**	18	14	27	25	**84**
Number of medication incidents that included Controlled Drugs (All Schedules)	**23**	6	7	8	9	**30**
% of Medication incidents that included Controlled Drugs (All Schedules)	**32.39%**	33.33%	50%	29.63%	36.00%	**35.71%**
% of medication incidents that cause harm	**0.00%**	5.55%	0%	0%	0%	**1.19%**
Number of near miss medicine errors/incidents	**13**	1	4	3	1	**9**

All CD incidents are reported via the South West CDLINs via quarterly reporting and attendance at the CDLIN meetings by the CHSW AOCD.

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

A number of these incidents continue to not be due to CHSW system failures but rather to the fact that the care team are continuing to be diligent in picking up errors either by their colleagues or external agencies, such as pharmacies and reporting these. The 1 medication incident that caused harm was one of these and has been detailed above.

The number of incidents and errors have increased from 2015/16 to 2016/17 but the continued training given during team meetings and due diligence of the nursing staff whilst and our skilled care staff who administer the medication (except C.D's) means that the number of actual errors is small in comparison to the number of administrations of medication (estimated at 54,000 for the year giving an error rate of less than 0.16%).

b. Medicine Management Audits and Reports

Medicine Administration Record (MAR) Audit		
Audit Tool	This audit tool has been developed in house, and is now part of the documentation audit.	
Target	Full compliance is the target but following discussions at clinical governance a tolerance of 85% is seen as acceptable with the addition of learning points to improve future compliance. This target will be reviewed in 2017/18 to reflect the standards being achieved.	
Result	Previous year: **93.61%**	2016/17: **92.07%**
Summary	The medicine chart audit continues to evidence safe standards of practice across all 3 sites. The slight drop is due to the addition of 2 more variables to audit which was thought would be useful for practice. Regardless of this there are still a number of areas that need to be addressed (see learning points below).	
Key Learning Points and Recommendations	• Recording of some children's weights still appears to be an issue there are some of the larger young people who refuse to be weighed at the hospice however a request can be made that this is done at visits to the hospital and the latest weight recorded as long as it is no more than 12 months ago. • Recording of allergies although good fell down for some children in that the reaction had not been completed.	
Progress to date	Recommendations for improvement have been raised at clinical governance, heads of care and regular monthly team meetings.	
Planned future actions	Changes to documentation and policy if needed will go through the relevant subcommittees	

c. Controlled Drugs

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	Previous year: **95.83%**	2016/17: **94.19%**
Summary	This year's result was based on 2 separated audits at 6 month intervals. September 16 and March 17. The overall results have remained fairly stable	
Key Learning Points and Recommendations	1. An improvement was required in the way in which paperwork was filed and available for audit access. This has been achieved to a degree but there is still some work to do. The SOP's need to be clearer and a project addressing these will be commenced late 2017. 2. We have some issues with ordering of stock controlled drug and are moving towards SLA's with the local trusts at 2 of our sites. This should enable us to tighten up on the processes around this. These should be in place towards the end of the summer 2017.	
Progress to date / Planned future Actions	1. Associated SOP's will need to be updated to reflect the new SLAs. 2. All SOP's are under review along with a revamp of the Medicine Policy to split up the policy from procedure to make it a more useable document. This is planned to be completed by end of the summer 2017. 3. The policy in relation to recording and monitoring of CD's has been raised with the medical teams as part of a training session and the AOCD now attends these meetings. 4. The AOCD continues to provide reports to the Clinical Governance Committee on the results from this audit and the AINMs reporting on a bi-monthly basis.	

3.2.3.3 Infection Prevention and Control Audits and Reports

A number of 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	**Data 2015/16**	**Data 2016/17**
Total Number of Infection Incidents and Near Misses	1	4
Number of MRSA Bacteraemia cases (post 48hrs admission)	0	0
Number of Clostridium Difficile (Post 72 Hrs after admission)	0	0
Number of Needle Stick Injury Incidents	1	2
Outbreaks of other diseases or infections	NR	2
% of Staff who have completed Annual Infection Prevention and Control Training	83%	86%

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	Previous year: **95.32%**	2016/17: **90.85%**
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. We believe the slight drop in compliance relates to a high number of new staff and we continue to monitor this closely.	

c. Consolidated Infection Control Audit Results		
Audit Tool	Hospice UK Toolkit	
Result	Previous year: **95.15%**	2016/17: **88.21%**

Summary

	Module	2015/16	2016/17
1	Policies and Processes	68%	81%
2a1	Hand Hygiene	95%	87%
2b1	Hand Hygiene- Observed Practice	91%	96%
2a2	Hand Hygiene	X	95%
2b2	Hand Hygiene- Observed Practice	X	86%
3	Patient Areas	X	92%
4	Clinical Rooms	X	96%
5	Patient Bathrooms	X	97%
6	Patient Toilets/Bidets	X	99%
7	Sluice/Dirty Utility	79%	91%
8	Domestic Rooms	83%	82%
9	Care of Deceased Patients	X	76%
10	Sharps	X	83%
11	Protective Equipment	X	84%
12	Kitchen Areas (inc. Main Kitchen)	80%	77%
13	Public Areas	X	95%
14	Public Toilets	X	92%
15	Offices in Clinical Areas	82%	89%
16	Visitor Accommodation	93%	89%
17	Hydrotherapy Pool areas - (IPC adapted Tool)	91%	78%
	Overall Totals and Compliance for areas audited	85%	88%

	Following a review of infection control and prevention audits early in 2015/16 it was decided to move towards an audit tool 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 audit to cover an area of particular concern. This is the first year that this schedule has been followed in full so it is hard to compare with last year's compliance figures. The advantage of using this toolkit is that infection prevention and control audits can be spread throughout the year, ensuring continued vigilance by all staff.
Key Learning Points and Recommendations	Overall the compliance demonstrates good practice with some excellent results. There are 7 areas which dropped below the 85% benchmark set by CHSW. Following a review interpretation of the tool was identified as an issue which has identified the need for further reviewed and clarification of the tools for staff undertaking audits. For each individual hospice there are specific areas that need to be addressed and these now form part of their action plans. The lowest result was seen in the audit of deceased patient care and the key learning from this audit it the lack of consistency in recording across the three bases. A review of the SoP has been given a priority in the year ahead with a focus on providing clarity for staff about standards which will be monitored through repeat audit next year. To help drive forward the infection control agenda each site has identified an Infection Control lead to improve consistency and drive the agenda forward. The Senior Team Leader Quality is working with the leads and the Practice Educator at each site to ensure that the audits take place and that learning is then disseminated to their respective teams. During 2016/17 there has been a major piece of work being carried out by the Policy and Practice Committee with the Head of Quality and Compliance and the Infection Control leads on ensuring that policies and processes for infection control and prevention are reviewed. These are due for review and ratification by the end of July 2017 and should go a long way in setting up a more systematic approach to infection control and prevention. Part of this work has also included the development of guidance and resources to help staff easily find information when it is required. It is acknowledged that the amount of change and work already started in this area is having a positive effect.

3.2.3.4 Safeguarding Children and Adults

As part of the requirements included within the NHS standard contract Children's Hospice South West (CHSW) holds with Clinical Commissioning Groups (CCG) across the South West is for the organisation to provide a report on our performance against 10 core safeguarding children standards. These are:

1. Governance and Commitment to Safeguarding Children
2. Policy, Procedures and Guidelines
3. Appropriate Training, Skills and Competences
4. Effective Supervision and Reflective Practice
5. Effective Multi-Agency Working
6. Reporting Serious Incidents
7. Engaging in Serious Case Reviews
8. Safe Recruitment and Retention of Staff
9. Managing Safeguarding Children Allegations Against Members of Staff
10. 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 that are unique to adult safeguarding as covered in the NHS key performance indicators statements are:

1. Prevent
2. Deprivation of Liberty Safeguards (DoLS)
3. Mental Capacity Act
4. Whistle blowing
5. Domestic violence and abuse
6. Learning Disability (LD) are being addressed & 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.

1. *Empowerment* – adults at risk are supported to make their own decisions
2. *Prevention* – It is better to take action before harm occurs
3. *Proportionality* – The least intrusive response appropriate to the risk presented.
4. *Protection* – Support and representation for those in greatest need.
5. *Partnership* – Local solutions through services working with their communities.
6. *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.

a. Safeguarding Incident and Training Data Report		
Quality Objective	**Data 2016/17**	**Compliance**
% Staff completing annual Adult Safeguarding Level 2 training	LBH	100%
	CF	75%
	LH	91%
% Staff completing annual Adult Safeguarding Level 3 training	LBH	100%
	CF	93%
	LH	70%
% Staff completing annual Child Safeguarding Level 2 training	LBH	96%
	CF	73%
	LH	91%
% Staff completing annual Child Safeguarding Level 3 training	LBH	93%
	CF	93%
	LH	95%

Summary

Level 3 safeguarding training is external. Hospice compliance reported separately as the levels definitions of Level2 and 3 differ between LSCBs across the southwest. For example Level 2 in Bristol is Level 3 Devon.

In addition all care staff receive at induction and annual training 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 will do catch – up sessions.

A with the exception of staff on maternity leave and on long term sick leave plan is in place for staff to complete training.

Further information on Safeguarding Incidents:

Little Harbour: There were no safeguarding incidents at Little Harbour or disclosed to staff during this period.

Little Bridge House: 3 of the incidents/concerns were reported to either the local safeguarding board or the relevant social worker involved. None of the incidents/concerns involved CHSW staff or care received.

Charlton Farm: All 4 safeguarding incidents/concerns were either reported to the local safeguarding board or family social worker. None of the incidents/concerns involved CHSW staff.

There were no incidents or safeguarding investigations relating to staff or care received.

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 that 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. It is important that these are effective and audits and tabled reports have been developed that specifically look at these areas.

3.2.4.1 Care Documentation Audit		
Audit Tool	CHSW Audit tool	
Target	100% for each of the 3 areas of the audit with a tolerance of 85% with learning points and action plans put in place.	
Result	Previous year: **83.40%**	2016/17: **85.04%**
Summary	The aim of this audit tool is to facilitate local audit of the records kept and held by each hospice against the procedures set out in the CHSW policy. It is an important function of this audit to give assurance that records are created and maintained to the highest possible standards of accuracy and completeness whilst remaining clear and concise. The standards to which records are kept are set out within the CHSW policy and are intended to meet Regulation 17 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 which includes the following: "….. providers must securely maintain accurate, complete and detailed records in respect of each person using the service and records relating the employment of staff and the overall management of the regulated activity." And also standards and guidance set out by other related legislation and professional bodies including but not limited to: Data Protection Act 1998 Access to Health Records Act 1990 Records Management: NHS Code of Practice, Part 2 Annex (2nd Edition) 2009 NMC - The Code: Professional Standards of Practice and Behaviour for Nurses and Midwives GMC – Good Medical Practice: Guidance for Doctors' RCP – Approved Generic Medical Record Keeping Standards (2009) HSCIC – Standards for the Clinical Structure and Content of Patient Records. (2013) This audit tool allows care staff and the clinical governance committee to audit: • Retrospectively collected data • Recent admissions with a length of stay no more than 2 days longer than an average stay (3 days) or shorter than 24 hours. • Notes that reflect the involvement of the multidisciplinary care team in the management and care of a child or young person for the duration of their stay • Compliance by the multidisciplinary care team in maintaining good record	

keeping practice as set out in the CHSW policy

Process

This audit is divided into 3 parts the first looking at the "Medical Notes" that have been kept for the child and the second part looking at the associated "Care Plan" for the stay, finally a specific look at the MAR sheets. It is run on 2 occasions during the year and the results collated.

Results

	Medical Notes/ Daily Diary		Care Plans		MAR sheets	
Compliance %	**2015/16**	**2016/17**	**2015/16**	**2016/17**	**2015/16**	**2016/17**
CHSW overall	**77 %**	**92%**	**80%**	**73%**	**93%**	**90%**

Key Learning Points Recommendations	The inconsistencies highlighted last year with the audit tool have been addressed and the "in-audit" help page was developed to assist staff in the interpretation of the questions as required. Based on a qualitative review compared with the audit from last year there has been a slight overall improvement in compliance however the care plans seem to have suffered particularly with a drop in compliance against the audited areas. The main areas for improvement are: • Ensuring that all pages are dated properly • Ensuring that gaps at the end of entries and pages are scored through properly • Care Plan versions need to be consistent, some were not up to date and in the correct order. • Use of Pain assessments for all children
Progress to date / Planned future actions	Work by the documentation group has helped with ensuring that the documentation in the care plans in particular are up to date and reflect best practice. This has helped to a certain extent but the whole issue of care planning and use of care plans will also be the focus of a project during 2017/18 of the use of digital and point of care technology which may streamline the processes much better.

3.2.4.2 Departure Letter Audit		
Audit Tool	CHSW Audit tool –(Database Query Tool)	
Target	100% all planned respite letters to be sent within 5 working days and emergency stay letters within 48hours (2 working days)	
Result	**2015/16:** 98.8% - Respite 94.4% - Emergency	**2016/17:** 99.26% - Respite (1210 letters) 91.86% - Emergency (86 letters) 98.77% - Overall (1296 letters)
Summary	This was the first year that 100% of all letters were looked at. Previously a sample of 300 random letters across the organisation were looked at as a sample group. In total there have been just 16 letters that did not go out in time. 7 of these related to emergency letters which were sent out following the bank holiday periods, they were delayed due to the doctor who dictated them not being on duty to sign until after the 2 working day cut off. The 9 Respite letters that were outside of the cut off period were due to a number of reasons but mostly due to oversight during very busy periods.	
Key Learning Points Recommendations / planned actions	This was discussed at clinical governance and in future another doctor or designated person can review and sign the letter on behalf of the doctor who dictated it. Also systems have been put in place by the administrators at each site to ensure that the letters are dictated and processed in a timely way and not missed.	
Progress to date	The Senior Administrators have written SOP's for their sites and an overriding statement will be included in the policy and procedure for the next review.	

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 Committees' agenda. 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 that 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 2016/17 we had the following complaints and concerns raised, 3 Formal complaints received and all dealt with within our complaints policy framework and timeframes. There were also 7 informal concerns raised which were dealt with within the complaints

policy framework and timeframes. There were no consistent themes in the concerns and complaints raised.

Learning from these incidents has been disseminated at local level and where appropriate across the organisation. Discussion has also been entered into as part of the clinical governance framework and meeting schedule. The discussions from last year have led to an adjustment being made to our care database in order to pick up informal concerns and compliments more consistently in future. It will also allow us to analyse more closely all Compliments, Concerns and Complaints.

CCG	Type of Complaint
Kernow CCG	1 formal complaint and 1 concern
New Devon CCG	1 formal complaint and 4 concerns
Somerset	1 formal complaint and 2 concerns

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 being 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.

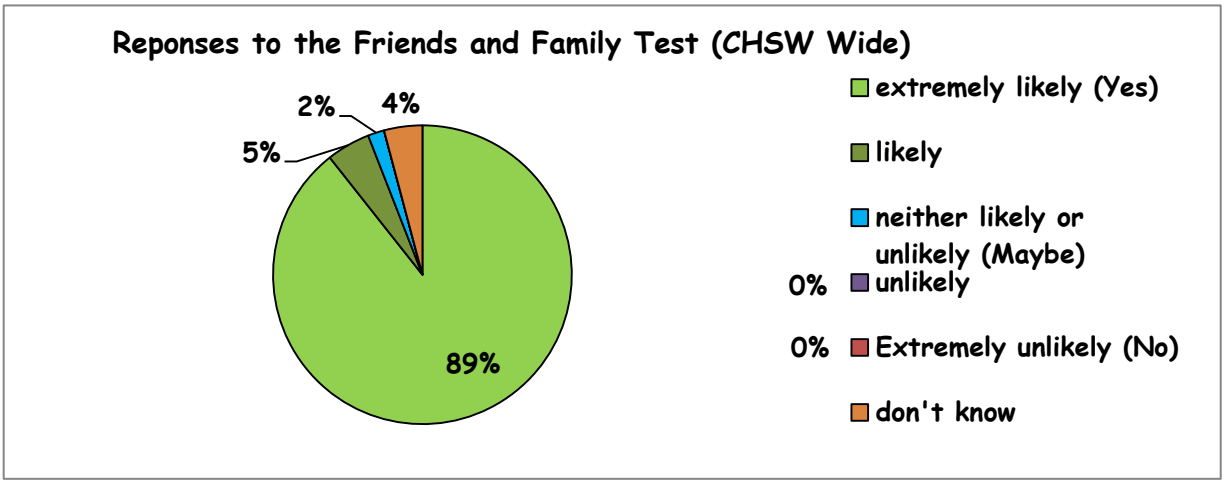
3.2.5.2 Friends and Family Test Audit

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 Children's Hospice South West 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 that lead to good experiences for the children / young people and families that use our services.

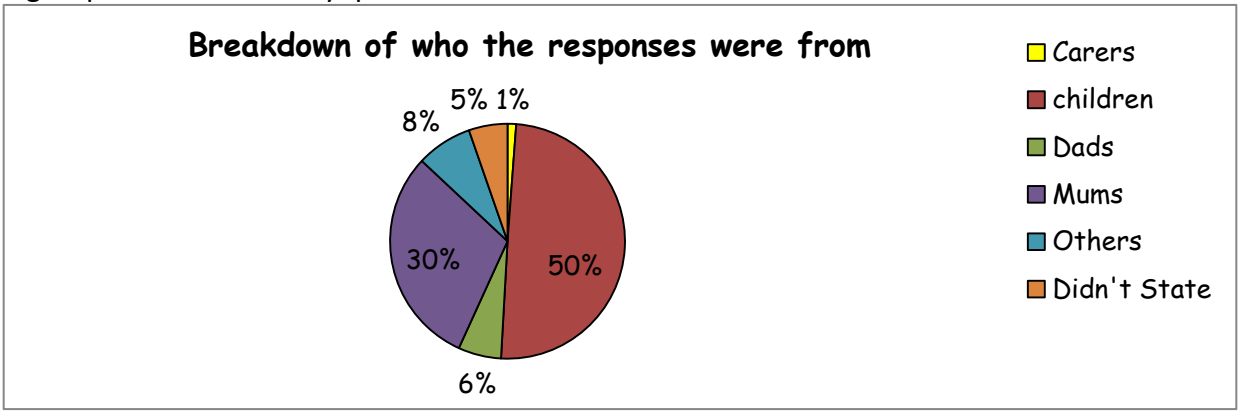
Last Year CHSW invested in a data collection platform which has been specifically developed to engage children and young people in participating in feedback about their care. The Orovia project (named after the company that supply and have developed the platform) uses the National Paediatric Toolkit™ (NPT) . This is 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 – in fact anywhere where the opinions of this traditionally hard-to-engage audience are sought. The toolkit is installed on i-pads at each hospice site in the reception areas and it has also been installed on portable tablets to offer to the Children, young people and their families for point in time recording of satisfaction and FFT. We are very grateful to Lifelites in their support for this equipment.

We also ran a paper based child friendly version of the Friends and Family test using the "Ask Monkey" questionnaires which are also used by NHS paediatric centres and are produced by monkeywellbeing.com and a paper based larger satisfaction survey for parents and carers.

Friends and Family Test Audit		
Audit Tool	National Paediatric Toolkit platform - Orovia	
Result	**Previous Year: 94%**	**2016/17: 94%**
Summary	As we used both and adult and child friendly version of the friends and family test the collation of the results was done by linking children's' answers of yes to the extremely likely category , no to extremely unlikely, maybe as neither likely or unlikely and recording don't know independently. This gave us an overall result of 94% being extremely likely or likely to recommend us to friends or family. The full break down of the results can be seen in the pie chart below. In total we received 169 responses which is more than previous years (almost 20% increase on last year):	



The breakdown of who made the responses was very interesting as 50% were children who use the service of which 18% were affected children and 32% were siblings. Although mums are always willing to respond to questionnaires we put out for this survey 6 % were from dads a group who are normally quite non vocal.



3.2.5.2 Feedback and Comments

Comments and Compliments are also captured as part of the questionnaires and satisfaction surveys which were run from the Orovia Platform and from our social media networks, comments cards and by direct contact from families who use the service by letter and e-mails. Some of the comments made which are very typical of the large number we receive are shared below:

For Little Bridge House

"Generally looking after our children so well, that as parents we are confident to leave their care in the hands of the carers. Having carers with experience and knowledge of supporting us as a family. Very lovely carers, enable parents to have a complete break over 24hr periods, sibling support workers looking after siblings."

"There is so much I want to say but just can't find the words. How can we possibly begin to put on paper what you and everyone at LBH has come to mean to us over the years. LBH became our haven, somewhere we could come to shut out the world, somewhere we could feel totally relaxed for a few days. I remember saying after our first visit that I felt my batteries had been recharged and I was ready to take on the world again. And that's exactly how I've felt after every visit. LBH became a massive part of our lives and it's hard to imagine life without the love and support we have received. The last 12 years have flown by and those 2 little 8 year old girls have blossomed into 2 beautiful and inspirational young women. Soon to celebrate their 21st Birthday. I just want you to know that you and everybody at LBH has helped influence them to become the confident, independent women they are today. Thank you from the bottom of our hearts for your devotion and kindness. We are really going to miss our visits and all of your smiling faces. I won't say goodbye as we will be back to see you all and we will continue to raise awareness of your amazing work whenever we can. With all our love and gratitude."

"…You somehow managed to make the unbearable bearable and we will always be in your debt…"

"To everyone at LBH, Thank you for all the care and support you have given all of us over the last few years. We have such fond memories of our time spent here. Little Bridge will always be in our hearts. Kindest Regards."

For Charlton Farm

"I have really enjoyed going to Charlton Farm and I never get bored even after 5 years of coming. I really enjoyed going out to places with the sibling team but I also enjoyed just sitting around and getting a chance to relax. The amount of effort that goes into making my stay amazing is brilliant and it never fails to impress me."

"You always look after us when we need it …."

"Firstly, just a quick but heartfelt thank you from all of us to all of you: having spent most of the past month at Charlton Farm, we've really come to appreciate the 'home from home' atmosphere which you try you utmost to make possible - and succeed. We can more or less say that we've have excellent support from the whole team. Thanks one and all."

"You provide a peaceful, caring, friendly and restful place where we can relax knowing our child is looked after in a professional yet homely way."

"Firstly, just a quick but heartfelt thank you from all of us to all of you: having spent most of the past month at Charlton Farm, we've really come to appreciate the 'home from home' atmosphere which you try you utmost to make possible - and succeed. We can more or less say that we've have excellent support from the whole team. Thanks one and all."

For Little Harbour

"*We have been coming to Little Harbour from the first year it opened we have always received a warm welcome and fantastic care for our young man. There has always been someone to listen to us and to support us in so many different ways."*

"There is absolutely nothing I can think would improve the amazing service provided for the child, siblings and whole family, Thank you!!"

"I have had a wonderful relaxing stay. Thank you for all you care and kindness xxxx"

"'Little Harbour made us all enjoy and relax and consume every second we had with our beautiful girl. So we could be together as a family and have precious memories of us all there. Thank you really doesn't justify how we feel."

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 that 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:

- interview children and families in order to understand their experience of care and assess the standard of care being provided;
- interview staff to understand their experience working for the organisation;
- to inspect the hospice;
- to inspect the record of complaints held by the hospice;
- to prepare a written report on the conduct of the hospice;
- to ensure engagement of the trustees with the service;
- assuring the Executive Committee of the quality of the service being provided;

The trustees visited all three hospices during the reporting period. 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. Their reports are disseminated to the local team and to the executive board for consideration and recommendations are made on improvements that could be made.

a. Summary of the actions identified for care:

Hospice	Highlighted Issue	Update
Little Bridge House	Bed vacancies	Alternative shifts patterns currently being piloted at LH to provide better cover and enable increased bed occupancy. Increased Day Visits have been popular and reached children who would not have utilised services.
	Shared learning across the organisation	Case presentation at South West Palliative Care Network. New processes introduced by Director of Care to improve join learning.
	Sibling outreach work to be more structured	Review of the Sibling Team planned as part of care review.
Charlton Farm	Development opportunities for carers	This is included in the CHSW 2017 / 18 nursing recruitment and retention strategy.
	Parents to be informed of visits	Head of Care will work with Trustees to achieve ahead of next visit.
	Larger sensory room	There has been investment in more mobile sensory equipment to ensure children have access across the site not just within the sensory room.
Little Harbour	Flexibility of shift pattern	A pilot is underway of mixed shift patterns (long and short days) which will run for 6 months then be evaluated.
	Shared learning across the organisation	Case presentation at South West Palliative Care Network. New processes introduced by Director of Care to improve join learning.
	Further development of the bereavement service	In the next year there is a plan to recruit into a Head of Family Support post which will have responsibility for leading this project.

3.2.6.2 Commissioner (CCG) Visits

As part of the scrutiny of our service by the CCG's, 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 only one CCG requested a site visit. BANES CCG visited Charlton Farm, although no formal report was made they expressed their thanks for the visit and the insight into the provision of paediatric palliative care and respite services provided by the team at Charlton Farm. It is envisioned that in the future more of these visits will take place and that the regular contract reviews may be the platform for this to happen.

3.3. STATEMENTS FROM COMMISSIONER AND LOCAL SCRUTINEER

CHSW submitted our 2016/17 quality account to NHS Bristol, North Somerset and Gloucestershire CCG who kindly replied with the following statement:

Statement from NHS Bristol Clinical Commissioning Group (14th June 2017)

Bristol, South Gloucestershire and North Somerset CCGs (BNSSG) welcomed the opportunity to respond to Children's Hospice South West (CHSW) quality account for 2016/17. This statement is made following a review by members of its Quality and Governance Committee and quality colleagues within BNSSG.

BNSSG CCGs congratulate CHSW on their achievement of the overall CQC rating of "Good" with all three hospices being rated as 'good'. Notably 2 hospices achieved "Good" and 1 hospice was rated as "Outstanding" for the 'caring' domain.

The CCG was pleased to note the commitment to research and particularly the work being undertaken to look at benchmarking measures for children's palliative care with the aim of developing an outcomes framework for children's hospice services that will enable common and robust monitoring of care of children in hospices.

BNSSG CCGs would like to draw particular attention to the engagement of CHSW in the Child Death Overview Panel (CDOP) and the difference they make to families, noting that this notable practice is frequently mentioned in cases where they have been involved.

The report also identifies services managing higher demand whilst developing improvements to sibling and bereavement support.

The CCG was pleased to see the inclusion of patient feedback and experience within the report and the positive work undertaken to engage with children/young people and their families including the introduction of a child friendly version of the friends and family test.

BNSSG CCG noted the decrease in the infection control audit results. We support the approach being taken to improve these results and look forward to seeing the results of the implementation of actions and recommendations from this.

BNSSG CCG noted the minor areas for improvement in relation to the CHSW services that were identified through the CQC inspection, including; improvements to staffing to improve the number of families that can be supported in Little Harbour; record keeping and assessing periodically staff competency for completing specific tasks at Little Bridge House.

The CCG noted the excellent practice with DoLs champions at each base and good awareness of transitional ages. The report demonstrates awareness of the new statutory guidance expected with a plan to implement.

BNSSG CCG also acknowledge the excellent innovation of the paediatric rotational nursing post as opportunities to gain experience in this area is very difficult.

We observe that compliance for safeguarding training is good with 90% achievement for training at all levels, however would like to see a proposed trajectory for Charlton Farm whose current training level are noted to be 75% for Adult Level 2 and 73% for Children's level 2.

BNSSG CCG also welcome the invitation to undertaken an observation assurance visit in 2017/18.

Having reviewed the quality account BNSSG CCG considers that the report provides an accurate and comprehensive reflection on the quality performance during 2016/17. The CCG welcomes the improvements and progress made by CHSW and their acknowledgement of where further improvement work is needed and we look forward to working with CHSW in 2017/18.

Cecily Cook, Quality Assurance and Improvement Lead Nurse. Bristol CCG

APPENDIX 1 – Topics and Tabled Reports Schedule 2016/17

CLINICAL GOVERNANCE
TOPICS FOR MEETINGS 2016 - 2017

DATE OF MEETING	TOPIC	TABLED REPORT
3rd March 2016	**Health & Safety** 1. Moving and Handling Audit	• Bi-Monthly AINMs Report • Annual Infection Control Report • CD Self-Assessment Report
5th May 2016	**Documentation & Education** 1. Documentation audit – Practice Educators 2. Version control audit – Heads of Care 3. Education audit – Practice Educators 4. Audit of departure letters (quantitative) – Admin team	• Bi Monthly AINMs Report • Education and Training Review - Practice Educators
7th July 2016	**Annual Reports** 1. Annual Safeguarding Audit 2. Annual Friends and Family Test	• Annual Quality Account • Annual Safeguarding Report • Annual AINMs Report/Summary
1st September 2016	**Medical Directors Audits and Reports** • Audit of departure letters – content (qualitative audit) • Audit of end of life plans	• Bi Monthly AINMs Report • In house deaths • Resuscitation events • Emergency transfers
3rd November 2016	**Medicine Management** 1. Medicine chart audit – Heads of Care 2. Medicine Management Audit	• Accountable Officer Report
JANUARY 2017	**Transition and Challenging behaviour** **1. Transition Audit** 2. Planning topics	• Bi Monthly AINMs Report • Report on managing challenging behaviour – Julie Stanway

DATE OF MEETING	TOPIC	AUDITS AND REPORTS
2nd March 2017	**Health & Safety**	• Moving and Handling Audit • Infection Control Audits and Report • Sepsis Audit and Report
2nd June 2017	**Documentation & Education**	• Documentation Audit • Version Control Report • Education/ training Audit and report • Departure Letter Audit
4th August 2017	**Annual Reports**	• Annual Safeguarding Audit and Report • Annual Friends and Family Test • Annual Quality Account • Annual AINMs Report/Summary
7th September 2017	**Medical Directors Audits and Reports**	• Referrals Audit • Departure Letter Content Audit • End of Life and Symptom Control Reports • Resuscitation and End of Life Plans Audit
2nd November 2017	**Medicine Management**	• Medicine chart audit • Medicine Risk Management Audit • Medicine Errors Report • Accountable Officer Report • Controlled Drug Audit
4th January 2018	**Transition and Behaviour that Challenges** **Planning for 2018/19**	• **Transition Audit** • Behaviour that Challenges Report

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 that 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.
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 that 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 in order 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.
CDOP	Child Death Overview Panel – This is a multiagency panel set up by the Local Children's Safeguarding Board (LCSB) under Regulation 6 of the Local Safeguarding Children Boards Regulations 2006. It has the responsibility to review all circumstances in relation to the deaths of any children for a local area.
CEO	Chief Executive Officer – is the most senior corporate officer,

	executive or leader in charge of managing an organization.
CHSW	Children's Hospice South West – the three hospice sites are: **CF** = Charlton Farm, **LBH** = Little Bridge House, **LH** = Little Harbour
Citrix	This is the Central Server for the management of the organisations computer system.
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 proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care.
Cyber Security	The body of technologies, processes and practices designed to protect networks, computers, programs and data from attack, damage or unauthorized access.
DoLs	The Deprivation of Liberty Safeguards are 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	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 to give your views after receiving care or treatment across the NHS.
Gap Analysis	A technique that 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	The General Data Protection Regulation (GDPR) is a legal framework

	that sets guidelines for the collection and processing of personal information of individuals within the European Union
IG	Information Governance - is the set of multi-disciplinary structures, policies, procedures, processes and controls implemented to manage information.
IT	the study or use of systems (especially computers and telecommunications) for storing, retrieving, and sending information.
Lifelites	Lifelites is a charity that provides specialist entertainment and educational technology packages for Children's Hospices. LifeLites.org
Monkey Survey	A child friendly survey produced by Monkeywellbeing.com this is used to obtain information and valued feedback on children and families experience of their care.
MRSA	Methicillin-resistant Staphylococcus aureus infection is caused by a type of staph bacteria that's become resistant to many of the antibiotics used to treat ordinary staph infections.
NMDS	National Minimum Datasets - is a minimum set of data elements agreed for mandatory collection and reporting at a national level.
NPT	The National Paediatric Toolkit is a unique innovation that uses animated methodology to capture the opinions and experiences of children and young people in settings such as healthcare, education and social services
Orovia	This is the company that has developed the software and support package for the National Paediatric Toolkit.
PPM	Paediatric Palliative Medicine - specialized 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.
SOP	Standard Operating Procedures – is a written procedure prescribed for repetitive use as a practice, in accordance with agreed upon specifications aimed at obtaining a desired outcome.