children's hospice SOUTH WEST

Quality Account 2017 - 2018

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

www.chsw.org.uk

Registered Charity No. 1003314

Contents

Introduction

This Annual Quality Account for Children's Hospice South West (CHSW) is compiled from data for the period 1 April 2017 to 31 March 2018.

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 which 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 fourth Annual Quality Account. 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

This past year, despite sluggish economic growth and uncertainty, has seen the Charity's finances strengthen yet again, thanks to the generosity of thousands of people in the region. Of particular note was the number and record amount of legacy income received from those who remembered the charity in their wills.

The resulting and continued financial security has allowed us to provide more help to sick children and their families than ever before, as well as improving the range of services offered. We have invested more in staff training, clinical services and in care management in order to meet the needs of the increasing number of sick children with very complex medical needs. The scenario of increased medical and nursing complexity for those children and young people we care for will gather pace as the boundaries of the care the State can offer reduce and as medical advances are made.

This report makes such encouraging reading and thank you for whatever part you have played in our success.

Most importantly, I am assured the quality of the care we offer remains of an exceptionally high standard, well summed up in these words this year from two of our families:

"Without the support, guidance and care we received from all the team at Charlton Farm, we would not have coped."

"We were supported every step of the way from the early days to the end by an amazing team of carers who always showed so much care, respect and love for our very special children."

David Turner
Chairman of Trustees

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Chief Executive's Report

In 2017-2018 the Charity launched a new Strategic Plan setting out ambitions for the next five years.

The plan says what we want to achieve in response to the changing environment in which we work; in summary the key points are:

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

Above all, however, we want to deliver excellence in all we do. As our chairman has stated, Children's Hospice South West is well placed to face these challenges with confidence.

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

Thank you all once again for your continued support.

Eddie Farwell MBE
Co-Founder and Chief Executive

Director of Care's Report

We are incredibly proud of the reputation we have as a provider of excellence, and the feedback we have from children and families is inspiring. However, we also recognise there is much to achieve in the year ahead; with the arrival of the new Head of Education and Development we are reviewing our opportunities and standards for training including mandatory training and clinical competencies. We have introduced on-line training tools to support mandatory training and for the year ahead have prioritised a commitment to ensuring compliance levels for training and audits are met, ensuring the highest quality of care for children and families, and all staff are supported in their development.

This year we have focused on risk ensuring our teams are empowered to recognise and report risks, and that we use learning from incidents to improve safety and quality care. This has seen reflection and investigation tools embedded and we have introduced learning summaries to help us share the learning across the organisation.

The Care Team have been responsive and adaptive in new approaches to working, demonstrating their commitment to quality and delivering excellence. We have managed this year with some significant vacancies in our quality roles; we are pleased to report as this year closes the majority of these posts are now recruited into. In addition, we have developed a new role of senior carer recognising the expertise our carers have and the valuable role they can contribute to quality monitoring and staff training.

Allison Ryder
Director of Care

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Part 2: Priorities for service quality improvement 2017/2018 and statements of assurance from the board

2.1 Priorities for service quality improvement 2017/2018

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. The following tables set out our achievements on the priorities set in the last financial year and look forward to the priorities for clinical quality improvements in the coming financial year, why they have been identified and how they will be achieved, monitored and reported. They span the three key areas of Patient Safety, Clinical Effectiveness and Patient Experience.

2.1.2 Achievements on priorities for 2017/2018

Priority area	Achievements to date
Patient safety	
1 Deprivation of Liberty Safeguards (DoLS)	This year CHSW continued to refine and implement the organisational approach to DoLS established last year. This included: Clear organisational leadership for DoLS (Deputy Director of Care), with champions at each base at a Senior Care Management Team level. This has also been strengthened by the addition of a Head of Psychology and Family Support at the end of this reporting period who will support these champions. Guidance and training for staff which has been incorporated into the annual mandatory training schedule. The ongoing development of this will include the expected legislative changes and the updated guidance as it is published. Embedding of DoLS into work with young people over 14 years as part of transition care has progressed and all young people now are assessed using the documentation developed last year and refined this year. In recognition of relevance for the children and young people accessing our service and the additional National Guidance due to be published we will continue to have a safeguarding theme next year.
2 Information Governance	The organisational aim for this year was: 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. CHSW has an Information Governance Committee chaired by the Director of Care and a working group specifically focusing on the impact of GDPR ensuring we are ready to meet the new legislation. This will continue to be a focus for the year ahead to reflect the new changes from May 2018.
Clinical effectiveness	
1 Improved use of technology to support care records	Work has continued with the care database, and the range and number of reports which can now be gathered from the system has increased. In line with the work on GDPR, action plans regarding scanning and storage of archived records with set review dates for destruction are on target. Plans for full digitisation of care records to make them point of care records are still in the early stages with several options on the table.
2 Implementing a recruitment and retention strategy to ensure the workforce is responsive and resilient	This year has seen the implementation of the recruitment and retention strategy which includes new development posts including the clinical administrator and the senior carer role. We have adopted a more flexible approach to working and included a 12.5 hour shift in our mix of working patterns which has had positive feedback from families with increased consistency and the ability to support more flexible outings and activities. We have welcomed our first rotational nurse at Charlton Farm and due to the success of this, we are seeking to recruit for further rotational posts. For the first time we have also recruited and supported preceptor nurses, an exciting development for the team.

Priority area	Achievements to date
3 To ensure our electronic information on incidents is data rich, viewed thematically and shared across the organisation	This year has seen a focus on risk. We have worked hard to ensure reporting is transparent and timely. Staff have embraced the new reflection tool which helps us understand and learn from incidents in a positive way. There is a weekly risk meeting where the Senior Care Management Team meet to review every care incident/risk across the three sites and share analysis and learning. We also review the week ahead to proactively manage any potential operational or clinical risks we can predict. We use the RCA tool kit to support incident investigation, and where learning is identified a learning summary is produced and shared with all three Care Teams. Each team discusses their local incidents at team meetings to engage the whole team in learning. This has embedded the values of risk management into the culture of care at CHSW and the increasing number of incidents reported is not an indication that we are a riskier organisation, but that staff are more able to recognise risk and feel able to report it. We recognise and promote learning from incidents and therefore continuously strive to improve care and safeguard children and young people.
3 To ensure we have a programme of learning and development for staff	It has been a positive year for learning and development at CHSW. We have seen the first UWE Bristol (University of the West of England) Palliative Care course launched after many years of work in partnership with Jessie May Trust and Bristol Royal Hospital for Children to develop the course. We have invested in external courses for specialist skills - safeguarding supervision and behaviour which challenges. We have also embraced online learning 'eLfH' specifically to support mandatory training. Successful recruitment into the Head of Education and Training post has seen the focus start on reviewing clinical competency pathways for staff which will continue to be a focus for the year ahead.
Patient experience	
1 Feedback from children and families	At CHSW we continue to get really positive feedback from children and families. The new senior carer role has shown how this can be taken forward with new innovative ideas on how we gather feedback including 'supermarket' style coupons!
2 Development of family support (sibling and bereavement service)	We continue to support more families and siblings. This year we have increased the support available to the Charlton Farm Sibling Team to reflect the increasing numbers of children and young people. Successful recruitment in the Head of Family and Psychological Support role will see this area develop further in the year ahead with a focus on family engagement. We have also reviewed our Senior Team Leader roles and identified more dedicated time for them to focus on the sibling and bereavement services with some exciting ideas coming forward.

* See also Section 3.2.6.2 which summarises specific care priorities for improvement set by each hospice. These are to be met in addition to the organisational priorities as above.

2.1.3 Priorities for 2018 to 2019

Priority area	How priority identified	How priority will be achieved	How progress will be monitored
Safety			
1 Safeguarding children and young people	• Legislation • CQC requirement • Safeguarding • Whistleblowing and Freedom to Speak Up	• Training levels to be reviewed and compliance monitored • New legislation will be adopted as required/released • Awareness campaign on speaking up at CHSW	• Policy and Practice Committee • Audit of Practice and Training
2 Information Governance	• 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 monitoring of audit data and effectiveness	• CHSW Strategic Plan • Key Performance Indicators (KPI) • Quality Assurance Monitoring	• Continue with improvement programme to ensure activity data is accurate and accessible • Quality Leads to review audit data as it completes and ensure full summaries are available • Action plans for those audits not meeting target which will include a revisit period within a maximum time frame of six months • Each hospice to include specific actions in their priorities for the year to rectify deficiencies in their current audit compliance	• Clinical Governance Committee • Senior Care Management Team • Quality and Compliance Team
2 To ensure we have a programme of learning and development for staff	• CHSW Strategic Plan • Quality Monitoring	• Clear standards for mandatory training and compliance monitoring • Continued review of competency and training framework • Development of accredited training for carers • Increased media for training staff including online solutions	• Clinical Governance
Patient experience			
1 Feedback from children and families	• CQC standards • Quality reporting • CHSW Strategic Plan	• To ensure we utilise a variety of methods to gather feedback and engage with children and families effectively • To ensure user experience 'child's voice' is clearly captured • To increase the levels and variety of feedback we receive and strengthen the links to measuring success and influencing service developments	• Clinical Governance • Quality Assurance Monitoring
2 To develop externally facing, responsive services	• CHSW Strategic Plan	• To increase collaborative and 'in reach' relationships with external partners • To develop new ways of working including day visits • To ensure children and families are referred appropriately and have choices regarding the service they access	• Activity Monitoring

2.2 Statements of assurance from the board

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

2.2.1 Review of services (this includes services provided to the NHS during 2017/2018)

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.

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

- Strive to provide the highest level of care, clinical expertise and enrichment opportunities for children who are expected to die in childhood.
- Continue to provide holistic care which meets the needs of all family members.
- Maximise our services to as many families as possible in ways they want and in partnership with others.
- Promote the needs of children with life-limiting conditions both regionally and nationally.
- Share our expertise widely through the provision of education.

We provide hospice care for children with life-limiting conditions and their whole family across the South West. These services are offered on referral from several sources including the NHS, Social Services, direct family referral and other organisations and individuals. The care we offer is wide ranging: respite and short breaks, emergency care, palliative care and end of life care. We operate three hospices: Little Bridge House in North Devon, Charlton Farm in North Somerset and Little Harbour in mid Cornwall. (Please click on the links for more information and video tours of our three hospice locations).

We offer a home from home where children with life-limiting conditions and their families can take a short break away from home to recharge their batteries in a homely, warm and welcoming environment. We aim to provide a much needed break from the ongoing strains of caring for their children at home, juggling professional and medical appointments as well as maintaining family life and employment. In the main we provide respite, the chance for families to get away from it all, but we also offer emergency and palliative care in a peaceful and comfortable setting.

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 2017/2018, 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 person's care at the hospice. During 2017/2018 CHSW has continued to be in receipt of an NHS England Children's Hospice Grant and has NHS local commissioning agreements with the following Clinical Commissioning Groups (CCGs):

Clinical Commissioning Group (CCG)	Number of children supported (cumulative)	Number of children supported at the end of period (31 March 2018)
North East Somerset (BANES - Bath and North East Somerset)	21	17
Bristol (BNSSG - Bristol, North Somerset and South Gloucester)	144	131
Wiltshire	21	20
Kernow (Cornwall and Isles of Scilly)	94	84
NEW Devon (North, East and West Devon)	143	119
South Devon and Torbay	41	41
Somerset	80	71
NHS Local Commissioning groups where there is currently no agreement in place and children out of area	3	2
Total number of children supported	**537**	**485**

As can be seen in the previous table there has been significant fluctuation throughout the year in our four biggest CCGs in terms of the number of children supported (Bristol, NEW Devon, Kernow and Somerset); this is based on the cumulative number of children supported and those being supported at the end of the financial year. More information is available in the referrals section of this report.

For the year 2017/2018 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 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. There has been some movement in this area with the negotiation and introduction of 'Standard Short Form' contracts (our preferred option) and 'Grant Agreement' contracts being used as current contracts come up for review and renewal.

2.2.3 Goals agreed with commissioners

Use of CQUIN Payment Framework

During 2017/2018 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 2017/2018 CHSW was ineligible to participate in the national clinical audit and national confidential enquiries. This is because there were none which 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 which take place, as there are others which are performed and disseminated across the organisation in other ways. It does, however, provide a focus on some of the areas which need to be audited in line with our regular reporting mechanisms to those who commission our services.

During 2017/2018 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 is commented on in detail in Part 3 of this report.

2.2.5 Commitment to research and education

The number of children/young people receiving services (funded by the NHS) provided or subcontracted by CHSW in 2017/2018 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 who were involved in any such research.

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

2.2.5.1 MyQuality: My Quality of Life Assessment tool

We have continued to make available the internet based quality of life assessment tool for children and parents to use. This tool can be used by families to identify the things which 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 care can be adapted to meet the child's changing needs. Dr Nicky Harris 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 Dr Harris.

2.2.5.2 Aurora: electronic prescribing project

During 2017/2018, CHSW continued to participate in the ongoing 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 several settings, such as the child's home, when needed. The Aurora project is ongoing and CHSW is involved alongside teams in Bristol Royal Hospital for Children and community palliative care services.

2.2.5.3 Medical input into children's hospices

During 2017/2018 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 regarding the way in which PPM is established and utilised by children's hospices. Dr Frost has presented her findings so far at the Together for Short Lives conference and is looking at further areas highlighted by the study in which investigation can be continued and used to improve service provision.

2.2.5.4 Benchmark group

During 2017/2018 our Head of Quality and Compliance continued to work with a group of Quality Leads from other Children's Hospices across the UK as part of a steering group looking at quality benchmarking measures for children's palliative care. Although in its early stages, the aim is to develop an outcomes framework for children's hospice services.

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 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)

2.2.5.5 Paediatric nursing rotational post

In 2017, an exciting opportunity for two highly motivated newly qualified staff nurses was developed. This was a rotational post between Bristol Royal Hospital for Children, Children's Hospice South West (CHSW) and Jessie May. The post consists of a 12 months secondment at the Bristol Royal Hospital for Children followed by a year in CHSW (Children and Young People's Hospice) and Jessie May (Community outreach service for Children and Young people with life-limiting conditions). Throughout the rotational process the nurses' evaluation will be audited to ensure that each nurse is enabled to reach their full potential. The aim of the post is to be able to support the joint working of three organisations and to support staff to develop skills and knowledge in all areas of palliative care having in depth insight into the journey of families and the care they receive in different settings. It is hoped these nurses will remain in the South West sharing and retaining their skills for local children.

Evaluations from the current rotational nurse post are being undertaken by the University of South West England. These will help us measure the impact of the programme and inform improvements for the next cohort.

2.2.5.6 Palliative care modules with UWE Bristol

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

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

This is a dynamic and exciting new learning opportunity which the Head of Education and Development is taking forward, strengthening CHSW partnership working with UWE Bristol.

2.2.6 What others say about us

2.2.6.1 CQC

CHSW is required to register all three 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 2017/2018.

During 2017/2018 a change of registered manager was made at our Charlton Farm Hospice; apart from this there were no other changes to our hospice registrations with CQC.

There have been no inspections during 2017/2018 as all three of our hospices were inspected by CQC during 2016/2017 and received the following ratings (click on the site name for link to full report):

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

Following the inspection changes from the CQC we are now under the Hospital Inspection teams which is a welcomed move away from the Adult Social Care teams. It is hoped that with the work CQC are doing on the inspection framework for children's hospices, future inspections will more accurately reflect the work and performance of the children's hospice sector.

2.2.6.2 Users' experiences

Further feedback from 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 2017/2018 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 2017/2018:

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: Little Bridge House, Charlton Farm 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 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 2017/2018 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.

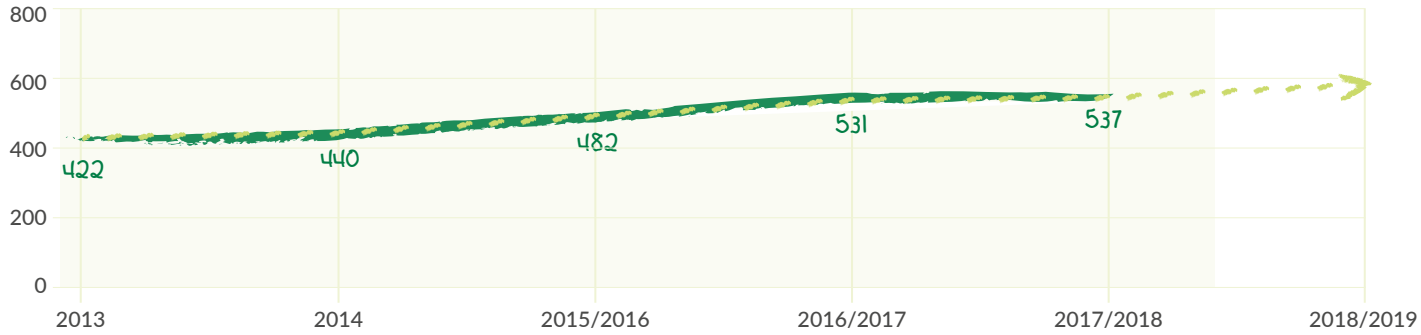
3.1.1 Activity data

Caseload activity	2016/2017	2017/2018
Children supported (cumulative total)	531	537
New referrals	125	104
Referrals accepted	110	76
Referrals declined/withdrawn	19	26
% of referrals processed within the CHSW target response time	93%	97%
All deaths on caseload	42	31
Discharge/deferments	23	21
Families using the service (cumulative)	514	522
Families with more than one child using the service	17	18

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 continues to increase steadily year on year. At the current rate of growth, it is projected by 2020 CHSW will be supporting close to 600 children and their families.

Cumulative number of children supported by CHSW

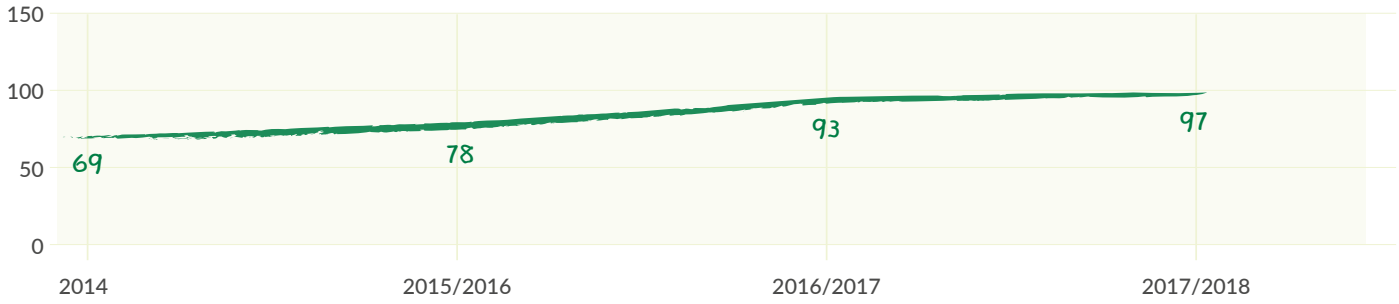


CHSW cares for children of all ages, from newly born infants to teenagers, and can continue to care for some very poorly young adults who are in the end stages of their life up to age 21. The largest age group of children who use Children's Hospice South West are those of Primary school age, five to 11 years old. There has been very little change in these ratios over the past three years.

Children using CHSW by age group:	2015/2016	2016/2017	2017/2018
Pre-school (age four years or under)	16%	17%	20%
Primary school (age five to 11 years)	40%	39%	40%
Secondary school (age 12 to 17 years)	28.5%	29%	23%
Young adults (Over 18 years)	15.5%	15%	17%

During 2017/2018, 104 new referrals were received by CHSW, a slight decrease on the previous year. The overall trend in the last four years has been increasing which demonstrates the ongoing need for our services for children with life-limiting conditions and their families. One of CHSW's audit points is the target response time for processing of referrals, which has increased to 97%. This shows our commitment to ensuring children and their families are given decisions on care provision in a timely manner at an anxious and distressing time for them.

Percentage of referrals processed within expected time frame



What is important to note is that of the 104 referrals, 76 were accepted during the year, but of the 26 children who were recorded as not accepted for hospice care, for 12 of these children (46%) 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 continue to raise awareness about our service and the group of children we care for, and to address fears and anxieties amongst families about the use of a hospice.

A further 10 (38%) of the children were not accepted because they did not meet the diagnostic or assessment criteria. Whilst families recognise 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, in early 2017, film clips were made available, to promote CHSW's service to both professionals and families of children with life-limiting conditions. These short films are available on the website, along with a new information sheet specifically targeted at professionals, and will help address misconceptions and fears about a children's hospice and provide a clearer understanding of CHSW's and 'children's hospice' care for both professionals and children and their families. During 2017/2018 the website was relaunched. The new format will make it easier for both families and professionals to access information and resources.

During 2017/2018 we offered nearly 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.

Care activity	2016/2017	2017/2018
Emergency bed care nights	390	326
Planned bed care nights	3,700	3,702
Total number of bed nights of care	**4,090**	**4,028**
Parent/carer stay nights	4,854	4,852
Siblings stay nights	3,181	3,095
Total number of family stay nights	**8,035**	**7,947**
Total stay nights	**12,125**	**11,975**

Each family is given an allocation of nights, so they can plan short breaks during the year. However, when children become unwell and require symptom control, or require support after a hospital admission or end of life care, we provide emergency care.

In addition to the bed nights indicated above, CHSW has also provided 130 'day visits' for children and their families, an increase of 7.5% on last year; these are provided both as an introduction to the Hospice and to support children's and/or families' needs including access to specialist equipment, treatment and social support.

We also support more children who require additional support (two nurses/carers) during their stay; this is not captured from the data currently provided but does impact on the number of total bed nights available.

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

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

Little Bridge House

"I wouldn't be here now if it wasn't for the amazing support I received after my beautiful daughter spent her last four days of her life at Little Bridge House. She died with dignity and surrounded by love. Thank you for being there for her then and being there for me ever since."

"Thanks for a lovely extended stay over the weekend just gone. We really enjoyed ourselves, and the service you all provide at Little Bridge House was second to none as always."

In response to the question on the satisfaction survey 'What was the best thing about your stay at Little Bridge House?'

"Being together as a family spending time doing all the things we are unable to at home. No cooking and cleaning, meaning our weekend was stress free to enjoy the little things in life."

Charlton Farm

"Charlton Farm is an incredible place. The atmosphere is peaceful and laid back. The staff are fantastic and nothing is too much trouble. After a very long and stressful hospital stay, it's a relief to be able to find some peace here, even if it's only for 10 minutes per day. The food is delicious, as are all the many sweet treats! All of the staff are always around for a chat, which is sometimes just what you need. I have never used Charlton Farm's services before but I have been blown away by what an incredible place it is."

"Everything was so calm and chilled and relaxed, and I could see straight away that T absolutely loved it. She loves everyone there, she gets so excited. We stay there as a family although when we're there T doesn't want me or her dad or her brothers near her. She sees it as her time, her play time. It's fantastic for us as we can spend time with the boys and we don't have to worry about her. In fact, the last two times we've stayed T has asked to be there by herself, but we haven't been quite ready to leave her completely!."

In response to the question on the satisfaction survey 'What was the best thing about your stay at Charlton Farm?'

"So many things - lovely chats with staff, time to relax thanks to the sibs team, children both had so much fun, food, music therapy."

"I always enjoy the food- relaxed atmosphere. Knowing your child is cared for."

Little Harbour

"Little Harbour and its staff are second to none in quality, nothing is too much trouble. The staff genuinely care and they want to make the experience for both our child and ourselves a priority. Everything is well thought of and planned. Nothing could be improved, it's first class!!!"

"We cannot thank you enough for all the help, love and support this year. We really don't know how we would have got through it without you guys. In the nicest possible way I wish we'd never needed to meet but we are so glad we had you and feel like we have gained so much even though we lost more than we could imagine. Eternally grateful. With Love B, R and T."

"Boring (I know) but you are all amazing. Thank you oooooodles x"

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. Each of those days are filled with a wide range of exciting activities to ensure children and families do not simply get a rest but also enjoy fun filled opportunities which enrich each day and allow families to enjoy quality time together.

At each of our hospices children and their families can enjoy themselves in our art therapy rooms, soft play rooms, sensory rooms, hydrotherapy pools, and family activity rooms, complete with an up to date suite of computers, computer games and a wide range of musical instruments to support everything from an in-house rock concert to music therapy. Outside the gardens are full of exciting opportunities for outdoor play and all our hospices have a wide range of family friendly destinations on their doorstep for trips and outings.

3.1.4 We enriched 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. 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, whilst 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 child with a life-limiting condition at home) but they gain tremendous support from talking together and finding 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 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 the children are very dependent for their care and some may need more staff than usual. We know that the number 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 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 in 2017/2018 a new Head of Education and Development post was instigated and filled. It is envisaged that she will take CHSW's commitment to excellence and development of our care staff forward and strengthen the partnerships we already have with Higher Educational establishments as well as developing new ones. She will also be working with the Practice Educator and Care Teams to ensure they continue to have the necessary skills and knowledge to care for the children safely and competently.

To help us better respond to the clinical and nursing needs of the very sick children we care for, we also employ Children's Palliative Care Medical Staff including Paediatricians. These doctors are expected to support the clinical learning of all care and medical staff, both within CHSW and externally. At each site there is a designated Medical Director who supports the local medical and Care Teams as well as a Senior Medical Director who provides overarching support and governance based at Little Bridge House. This year at Charlton Farm we have invested in a permanent medical post, Dr Emma Heckford. She has dedicated time to work alongside the team at Bristol Royal Hospital for Children significantly improving the quality of joint working and our connection with children who frequently use both services.

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 several 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 which have been included:

> Just a big thank you to all your staff who looked after M this week. Mum is very happy with the care your staff provided, as are all our staff with all the help they received.

Home Care Team, Cornwall

> Many of the families I work with use Charlton Farm for either respite care or, sadly for some, end of life care. Although some families are reluctant to go at first, once they do they frequently talk of their surprise that it is such a happy and relaxed place where they can be a family and create special memories together. The Care Team do a fantastic job of offering families care during some of the most difficult moments of their life and in finding a way of supporting families to make the most of the precious time they have. As a clinical psychologist supporting these families, I know that if they are staying at Charlton Farm they will have a team of dedicated professionals thinking about their needs every step of the way. The team do an amazing job of working in partnership with the families so whilst the team care for the family as a whole, the family are able to focus on what is most important to them - being together. It is hard to put into words the difference this makes but as a professional I am extraordinarily grateful to all the team and the amazing work they do.

Palliative Care Psychologist

> A little note to say a huge thank you for extending such a warm welcome and giving up so much time of your time to R and myself when we came to visit Little Bridge House on Friday. We had both been looking forward to the visit and it was a real pleasure to meet you. I think we already knew it would be a special place but it was really inspiring to actually see and feel what special work goes on there. It's obvious that you all work incredibly hard to create a uniquely special 'Little Bridge House' atmosphere for the children and their families so that they always feel safe and supported in your care. It will make a tremendous difference to have that knowledge, inner confidence and belief in the hospice when we are speaking to parents about the service you provide. Having met you and heard about the roles of other staff in your team it will be now be so much better whenever we need to call you or talk about your service in any capacity. Thank you for the delicious lunch too. That was a very unexpected bonus and helped us feel as nurtured as all your guests!

Family Support Nurse, Paediatric Palliative Care and Bereavement Support Team

In the year ahead, we plan to build on these professional relationships further, with the knowledge and understanding that through joint working and collaboration we can really make a difference to children with palliative care needs and their families.

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

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

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

Bereavement support	2016/2017	2017/2018
Number of bereaved families with whom we have had contact	306 (58%)	282 (78%)
Total number of bereaved families still requiring contact	528	362
Number of families using 'Starborn'	23	16
Number of children who died	42	31
Number of 'in house' deaths	10	12
Number of nights 'Starborn' used	145	101
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)	8,655 (361 days)	5,061 (211 days)

Facts and figures	2013/2014	2014/2015	2015/2016	2016/2017	2017/2018
Number of children who died	35	33	38	42	31

From the data above, although there is a significant fall this year in the number of bereaved families whom we support, this is accounted for entirely by a data cleansing exercise which took place earlier in 2018 during our family review process and those families with whom we no longer have contact or who have asked for no further contact have been archived. We can and have had families wishing to re-establish contact and it is made clear to those families that this is always an option.

For those families with whom we have contact we continue to have a significant percentage who have had contact this year (78%).

Despite overall care nights decreasing the ratio of nights which children and families use Starborn after death has increased this year (from 3.2 to 6.3 nights average stay). 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'.

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

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

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

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

We now have Senior Team Leaders (Family Support/Bereavement) for all three of our hospices and at the beginning of 2018 a full time Head of Family and Psychological Support was appointed who will be looking at the ways in which we provide and improve the psycho/social and bereavement care available to families and staff, and new ways in which we can measure this progress.

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 we use a wide range of quality assurance activities which vary year on year to encourage ongoing participation by users.

CHSW is required to report to NHS commissioners on the quality of its services via the NHS Standard Contract. This however varies between each CCG group, so a quality schedule has been devised to cover not only the Key Performance Indicators (KPIs) which the CCGs require but also those which 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 which was used for the Clinical Governance Committee discussions in 2017/2018. The QA activities which CHSW has been engaged in as part of this organisational wide approach to monitoring and auditing of service quality and provision are conducted around three 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
- AINMs report
- Complaints report
- Medicine incident report
- Safeguarding report
- Emergency transfer report
- In house death and difficult symptom control report
- Resuscitation events report

Management and administration

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

User experience and satisfaction

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

As well as these, other QA activities include:

- CQC inspection report summary (external)
- Provider visit (trustees) report summary (internal)
- Commissioner visits (external)
- Regular KPI and activity reporting to commissioners and other NHS England bodies.

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 this year a process of regular weekly risk meetings have been established to assess AINMs reports and increase organisational openness, sharing and learning which in turn supports continuous improvement in all areas of service provision. In addition, a CHSW reflective tool has been developed and is widely used by staff in response to incidents and learning summaries shared across the organisation to support learning.

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

3.2.3.1 Accident Incident and Near Miss Reporting (AINMs)

Quality objective	Data 2016/2017	Data 2017/2018
Number of SIRIs	0	3
Incidents requiring reporting under RIDDOR	4	1 (1 of the SIRIs was also reported under RIDDOR)
Number of Never Events reported	0	0
Number of Falls categorised at level 4 or above	0	2
Infection control		
Number of MRSA bacteraemia (post 48 hours)	0	0
Number of Clostridium Difficile (post 72 hours)	0	0
Needlestick/Sharps injuries	2	1
Pressure ulcers grade 2 and above		
Admitted with PU	1	1
Developed within 72 hours	4	2
Developed after 72 hours up to 72 hours post discharge	0	0
Duty of candour breaches		
Concerns raised under whistleblowing policy	0	0
Disclosure of information about poor care which has resulted in death or serious injury	0	0
Breaches in Duty of Candour disclosure/reporting	0	0
Information governance		
Breaches by CHSW	11	18
Breaches involving CHSW information but not by CHSW	3	1

Comments

SIRIs:
The first SIRI was a medication error. This was fully investigated using the RCA framework and was reported to all the relevant authorities. Although this error was significant it was a near miss in terms of consequences as the dose given was within the therapeutic range acceptable for a child receiving pain relief and no harm was observed for this child. However, the learning gained from the RCA has provided the Care Teams across the organisation significant benefits in their practice and competence. This has been evident in the increased awareness of staff to ensure that when involved in the administration of medicines they are making sure this is done in a way which minimises interruptions and distractions. They are also using 'Stop, Think' moments as part of their practice to ensure which processes are followed correctly. This has led to a complete review of procedures and training for medications, strengthening how we support staff through learning and clear guidance.

The second SIRI was a child (at risk of fractures during normal handling) who was reported to have sustained a fracture; this was discovered seven days after the stay and despite a full investigation of care it was inconclusive as to when and where the fracture had occurred. Whilst we do not know if the fracture occurred during their stay at a CHSW it was fully investigated. Learning from the RCA has included the development of manual handling assessments which now have a 'red flag' for children who may be at risk of developing fractures and training has been delivered to all staff on the importance of recognition of the risk factors for fractures in a population who are at higher risk of fragility fractures due to their conditions, medication, complex care needs and specific manual handling requirements. This is enhanced with the use of daily pain scores which can be an initial indicator of underlying problems with this group of children.

The third SIRI was a shower trolley which failed and collapsed whilst being used by staff with a young person in our care. Fortunately, no significant injury was identified which was confirmed by a visit to the local hospital as a precaution (therefore classed as moderate harm because of the need for transfer out). This incident was also reported under RIDDOR. Both the company and CHSW investigated this incident and our RCA found that the incident was unavoidable; staff had acted appropriately at all times. Learning around this incident has highlighted the importance of equipment checks prior to use although in this case they were done, and it would not have been possible to predict the failure as the breakage points were hidden from normal inspection practice. An interesting fact was that the make of shower trolley (which is a bespoke piece of equipment) is no longer recognised as a piece of medical equipment and therefore reporting comes under trading standards and not the MHRA.

Other RCAs:
As well as the three SIRIs, four further incidents were investigated using an RCA approach as learning for the teams involved and for the organisation. These have been carried out because CHSW recognise the benefit of using the RCA approach to learning from incidents and the potential for harm from specific incidents, and have been reported externally to CHSW as appropriate. Learning summaries are used to ensure learning is disseminated across all three sites.

In Summary:
We recognise that to ensure transparency we have a low threshold for reporting incidents and risks promoting a culture of safety and learning. However, we also recognise within our current reporting framework we are unable to separate 'external' incidents and risks (CHSW has spotted and reported but outside of our control or investigation remit) and nor do we currently 'downgrade' incidents, when assurance received. This will be reviewed in the year ahead to help us provide clarity in our reporting schedules.

Safeguarding incidents	Data 2016/2017	Data 2017/2018
Adult safeguarding incidents occurring on hospice premises: concern relates to family care (staff not involved in incident)	1	0
Adult safeguarding incidents occurring on hospice premises: staff involved in concerns raised	0	0
Adult safeguarding concerns disclosed to staff not occurring on hospice premises and no staff involvement in incident.	0	4
Child safeguarding incidents occurring on hospice premises: concern relates to family care (staff not involved in incident)	5	4
Child safeguarding incidents occurring on hospice premises: staff involved in concerns raised	0	3
Child safeguarding incidents disclosed to/by staff not occurring on hospice premises and no staff involvement in incident.	2	9

Comments

The increase in the number of safeguarding incidents disclosed by and to staff and being reported highlights the staff's awareness of the importance of recognising safeguarding issues and the importance of the relationships they build with the families which allows for an environment of openness and candour. CHSW will always report an incident to the multiagency forum/lead for advice preferring to act with caution and downgrade an incident, and take no action, to ensure we have a robust transparent safeguarding culture. The three incidents which were raised as involving staff were all investigated with multiagency advice/support and no further safeguarding action was required or taken, as they were found not to meet safeguarding criteria. These have now, after full investigation, all been resolved. In the year ahead, we will explore how we can capture safeguarding concerns but separate them from safeguarding incidents.

Care health and safety incidents/accidents	Data 2016/2017	Data 2017/2018
Child	24	32
Sibling/family	73	58
Staff/contractor	23	18
Equipment/facilities only	27	23
Care near miss health and safety incidents/accidents		
Child	2	0
Sibling/family	2	1
Staff/contractor	0	0
Equipment/facilities only	4	2
Clinical incidents (exc medicines and safeguarding)		
Child	146	119
Sibling/family	6	17
Staff/contractor	20	48
Near miss clinical incidents (exc medicines and safeguarding)		
Child	7	5
Sibling/family	0	0
Staff/contractor	1	0
Total incidents and accidents (all inc medicines and safeguarding)	**370**	**551**

Data relating to children with life-limiting conditions only	Data 2016/2017	Data 2017/2018
Total number of incidents	183	369
Number of incidents leading to moderate or severe harm	4*	11

*It is noted that all four incidents 2016/2017 categorised as moderate or severe harm were influenced by external factors.

Comments

Of the 11 incidents categorised as moderate harm, six were influenced by external factors outside of the control of CHSW.

Of the five for which we did have an element of control, two were due to behaviour which challenges, where the children involved hurt themselves. One was the SIRI with the shower trolley, one was a head injury following a drop seizure which required transfer to hospital and minor treatment and one was emergency treatment for a child whose ketones had risen above a safe level. All the 11 incidents were investigated to some level with the majority having an RCA approach being used. All that involved CHSW staff directly have also led to the staff being asked to prepare reflective practice reports. The learning from both the investigations and reflective practice reports are shared across the organisation using learning summaries. In the year ahead, we are reviewing our framework to provide a separate category for external incidents with the aim of improving clarity for reporting purposes.

Total number of full stays for children with life-limiting conditions	1525	1471
Incident affected stays (adjusted for stays where more than one incident happened in that stay)	179	301
% of harm free stays	99.74%	99.25%
% of incident free stays	88.27%	80%

For 2017/2018, 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 have not been included but are discussed later.

Summary

Overall the number of incidents being reported has risen. This has been due to the focus this year on risk recognition, reporting, investigating, and learning from incidents. CHSW now have 'Weekly Risk Meetings' chaired by the Director of Care and use review and reflect processes with the Care Teams. This has significantly increased the staff awareness across the organisation and the need to capture these. Therefore, the rise in incidents can be seen as an effective safety campaign with transparency and an effective learning culture.

Key topics learning

Findings	Action plans/progress
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 focus on getting to standards required under the new GDPR legislation. This has heightened awareness in staff and led to an increase in reporting. All the incidents were very low level in terms of their risk, but it has led to several learning points around management in house of children's records.	• 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 being used as an opportunity to remind staff of the importance of IG in team meetings. • The need for accurate filing and subsequent archiving is to be part of the focus for next year in line with a proposed system for scanning/digitising of records. • Staff digital log in process has been strengthened and awareness and training for IG standards in place.
Findings	**Action plans/progress**
Completion of the AINMs cycle. It has been recognised through the weekly risk meetings that there is great value in the sharing of lessons learned and the completion of the PDCA (Plan, Do, Check, Act) Cycle as a method of managing risks	• To continue with the weekly risk meetings • For all significant risks to be investigated using the RCA tool kit as appropriate with action plans and learning summaries to be disseminated to staff across the organisation • To celebrate good practice as well as recognising the learning from practice which is not so good. • To refine and develop competencies within the Care Team to be able to investigate incidents properly and complete the PDCA cycle.

3.2.3.2 Medicine administration

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

a. Medicine incidents and error reporting

	Year end 2016/2017	Q1	Q2	Q3	Q4	Year end 2017/2018
Number of CHSW medication incidents which cause harm	0	0	0	0	0	0
Number of external medication incidents identified by CHSW which cause harm	1	0	3	1	0	4
Total number of medication incidents	84	32	51	57	48	188
Number of medication incidents which included controlled drugs (all Schedules)	30	12	21	24	24	81
% of medication incidents which included controlled drugs (all Schedules)	35.71%	37.5%	41.2%	42.1%	50%	43.1%
% of medication incidents which cause harm	1.19%	0%	0%	0%	0%	0%
Number of near miss medicine errors/incidents	9	1	3	1	0	5

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 locally at the hospice monthly team meetings and at the Clinical Governance meetings every other month. In addition, there are also weekly risk management meetings which are organisation wide.

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. We currently include these external incidents in our statistics and need to look at a separate category for these moving forward. There have been no incidences of harm due to medication incidents. The proportionate number of CD incidents rose in the latter two quarters in part due to a change in practice to reflect a safer way in which to manage children's own Midazolam supplies. This took some time to refine and led to several incident reports which assisted in this process.

b. 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	2016/2017: 94.19%	2017/2018: 95.93%

Summary

This year's result was based on two separate audits at six month intervals, 17 September and 18 March. The overall results have remained stable

Key learning points and recommendations

- The SOPs - a project addressing these was commenced late 2017 and it is hoped that these will be signed off very shortly at the same time as the reviewed Medicine Management and Administration Procedures. The drafts are in place and in use.
- We still have some challenges with the ordering of stock controlled drugs and to address this we have gained an SLA with the local NHS Trusts for one of our sites and are pursuing it for the others. This has enabled us to tighten up on the processes around this.
- Investigation of the CD incidents highlighted a problem with the management of children's own supply of Emergency Controlled Drugs in house. This has led to a change in the SOP and a poster/training campaign. This took a little while to embed but the associated incidents have now been reduced considerably.

Progress to date/planned future actions

- Associated SOPs will need to be ratified.
- The AOCD continues to provide reports to the Clinical Governance Committee on the results from this audit and the AINMs reporting on a bimonthly basis.

3.2.3.3 Infection prevention and control audits and reports

Several audits are completed for infection control and reported as the 'Consolidated Infection Control Audit Results' as an annual report to the clinical governance group. In addition, 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 2016/2017	Data 2017/2018
Total number of infection incidents and near misses	4	13
Number of MRSA Bacteraemia cases (post 48 hour)s admission)	0	0
Number of Clostridium Difficile (Post 72 hours after admission)	0	0
Number of needlestick injury incidents	2	1
Outbreaks of other diseases or infections	2	3
% of staff who have completed annual Infection Prevention and Control Training	86%	81%

Comments

The % for training includes all staff and does not exclude those staff on long term sick, maternity leave or those who are on our Bank.

It should be noted that the way in which we collect and process data on training is currently being reviewed by our new Head of Education and Development and Head of Quality and Compliance in order to track training and competence in a much more robust way.

With the exception of staff on maternity leave and on long term sick leave a plan is in place for staff to complete outstanding Mandatory Training (including Infection Prevention and Control). The data will be reassessed at the end of Q1 2018/2019 to ensure all staff have completed this training.

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	2016/2017: 90.85%	2017/2018: 90.50%

Summary

Hand Hygiene is included here as well as in the Consolidated Results as it is a specific QA activity which 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. It particularly relates to one site and at the first of the six monthly audits at the beginning of the reporting period. The subsequent audit showed a considerable improvement in hand hygiene knowledge and process. The observed practice audits were very good at all sites at both six monthly audits (95% and 97% respectively).

c. Consolidated infection control audit results

Audit tool	Hospice UK Toolkit suite of audits and IPCN adapted Hydrotherapy pools audit	
Result	2016/2017: 88.21%	2017/2018: 81%

Summary

Following a review of infection control and prevention audits early in 2015/2016 it was decided to move towards a suite of audit tools which 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 concern not addressed in their suite of audits.

Key learning points and recommendations

We recognise there has been an overall drop in the compliance levels for all infection control audits. The main issue appears to have been an inconsistent team of infection control leads; we believe this has been influenced by staff changes. This is being addressed and new teams at each site have been identified, and under the guidance of the Head of Quality and Compliance will have regular quarterly meetings to review the audit results, to discuss any AINMs which link to infection prevention and control risks and provide opportunity for education in infection prevention and control. The new leads will also be supported by the organisation lead within the Housekeeping Team who will also attend these meetings whenever possible.

In addition to this the cleaning schedules are being reviewed and a new Cleaning Manual which will specify the SOPs for cleaning in line with infection prevention and control measures and frameworks introduced.

The permanent housekeeping staff are linking with the Association of Health Cleaning Professionals in order to help them keep up to date with current practice.

In the year ahead, work will focus on basic compliance to ensure this standard improves next year.

3.2.3.4 Safeguarding children and adults

It is a requirement of the NHS Standard Contract held by Children's Hospice South West with Clinical Commissioning Groups (CCGs) across the South West, that the organisation provides a report on our performance against 10 core standards relating to the safeguarding of children. These are:

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

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

- Prevent
- Deprivation of Liberty Safeguards (DoLS)
- Mental Capacity Act
- Whistle Blowing
- Domestic Violence and Abuse
- Learning Disability (LD) are being addressed and met

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

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

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

a. Safeguarding training data report

Quality objective	Compliance 2016/2017	Compliance 2017/2018
% staff completing annual adult safeguarding level 2 training	89%	81%
% staff completing adult safeguarding level 3 training	88%	69% *
% staff completing annual child safeguarding level 2 training	87%	81%
% staff completing child safeguarding level 3 training	94%	85%

*External training arranged but falls outside the reporting period; all staff have training at a lower level.

Summary

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

It is acknowledged that it is often difficult to engage bank staff with in-house training, therefore the use of eLfH and other online training platforms are being used and investigated for the future, as well as accepting evidence of training from other relevant organisations. (eg evidence of completion of NHS or Social Services courses).

With the exception of staff on maternity leave and on long term sick leave a plan is in place for staff to complete training. The data will be reassessed at the end of Q1 2018/2019 to ensure that all staff have completed level 2 and 3 training. Bank staff will not be able to book shifts until their training is complete.

3.2.4 Management and administration

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

3.2.5 User experience and satisfaction

3.2.5.1 Compliments, complaints and concerns

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

CHSW prides itself in the very low numbers of complaints and concerns 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 which may be a future cause for concern or complaint. During 2017/2018 we had one complaint and 13 concerns raised; all were investigated as appropriate and dealt with within our complaints policy framework and time frames. There were no consistent themes in the concerns and complaint raised and all have been resolved.

The change this year has been that we are also actively collecting compliments which are received both formally and informally on our database. This is addition to the collection of data through satisfaction surveys and questionnaires. This is in its early phases but so far, the comments received are very encouraging.

The high level of engagement we have with the children/young people and their families allows us to continually assess their needs, plan the care required and evaluate its outcomes. As such the staff are continually seeking and receiving feedback from the children/young people and their families regarding the specifics of the care required and provided. This information has traditionally been recorded in the individual care plans and clinical records and although this remains so, we now capture and disseminate this information in a variety of ways which ensures that learning can be shared across the organisation. It was important that we could show that we were meeting our vision of "Making the most of short and precious lives" whilst at the same time enriching the lives of the children/young people and families using our services.

3.2.5.2 Friends and family test audit

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

Friends and family test audit		
Audit tool	National Paediatric Toolkit platform - Orovia and questionnaires (Monkey Wellbeing)	
Result	2016/2017: 94%	2017/2018: 92%

Summary

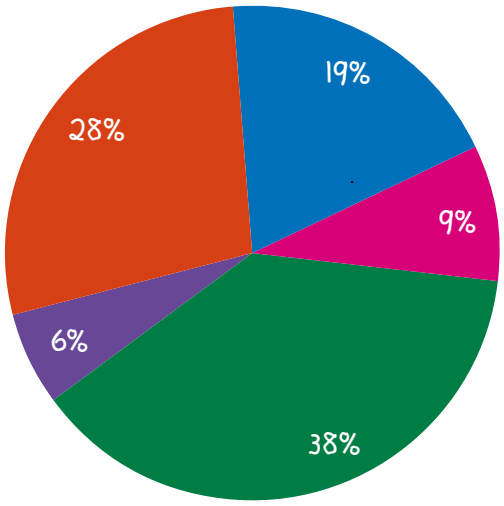
This year's results are just those from the Orovia platform as other questionnaires still need to be analysed but interim review has shown that they reflect the results which have come out of Orovia.

170 responses were received over the period, with 38% coming from parents, 19% from children with life-limiting conditions and 9% from siblings. 34% did not tell who they were or selected other.

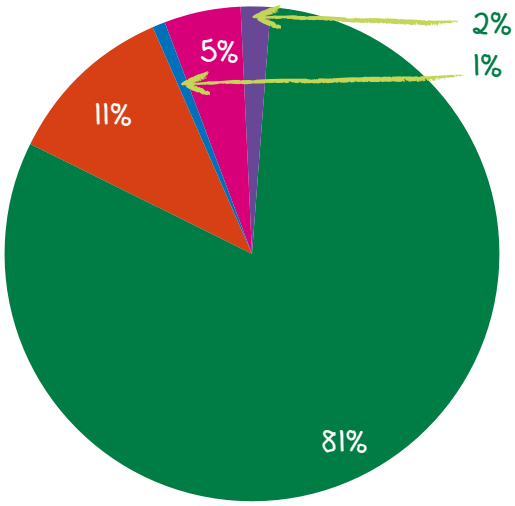
92% were extremely likely or likely to recommend us, with 7% not knowing or not responding to that question. A further 1% which equates to two respondents answered extremely unlikely but did not leave details to follow this up (other comments/answers were neutral or positive).3.2.5.3 Feedback and comments

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

Who responded	Total responses	%
Child/young person using the service	32	19%
Sibling	15	9%
Parent/carer	64	38%
Other	11	6%
No response	48	28%



How likely are you to recommend our service	%
Extremely likely	81%
Likely	11%
Neither likely or unlikely	0%
Unlikely	0%
Extremely unlikely	1%
I don't know	5%
No response	2%



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3.2.6 Other quality assurance activity

3.2.6.1 Trustees assurance visit reports

Under regulation 17 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Regulations 4 to 20A) CHSW is required to have systems and processes which ensure 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 which the purpose and aim 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;
- Inspect the hospice
- Inspect the record of complaints held by the hospice
- Prepare a written report on the conduct of the hospice
- Ensure engagement of the Trustees with the service
- Assure the Executive Committee of the quality of the service being provided

The Trustees visited all three hospices during the reporting period and used a new reporting form which follows the same format as the CQC inspections in terms of looking at the Safe, Effective, Caring, Responsive and Well Led domains. During these visits the Trustees are looking for assurance on the full organisational working of the hospice including the actions of departments other than Care but concentrating their report on Care. Their reports are disseminated to the local team and to the executive board for consideration, and recommendations are made on improvements which could be made. This is a helpful inspection and feedback process and is a valuable tool for the Care Teams to support continuous improvement.

3.2.6.2 Summary of the priorities identified for care:

Alongside the priorities for improvement CHSW has set for 2018/2019, each hospice has its own specific targets which they will be working towards. This will be monitored predominantly by the Senior Care Management Team and the Quality Assurance Teams.

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Little Bridge House			
Care of the child, young person and family at end of life	This is our area of excellence, always striving to improve and learn	To continue to train and support staff in this area of care. To involve our doctors in training	Feedback from staff on their confidence levels when caring for a child at EOL
In the moment training	This became apparent when issues brought to care managers by staff which involved a large time gap, often weeks, from the incident to the communication with their manager. This is not helpful for the staff member or the managers	Training of care managers initially then for other staff to have this training	Less incidents where staff have not felt able to deal with issues themselves or feedback is delayed
To help and support a newly qualified Children's Nurse to work within Little Bridge House	To enhance and support the nurse recruitment issues	Nurse recruitment is always a challenge, both locally and across the country. By supporting a newly qualified children's nurse we can share our knowledge and excellence around family centred care, whilst developing and supporting the development of their more acute skills	For the HOC and Director of Care to work with the manager of children's services at our local hospital. This may lead to a joint approach or shared placement within the hospice and the children's ward/SCBU
To continue to gather feedback from outside agencies when working with them	From CQC inspection highlighting the need for written feedback	Letter was devised following our inspection and this has been in use since then	To ensure feedback forms are sent out. To celebrate successes and to respond to issues identified, and to share learning and to feedback to the relevant parties

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Charlton Farm			
Improving systems for updating Care Plans and Documentation at the beginning of a child's stay	Care Plan audit Child and Family feedback AINMs report	Establish a working party to identify alternative models and recommend potential developments	Continued cycle of documentation auditing and family feedback
Ensure infection control standards are consistently monitored and reported, aiming for a high level of compliance in all standards observed	Infection control audits	Clinical Senior Team Leader and Infection Control links to plan joint time to review existing Infection Control plans and organise Infection Control activity for the upcoming year, planning time for all audits to take place and to develop systems to ensure Care Team are aware of the practices and standards required	Infection control audits
Minimise the impact of accommodating emergency admissions on planned respite visits	Care activity	Ensure recruitment is proactively managed to ensure establishment levels remain high Implement a staffed emergency bed in order to accommodate request with minimal cancellations of planned respite	Care activity and MPR review. Decreased level of cancellations should become evident
Documentation and medicine standards to be reviewed and highlighted as part of routine practice, ensuring standards remain a constant year-round focus	MAR and Documentation audits	Develop a daily monitoring tool to provide clarity on standards Tool to be used routinely to collect data and to allow regular feedback and guidance for the Care Team	Documentation audits Review of evidence collected using monitoring tool
Increase in reach offer to CHSW Children admitted to local hospitals	Review of in-house deaths	Develop link roles from within the Senior Care Management Team and to plan/allocate time for in reach activities	Review of in-house deaths Review of Care Team rota Feedback from other services
Feedback from families	Feedback cards and Orovia tablet	Ensure a comprehensive range of feedback measures such as feedback cards, satisfaction surveys and Orovia tablet are available and utilised by families Promote these measures by highlighting some quality champions	Review of feedback numbers

Priority area	How priority is identified	How priority will be achieved	How progress will be monitored and reported
Little Harbour			
Improvement in standards of care/ documentation	Documentation Audit, concerns and complaints	Providing basic core training Review of ethos Standard setting	Recurrent auditing Monitoring by Team Leaders and Clinical Senior Team Leaders Action planning
Education and competencies	Audits have highlighted areas which need teaching/training Practice Educator post will be vacant from May 2018	Recruit into post Core Competencies rolled out Role supported by Senior Carer post and Senior Team Leaders	Staff completing competencies Improvement in Audits
To focus on outreach and raising awareness of service	Referral uptake low Regular support/advice being offered regarding palliative care and EOL management to external services	HOC and team to actively 'in reach' into local CCN teams and acute paediatric wards and neonatal units To work alongside and collaborate with external professionals to map out what gaps there are for the children and families	Attendance of meeting with outcomes Action plans Outreach hours to allow the team time to achieve this. Referrals to increase
To obtain more feedback and user satisfaction to enable us to provide a more responsive service to children/young people and families	Orovia Review of last year's feedback collation	Running Orovia surveys More interactive ways of gathering feedback	Senior Carer role and Generic Senior Team Leader to look at the year ahead and plan ways of gathering feedback and trialling new more inclusive methods

3.2.6.3 Commissioner (CCG) visits

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

Statement from Bristol, North Somerset and South Gloucestershire CCG Bristol, North Somerset and South Gloucestershire (BNSSG) Clinical Commissioning Group (CCG) has taken the opportunity to review the Quality Account prepared by Children's Hospice South West (CHSW) for 2017/18.

BNSSG CCG welcomes CHSW which provides an accurate reflection on the quality performance during 2017/18. The information presented has been reviewed and is in line with information provided to the CCG.

BNSSG CCG has noted the progress and achievements on the eight quality priorities set out last year but it is unclear which priorities have been fully or partially achieved. The CCG acknowledges the work put in place for these priorities although would have liked to have seen more detail provided on quality and patient outcomes. However the CCG is pleased to note that work is being carried forward into 2018/19.

The CCG supports the chosen areas for quality improvement for 2018/19, especially the inclusion of priorities to address both safeguarding and information governance However the CCG would have liked to have seen further detail regarding the measurable patient outcomes that are expected to be achieved from the proposed priorities and quality improvement work to be undertaken. The CCG is keen to see a reduction in reported information governance incidents next year as part of the improvement plan being put in place.

BNSSG CCG notes that there has been zero Serious Incidents (SI) reported in North Somerset although there were 4 reported in other CCG areas and is pleased to note that there have been no Never Events reported in this current year.

Within the CHSW has demonstrated continued good progress in improving patient experience and notes the good engagement undertaken with children/young people and their families. We would like to see more detail regarding the actions being taken in response to feedback but note that analysis is still being completed on surveys.

Infection incidents and near misses are mentioned in the report and are shown to have increased however; there is a lack of explanation regarding the reason for this increase or the action being taken. The percentage of staff who have completed infection control training and the control of infection audit results disappointing and the CCG would have liked to have seen further information of how CHSW plan to address this going forward.

The CCG welcomes the work undertaken to safeguard vulnerable children and adults. The decrease in the percentage of staff completing safeguarding training is noted and the CCG would have welcomed further detail on the plans being put in place to engage staff to improve compliance.

BNSSG CCG acknowledges the good work within CHSW and the Quality Account clearly demonstrates this. We note the areas that have been identified by CHSW for further improvement and we look forward to working with CHSW in 2018/19 to deliver those improvements.

Anne Morris

Director of Nursing & Quality

Appendix 1 - Topics and tabled reports schedule 2017/2018

Clinical governance topics for meetings 2017 - 2018

Date of meeting	Topic	Audits and reports
2 March 2017	Health and Safety	• Moving and Handling Audit • Infection Control Audits and Report • Sepsis Audit and Report
1 June 2017	Documentation and Education	• Documentation Audit • Version Control Report • Education/Training Audit and Report • Departure Letter Audit
3 August 2017	Annual Reports	• Annual Safeguarding Audit and Report • Annual Friends and Family Test • Annual Quality Account • Annual AINMs Report/Summary
7 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
2 November 2017	Medicine Management	• Medicine Chart Audit • Medicine Risk Management Audit • Medicine Errors Report • Accountable Officer Report • Controlled Drug Audit
4 January 2018	Transition and Behaviour which Challenges Planning for 2018/2019	• 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 which did not result in injury, illness or damage but had the potential to do so
AOCD (or CDAO)	Accountable Officer for Controlled Drugs, the 2013 regulations require healthcare organisations such as NHS Trusts and independent hospitals to appoint a Controlled Drugs Accountable Officer (CDAO) who has responsibility for all aspects of Controlled Drugs management within their organisation
CCG	Clinical Commissioning Group are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England
CD	Controlled Drugs are prescription medicines which are controlled under the Misuse of Drugs legislation (and subsequent amendments). These medicines are called controlled medicines or controlled drugs. Examples include morphine
CDLIN	Controlled Drugs Local Intelligence Networks, a legal duty of collaboration was included in the Health Act 2006 requiring organisations to share concerns, within certain constraints, about the use of controlled drugs. Local intelligence networks were set up and led by NHS England to bring together organisations from the NHS, independent health and other responsible bodies, regulators and agencies including the General Pharmaceutical Council, NHS Protect, Prison Services and the Police Services
CDOP	Child Death Overview Panel, this is a multi-agency 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

Glossary of terms and definitions	
CEO	Chief Executive Officer is the most senior corporate officer, executive or leader in charge of managing an organisation
CHSW	Children's Hospice South West, the three hospice sites are: Little Bridge House (LBH), Charlton Farm (CF) and Little Harbour (LH)
CQC	Care Quality Commission is the independent regulator of all health and social care services in England. Its job is to make sure that care provided by hospitals, dentists, ambulances, care homes and services in people's own homes and elsewhere meets government standards of quality and safety
CQUIN	Commissioning for Quality and Innovation. The system was introduced in 2009 to make a 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 unauthorised 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 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 which organisations use to determine what steps need to be taken in order to move from their current state to the desired, future state. Also called need-gap analysis, needs analysis, and needs assessment. Gap analysis forces an organisation to reflect on who it is and ask who they want to be in the future
GDPR	The General Data Protection Regulation (GDPR) is a legal framework which 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
Monkey Survey	A child friendly survey produced by Monkeywellbeing.com, this is used to obtain information and valued feedback on children's and families' experiences of their care
MRSA	Methicillin-resistant Staphylococcus aureus infection is caused by a type of staph bacteria which has become resistant to many of the antibiotics used to treat ordinary staph infections.
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 which uses animated methodology to capture the opinions and experiences of children and young people in settings such as healthcare, education and social services
Orovia	The company who developed the software and support package for the National Paediatric Toolkit
PPM	Paediatric Palliative Medicine, specialised medical care for children with serious life-limiting/life threatening illnesses. It focuses on providing relief from the symptoms, pain and stress of a serious illness, whatever the diagnosis. The goal is to improve quality of life for both the child and the family
SOP	Standard Operating Procedure, is a written procedure prescribed for repetitive use as a practice, in accordance with agreed upon specifications aimed at obtaining a desired outcome

children's hospice SOUTH WEST

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