



# Shooting Star Children's Hospices



**Quality Account  
2018/19**

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## Part 1: Statement from the Chief Executive

I'm very pleased to present the Quality Account for Shooting Star Children's Hospices covering the year 2018/19 which demonstrates significant progress on our previous years' priorities.

Shooting Star Children's Hospices cares for babies, children and young people with life-limiting conditions, and their families. We support families from diagnosis to end-of-life and throughout bereavement with a range of nursing, practical, emotional and medical care.

Our bespoke support is free of charge to families and includes a named key worker, a comprehensive range of therapies and support groups for the whole family, specialist nursing care and short breaks at our two hospices (Shooting Star House in Hampton and Christopher's in Guildford) or in the family home, symptom management, end-of-life care and bereavement support.

As a leading children's hospice charity, we're proud that both our hospices are rated 'outstanding' by the Care Quality Commission (CQC).

The aim of this report is to give clear information and assurance about the quality and safety of our services, to demonstrate that supported children, young people and their families can feel safe and well cared for, and that all of our services are of a high quality. The report will give clear status updates of the priorities identified for last year and will demonstrate the organisation's excellent progress and outcomes for all of those priorities. In addition the report will identify key priorities going forward for the coming year.

The Quality Governance and Risk Committee provides guidance, assurance and support to the Shooting Star Children's Hospices Board of Trustees on all matters relating to clinical governance, and monitors clinical governance activities through a robust reporting structure from floor to Board. The committee has a particular remit to ensure that the hospice has a culture of continuous learning and improvement and to champion an open approach to care.

We could not ensure such high standards of care without the hard work of our staff and volunteers, and together with the Board, I would like to thank them all for their support.

2018/19 remained another financially challenging year for both children's and adult hospices, particularly given the uncertainty of the economic climate. This coupled with a rising demand for services and care needs becoming ever more complex, thanks to medical advances, resulting in a need for greater staffing levels and expertise, one of the key priorities for us during 2018/19 was to review our approach to care service allocation.

This new approach will introduce a process to assess the child and families' level of need at the point of referral using evidenced based tools including the Surprise Question and Palliative Care Phases of Illness. The service allocation will then be tailored based on the medical needs of the child,



whether they're approaching end of life and the urgent needs of the family. During 2019/20 we will implement our new responsive care model.

Throughout the year we also gathered feedback to help shape our care service – through surveys, 'You said – We did' boards and various other feedback techniques – to ensure optimum patient experience. This included a bereaved family survey whereby 85% of families who filled in the survey reported being very satisfied or quite satisfied with bereavement support at Shooting Star Children's Hospices compared to 50% for external providers (this is a specific outcome measure against the NICE Quality statement 5: Support for grief and loss for parents and carers).

In 2018/19 we took further steps to engage CCGs and increase the number of respite nights spot-purchased by local authorities. This drive has proven hugely successful with 1,050 respite and 403 emergency nights for families funded by statutory services resulting in a 55% increase in income on last year. In 2019/20 we will be looking to secure this income via a standard NHS contract.

The Director of Care at Shooting Star Children's Hospices and all clinical managers are responsible for the preparation of this report and its content. To the best of my knowledge, the information in this Quality Account is accurate and a fair representation of the quality of care provided by Shooting Star Children's Hospices.

**Nigel Harding**

**Chief Executive**

**Please note:** In February 2019, the charity's name officially changed from Shooting Star Chase to Shooting Star Children's Hospices.

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

### 2.1 Key priorities for improvement in 2019/20

Following consultation with care managers and hospice leaders, and using feedback from service users, incidents and complaints, Shooting Star Children's Hospices identified the following six priority areas for quality improvement in 2019/20.

#### Patient experience

##### Priority one – Move to a responsive care model

In 2019/20 our first priority will be the implementation of the new responsive care model and its delivery. This change will be key to improving patient experience and clinical effectiveness and will require collaboration at all levels within the organisation and with our external partners. The change will be an innovative approach to the allocation of services and will introduce an assessment of the child and families' level of need using evidence-based tools including the Surprise Question and Palliative Care Phases of Illness.

##### In order to achieve this we will:

- Hold open meetings and individual discussions with families and ensure effective communication to our service users and external partners by the end of May 2019
- Provide detailed written and verbal information and support for staff about the change prior to, during and after implementation
- Complete the implementation of the new responsive service model in November 2019
- Develop new key performance indicators from April 2019 to provide the tools for ongoing audit of the new model
- Expand successful 'feedback fortnight' methodology to other services e.g. therapies
- Develop more opportunities for social interaction events for supported children and their families e.g. activity days, stay and play
- Review and implement a model for key working

##### Priority two – Work collaboratively to achieve national quality standards

Priority two is to work collaboratively with our partners, driving forward the NHS integration agenda, to deliver the highest quality standard of care for supported children and families.

##### In order to achieve this we will:

- Work with partners in the Child Death Review (CDR) programme to ensure a robust process compliant with CDR statutory guidance by Q3 2019/20

- Work with partners to develop and implement an Advanced Care Planning tool for use with the children and young people in our care
- Proactively engage and champion the development of a Paediatric Palliative Care Clinical Network in Surrey in order to progress work on the NICE quality standards e.g. real choice of place of death, and ensure shared learning in this specialist area by Q2 2019/20
- Scope a bid for the development of regional palliative care services in partnership with acute trusts and CCG's
- Review our processes and governance against the new Care Quality Commission Independent Healthcare standards and action any gaps in our services
- Expand transition clinical service partnership to London area

## Patient safety

### Priority three – Champion and sustain the culture of openness, learning and innovation at all levels within the organisation

As an organisation we are passionately committed to developing our leaders and staff at all levels to champion an open and fair culture which supports continuous learning and delivery of high quality, safe care.

#### In order to achieve this we will:

- Review and update our Quality, Risk and Governance framework policy and audit programme to encompass new developments
- Expand our commitment to developing clinical leaders and driving forward the NHS integration agenda. We're committed to sponsoring three leaders onto the Surrey 500 Leadership Training and a further Mary Seacole award in the summer
- Introduce the new Nurse Associate apprenticeship role to Shooting Star Children's Hospices and support two places for training during 2019/20
- Explore more formal partnerships with our affiliated universities
- Implement an electronic system for recording accidents and incidents
- Continue to improve and sustain mandatory training compliance

## Clinical effectiveness

### Priority four – Leading change and adding value

At Shooting Star Children's Hospices, as in other similar organisations, we're facing challenging times as the demand for our services and complexity of treatment grows, and resources become ever more squeezed. It is essential that we ensure the services we provide are affordable, continue to add value to the children and families we support and represent good use of our resources.

Our care staff are uniquely placed to lead positive change based on interventions that can add value to our families and do less of the things that create unnecessary process driven work.

In 2019/20 we will be building on the work completed in 2018/19 and implementing the new responsive care model. This change will be key to

managing the challenging demand for our services in a responsive way and will support the financial sustainability of the service overall.

**To achieve this we will:**

- Implement the new care model and release capacity for the children and young people nearing end of life or who are unstable, and for children who have been assessed as requiring statutory funded respite through their Education, Health and Care plans (EHCP)
- Aim to deliver an additional 350 statutory funded respite nights to children who are assessed as requiring additional support in their EHCP

**Priority five – Enhance care through clinical informatics**

At Shooting Star Children's Hospices we're committed to the use of technological solutions to support clinical effectiveness and support quality care.

**To achieve this we will:**

- Complete the review and development of all electronic care plans to ensure safe and effective risk planning
- Develop an innovation and publication area on our website
- Implement an electronic system for recording accidents and incidents
- Use the new care database to produce reliable data to inform and audit the implementation of the new care model

## 2.2 Statements of assurance from the Board

### Review of services

#### Participation in national clinical audits

During 2018/19, no national clinical audits and no national confidential enquiries covered the NHS services that Shooting Star Children's Hospices provides.

#### Participation in in-house clinical audits

As documented as part of the Priorities for Improvement above, Shooting Star Children's Hospices has a comprehensive internal audit cycle.

#### Participation in clinical research

The number of patients receiving NHS services provided or sub-contracted by the hospice in 2018/19 that were recruited, during that period, to participate in research approved by a research ethics committee was zero.

#### Use of the Commissioning for Quality Improvement and Innovation (CQUIN) payment framework

Hospice income in 2018/19 was not conditional on achieving CQUIN goals through the commissioning for Quality and Innovation payment framework. We do not use any of the NHS National Standard Contracts therefore we are not eligible to negotiate a CQUIN scheme.

#### What others say about us

The hospice is registered with the Care Quality Commission (CQC) and its



current registration status is unconditional. The hospice has no conditions on registration. The CQC has not taken any enforcement action against the hospice during 2018/19.

Both hospices have an outstanding rating.

#### Provider engagement

During 2018/19 we hosted two CQC provider engagement meetings, a staff focus group and ad-hoc meetings with users and families at Shooting Star House.

The CQC Engagement Manager gave us positive feedback on his focus group with our clinical staff and the families. He reported to us that he had no concerns.

The CQC manager offered us positive feedback on the notifications we regularly make for deaths and other notifiable incidents and was pleased with the level of detail included.

#### Data quality

The hospice did not submit records during 2018/19 to the Secondary Users Service for inclusion in the hospital episode statistics, which are included in

the latest published data. This is because the hospice is not eligible to participate in this scheme.

**Clinical coding error rate**

The Hospice was not subject to the Payment by Results clinical coding audit during 2018/19 by the Audit Commission.

## Part 3 – Review of quality performance

### Patient safety – progress made in 2018/19

This section describes the progress made against the patient safety priorities set for 2018/19.

#### Previous year priority one – Develop and measure the culture of a learning organisation

Our priority for 2018/19 was to continue to focus on the learning culture at Shooting Star Children's Hospices, embedding the new governance processes, building on previous work and introducing ways in which we could benchmark our outcomes effectively.

##### What we did

- We did a review of processes for body mapping and we implemented a new process, training and audit to ensure we provide best practice to safeguard children and ensure early identification of unexplained bruising and injuries.
- We developed and introduced into practice a bed-side safety check list and plan for high risk ventilation care.
- We rolled out learning on the “can do safely” initiative following an incident in another hospice, in particular around the importance of:
  - proactive incident reporting to enable learning
  - willingness to challenge – we carried out an audit of this
- We implemented a new privacy policy in line with GDPR.
- We appointed a Clinical Informatics Nurse and commenced work on reviewing care plans and risk assessments.

##### What the outcomes were

- The rate of medication incidents per administration remained low: 2018 Q4 Shooting Star House 0.04% and Christopher's 0.14%.
- A new body map and skin assessment audit was introduced with significant improvement in compliance from 31% in Q2 to 62% in Q4.
- Incident and accident reporting increased from 139 to 185 in 2018/19 and severity remained mostly low or very low, with just 10 moderate and no high. Complaints remained consistent with previous year.
- In the audit, 79% of staff said they felt able to challenge decisions and practices.
- We also have a Privacy Policy in place to ensure our practice is in accordance with the law on GDPR practices.

#### Previous year priority two – Care and nursing workforce and recruitment

Our nursing workforce continued to be a priority in 2018/19 with a key focus on development of skills and retention. Also, as we entered a phase of organisational change, there was a focus on staff support and leadership.

##### What we did

- We focussed on retention with our HR colleagues including proactive leaver's reviews, development opportunities and strengthening leadership.
- We implemented an improvement plan for mandatory training for care staff, and in particular for bank staff, and worked with team leaders to tackle individual poor compliance.
- We invested in clinical leadership initiatives including the Burdett rotation programme, the Mary Seacole leadership award and a programme of in-house team building workshops.
- We agreed to largely match the pay deal reached for NHS nurses, with just a few parts of the pay deal not matched.
- We worked with CHaL to review competencies for children's hospices, however this work was superseded by a project to develop a rotational program for nurses across the sector.

#### What the outcomes were

- Turnover of staff in care improved by 6% on the previous year to 23%.
- Nursing and care staff vacancies were minimised.
- Mandatory training for care staff and bank staff improved significantly:

	Quarter 1, 2018/19	Quarter 4, 2018/19
<b>Care (excluding Bank)</b>	69%	86%
<b>Care – Bank</b>	25%	72%

- The nursing staff pay award was implemented at the end of 2018/19 / beginning of 2019/20.
- The Team Leader at Shooting Star House achieved the Mary Seacole award.
- We currently have one nurse on rotation from Great Ormond Street Hospital (GOSH) with one of our nurses at GOSH.

### Clinical effectiveness – progress made in 2018/19

This section describes the progress made against the clinical effectiveness priorities set for 2018/19.

#### Previous year priority three – Enhance care through clinical informatics

Following the implementation of The Care Database, a key priority in 2018/19 was the implementation of the wider scope of the system and to further develop our use of informatics to improve safe care.

#### What we did

- We rolled out the additional systems of The Care Database including nurse rostering, reporting and therapy bookings.
- We appointed a permanent Clinical Informatics Nurse who:
  - developed the care database policy
  - focussed on troubleshooting and training

- implemented a care database bulletin to keep staff informed of changes and learning
- undertook a review of the care plans, included a complete redesign of the Airway, Breathing, Circulation (ABC) related plans.

#### **What the outcomes were**

- The Care Database operational policy is now in place.
- A new suite of respiratory care plans are in place and the first audit has been completed – ABC care plans completed audit; Shooting Star House = 95%, Christopher's = 70%.
- The Care Database has now been fully embedded in our care delivery allowing a fully auditable process.

#### **Previous year priority four – Leading change and adding value**

In 2018/19 we wanted to build on the clinical review undertaken the previous year to ensure we have a responsive, sustainable and affordable care service that would continue to support and care for our families.

#### **What we did**

- We undertook a detailed and extensive project to redesign our care model in line with our strategy of responsive care and in order to manage the growing demand for our services. The project team consulted widely with clinicians and managers, both internally and externally, and benchmarked with similar providers. We also engaged with service users on the design of the model.

The new approach will introduce a process to assess the child and families' level of need at the point of referral using evidence based tools including the Surprise Question and Palliative Care Phases of Illness. The service allocation will then be tailored based on the medical needs of the child, those approaching end of life and the urgent needs of the family. The outcome of the work was agreed by the Board in February 2019 and the implementation work will commence in May 2019 with all changes implemented by November 2019.

- We established professional working arrangements with our Health and Social care partners in order to increase the level of statutory funded respite we were able to provide.
- We appointed an experienced Family Link Worker to support families and help them navigate the challenging application process for short break respite provision from Health and Social Care.
- We delivered a bespoke training programme for a group of carers from special education needs services and commissioned by Health and Social Care.
- We continued to expand on the work started in 2017/18 to strengthen the therapeutic and non-therapeutic groups to ensure our service provision added the most value to families and the organisation.

**What the outcomes were**

- The outcome of the new care model review and the communication plan was presented and agreed by the Board of Trustees in February 2019 – the communication and implementation phase will commence in May 2019.
- We provided 1,050 respite and 403 emergency nights for families funded by statutory services. This is a 55% increase in income on last year.
- The carer training programme was highly evaluated with 100% of survey respondents saying that they felt that the Shooting Star Children's Hospices (then called Shooting Star Chase)/Tri-borough project had influenced their practice. 100% of respondents also said that all of the topics were relevant to their role.
- We have a refreshed suite of groups and have added additional opportunities for families to have social contact.
- New web pages are up and running for families to have instant access to information and greater transparency for bookings for groups.

**Patient experience – progress made in 2018/19**

This section describes the progress made against the patient experience priorities set for 2018/19.

**Previous year priority five – Move to a responsive care model**

Shooting Star Children's Hospices is committed to further developing our focus on co-design to shape our services and funding model.

**What we did**

- We undertook a bereaved family survey. We used this information to shape services including development of enhanced communication with families with children approaching the end of life and written information.
- We introduced a 'feedback fortnight' initiative as a tool to encourage families to give us their feedback in order to better understand our users views.
- We introduced 'You said: We did' boards to ensure we fed back to families any actions we had taken around their suggestions and to encourage further feedback.
- We developed and implemented a course for families with young people with complex cognitive disabilities to support them through transition.
- We engaged service users in our work to re-design our care model.
- We used innovative feedback methodologies including a sensory garden to collect feedback on different services.

**What the outcomes were**

- 85% of families who filled in the bereaved family survey reported being very satisfied or quite satisfied with bereavement support at Shooting Star Children's Hospices compared to 50% for external providers. This is a specific outcome measure against the NICE Quality statement 5: Support for grief and loss for parents and carers.

## Previous year priority six – Work collaboratively to achieve NICE quality standards

Following on from the benchmarking work we carried out in 2017/18, we made it a priority to work collaboratively with our partners to try to deliver a cohesive service to families with children at the end of life and to bridge the gaps.

### What we did

- We reviewed the Hospice at Home (H@H) end-of-life care provision and implemented a new out of hour's community nurse rota, seven days per week. This enabled us to build stronger partnerships with NHS Children's Community Nursing (CCN) teams and to jointly provide more effective 24-hour paediatric nursing support in the community.
- We're working with our partners to implement the new child death review process in September 2019. This will capture place of death nationally.
- We reviewed the model for neonatal care during 2018/19, but it was not feasible to develop a link nurse due to the high number of Neonatal Intensive Care Units (NICU's) we partner with. However, as part of this initiative we strengthened our referral pathways with key NICU's and promoted early referral.

### What the outcomes were

- More families able to have a real choice of where they want their child to be cared for at the end of life. *Clinical Nurse Socialist from GOSH, feedback*: 'this is how palliative care should be done' and, commented on the immediacy and responsiveness of the Shooting Star Children's Hospices team.
- We have seen an increase in antenatal and neonatal referrals to our service.

## Service Data

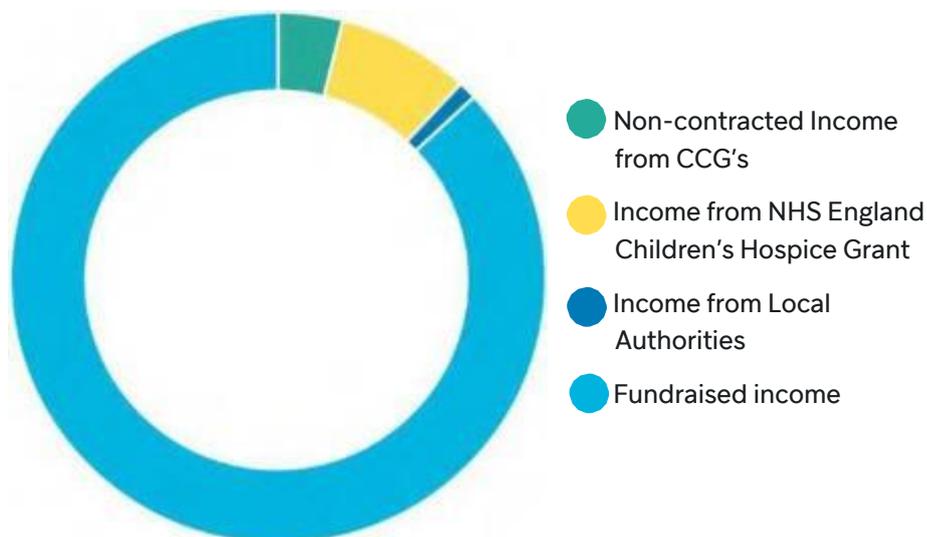
Shooting Star Children's Hospices did not provide any direct NHS services. We have reviewed all the data available to us on the quality of care across our services.

All services delivered by our hospices are funded through a combination of fundraising activity, the Children's Hospices Core Grant from NHS England and some ad hoc funded activity, usually emergency stays, from a range of CCG's and local authorities. The total funding received from CCG's in 2018/19 was £400,076 this came from 12 CCG's, however none was contracted income via a standard NHS contract.

Cost of running Shooting Star Children's Hospices care service	£7,181,292
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Non-contracted Income from CCG's	£ 400,076	5%
Income from NHS England Children's Hospice Grant	£ 640,107	7%

Income from Local Authorities	£ 247,500	3%
Fundraised income	£ 7,307,480	85%



Below is a snapshot of the services that we provide based on the data that we collect.

#### Children, families and siblings total

	C's	SSH	Total
Life-limited children supported	312	347	659
Bereaved families	83	156	239

The total number of LLC children and families supported has risen by 6% (30 more families). The number of bereaved families has increased by 8%.

#### Referrals

	Total
Received	173
Accepted	150

#### Deaths

	Total
Total	86
In the hospice	18

#### Nights

	Total
Respite	2,994
Emergency/EOL	403
Total	3,397

**EOL care**

	Total
EOL nights	260
EOL care in the community face to face contacts	263
Bereavement suite nights	151

**Hospice at Home activity**

	Total
Short break hours	8492
Average hours per child per year	13

**Children and families by CCG**

Each child's GP is linked to a Clinical Commissioning Group. There are 21 CCG's officially in our catchment area, although as can be seen from the list below, children also come from other CCG Areas.

CCG
NHS Barnet CCG
NHS Bracknell and Ascot CCG
NHS Brent CCG
NHS Central London (Westminster) CCG
NHS Coastal West Sussex CCG
NHS Crawley CCG
NHS Croydon CCG
NHS Ealing CCG
NHS East Surrey CCG
NHS Guildford and Waverley CCG
NHS Hammersmith and Fulham CCG
NHS Harrow CCG
NHS Hillingdon CCG
NHS Horsham and Mid Sussex CCG
NHS Hounslow CCG
NHS Kingston CCG
NHS Lambeth CCG
NHS Merton CCG
NHS North East Hampshire and Farnham CCG
NHS North Hampshire CCG
NHS North West Surrey CCG
NHS Portsmouth CCG
NHS Richmond CCG
NHS Slough CCG
NHS South Eastern Hampshire CCG

NHS Southampton CCG
NHS Surrey Downs CCG
NHS Surrey Heath CCG
NHS Sutton CCG
NHS Wandsworth CCG
NHS West London (Kensington and Chelsea, Queen's Park and Paddington) CCG

## Patient safety

Incidents by type and severity 2018/19:

	Very low	Low	Medium	High
Medication – Procedural	3	46	1	0
Medication – Transcribing	1	11	0	0
Medication – Prescribing	0	0	0	0
Medication – Near Miss	0	7	0	0
Security	2	5	0	0
Verbal Aggression	0	3	0	0
Violent Behaviour	3	9	0	0
Other – Care	1	39	0	0
Other	5	20	1	0
TOTAL	15	140	2	0

## Safeguarding report

There were 76 safeguarding concerns raised about children in our care in 2018/19. This is compared to 38 concerns in 2017/18. Following changes made to our safeguarding training, there has been a significant improvement in the understanding of safeguarding issues and the benefit of early reporting to aid interventions to help families.

Quarterly we audited the completeness, quality and timeliness of our safeguarding documentation, and referrals, against our policy process.

Quarter	Q1	Q2	Q3	Q4
%	84%	87%	86%	86%

The main failures against compliance were

- Safeguarding form not completed fully before end of shift – referral made verbally and actions taken
- Documented notes not highlighted as significant event i.e. red text

## Updated policies

In 2018/19 the following policies were reviewed and updated:

- Safeguarding Children
- Problem Solving – Volunteers Policy and Procedure
- Redundancy

- Whistle-blowing
- Volunteers Leaving
- Fire & Emergency Evacuation
- Asbestos Management
- Vehicles & Drivers
- Expenses
- Privacy Policy relating to GDPR
- Social Media
- Media and Marketing Selection Process
- Media Crisis Management
- Publications and Promotional Materials
- DBS
- Care Database
- Display Screen Equipment Policy

To do this, we researched other organisations' policies on these subjects, reviewed any new national guidance or legislation and devised procedures that make the reporting and tracking of any incidents easier for staff. We have changed the timescales of reporting safeguarding concerns in order to minimise the possibility of delay for children/young people. We have also devised an action plan and feedback element of the safeguarding form to ensure that there is a full circle of communication and information sharing as per lessons learnt in serious case reviews and recommendations nationwide. The feedback element of the form is to aid learning and development across the organisation.

### **Transition**

We have continued our ground-breaking practice in working with adult hospices triaging young people, and have established a quarterly meeting with London hospices this year.

### **Bereaved Family Survey 2018**

In June 2018 we sent a survey to bereaved families (whose child had died more than three months earlier) to better understand their experience of end-of-life care and bereavement support at Shooting Star Children's Hospices. The survey was compiled and consulted on by a wide range of staff and bereaved family members to ensure sensitivity, whilst being able to gather useful information to inform our service delivery for bereaved families.

The survey was sent out in June 2018 to all "open" bereaved families (130 in total) who had been bereaved more than four months on the date the survey was sent out. We received surveys back from 27 families, a 21% response rate. The survey had 17 questions, eight were about the care their child received at the end of their life, eight were about the bereavement support the family is receiving and the last question was for any other comments.

#### **Who responded/how had they used the service**

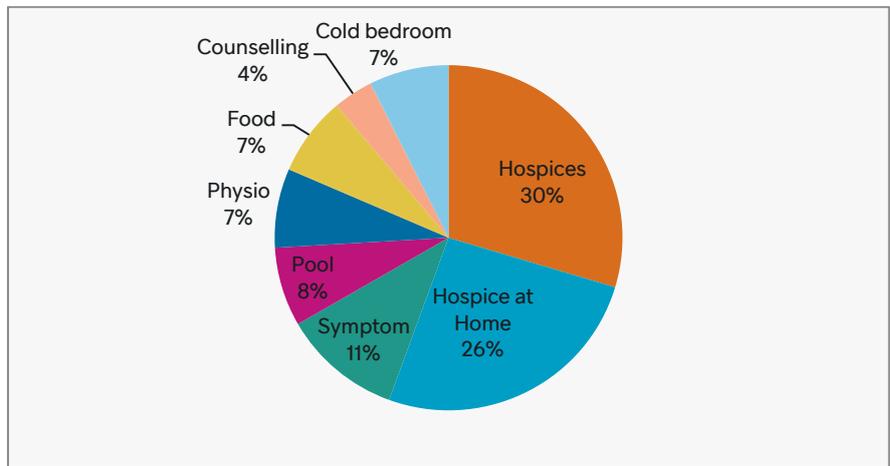
The key quantitative questions show us that the majority of the respondents had been using the service for "a few months" (41%) compared to "a year or

more" (41%) and "not known before" (18%). 33% of the children died at home, 33% in hospital and 33% in the hospice. This gives a great sample in terms of comparing different experiences.

Also, not from a direct question, but from written responses, at least 69% of the respondents' children used the bereavement suites and 12% used our cool cot/blanket at home. This means that 81% of the respondents used the hospice post-death services.

**A snapshot of the survey**

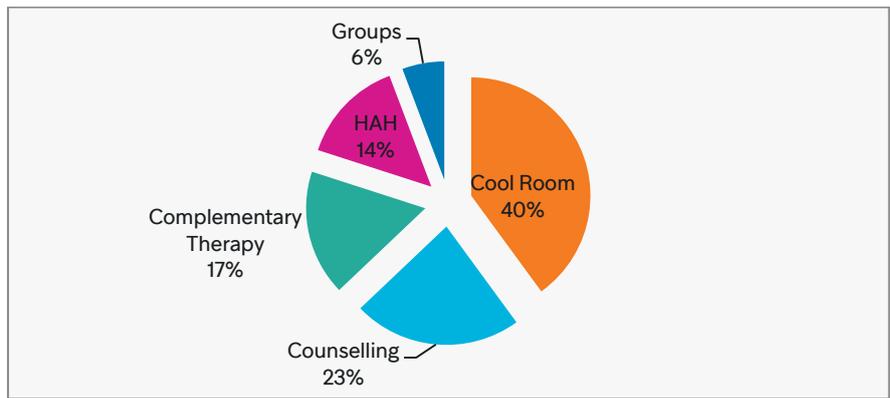
Which were the most beneficial Shooting Star Children's Hospices' services in the last few weeks of your child's life?



24 families answered this question and the answers were free text. The chart above shows the different parts of the service that were mentioned in the text answers, by volume. The answers included:

- "The care, empathy, the accommodation, medication, free meals, compassionate staff etc."
- "Explaining the palliative care and medication that can be given to relieve our child from pain – we had a lot of questions about Shooting Star Children's Hospices and palliative care and we always got the answers. It was very important for us to know that we could ask about everything related to our son's care."

How did you use the service in the weeks after your child died?



26 families answered this question. The pie chart above shows the proportion of answers that mentioned certain areas of the hospice.

Comments included:

- *"We didn't but we were very aware that we could and that was very helpful."*
- *"Continued visits from family support worker. We used the cold room afterwards until our son's funeral which was a really lovely facility. I would have struggled with him being in fridges at a funeral director."*

#### Were you made aware of the therapy support available from Shooting Star Children's Hospices?

All 27 responses answered this and three (11%) said that they didn't know, 89% said they did. This question links to:

NICE Quality Statement 5: Parents or carers of infants, children and young people approaching the end of life are offered support for grief and loss when their child is nearing the end of their life and after their death."

Nine families commented positively and this included:

- *"Counselling allows me time to talk with someone who will not judge and reassures me that what I feel is normal and expected."*
- *"It has helped me enormously to have someone to talk to and that I haven't had to make an effort at accessing this kind of support."*

There were also a couple of negative comments mostly relating to how services had been reduced and a lack of knowledge around how to access therapeutic services.

#### Did we inform you about other external services?

23 answered this question 65% said yes and 35% said no. This is linked to:

NICE Quality Statement 3: Infants, children and young people with a life-limiting condition and their parents or carers are given information about emotional and psychological support, including how to access it.

However, it is likely from some of the answers that this was not understood as external to Shooting Star Children's Hospices services.

#### Are you accessing other support services?

Only two of the 26 families who answered this question said that they were accessing external services.

#### Any other comments?

14 families chose to make comments. Nine of these were expressions of thanks and gratitude. Two of the nine were thanks and worries about funding cuts affecting the service in the future for other families.

The suggestions were:

- *"It feels lonely when the 3 years of memory days are up."*

- *"Our only suggestion would be the possibility of having an information leaflet when you leave, telling you what to expect. In the weeks' following R's death we weren't really sure what we should or shouldn't be doing, or what support we would receive. We also weren't sure who our support worker was. A leaflet saying "we will call you in x weeks" or "your support worker is x" or listing the services available would have been helpful as our brains couldn't retain much information."*

#### **What we did following the survey results**

- Communication was a key theme and in the future we will be providing better information, in a more timely manner and in writing about the services that we offer to bereaved families.
- This will include initial material sent out directly to all bereaved families within the first few weeks of their bereavement.