Contents

Executive Summary 3
Introduction 7
Stream 1: Existing best practice models and current provision in the South West. 10
Stream 2: Exploration of parent/carer needs for 24/7 specialist advice 14
Stream 3: Exploration of professional needs for 24/7 specialist advice 22
Stream 4: Technology and communication support structures 32
Stream 5: Staffing, training, governance, supervision 38
6: Summary, conclusions and recommendations 51
References 61
Appendices 62

Appendices

Appendix 1 Review of existing UK wide 24/7 specialist advice service models
Appendix 2 Telephone advice given by CHSW - current demand
Appendix 3 Post titles of online survey participants
Appendix 4 Organisations represented by online survey participants
Appendix 5 What are the advantages of your current system?
Appendix 6 What are the drawbacks of your current system?
Appendix 7 What would improve how specialist medical/nursing advice is provided?
Appendix 8 Linkage to other projects/areas of telecommunication development
Appendix 9 Training courses
## Acknowledgements

The Project Team owe a debt of gratitude to the parents/carers and professionals who generously gave their time and shared their views. We would also like to thank our colleagues for their support and contributions, in particular:

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tracey East</td>
<td>Head of Education</td>
<td>Children’s Hospice South West</td>
</tr>
<tr>
<td>Caroline Foyle</td>
<td>Research Administrator</td>
<td>University of the West of England Bristol</td>
</tr>
<tr>
<td>Richard Hain</td>
<td>Consultant/Lead Clinician in Paediatric Palliative Medicine, Senior Lecturer in Child Health</td>
<td>Cardiff University, Cardiff &amp; Vale University health Board</td>
</tr>
<tr>
<td>Nicky Harris</td>
<td>Medical Director, Charlton Farm</td>
<td>Children’s Hospice South West</td>
</tr>
<tr>
<td>Charlotte Mellor</td>
<td>Paediatrician Children’s Palliative Care</td>
<td>University Hospitals Bristol</td>
</tr>
<tr>
<td>Jan Randall</td>
<td>Administrator, Charlton Farm</td>
<td>Children’s Hospice South West</td>
</tr>
<tr>
<td>David Rogers</td>
<td>Database Analyst</td>
<td>University of the West of England Bristol</td>
</tr>
</tbody>
</table>

Finally, we are grateful to the Department of Health for providing funding for the project through the £30m for children and young people’s palliative care grant scheme, 2010.
Executive Summary

The 24/7 project investigated the need for and potential benefits of a 24/7 specialist children’s palliative care telephone advice service in the South West. This report proposes how this could be provided across the region, in collaboration with existing services.

The proposed service development supports the strategic vision of Children’s Hospice South West (CHSW),

“to be recognised regionally and nationally as a progressive centre of excellence in the care of children who are expected to die before adulthood and their families”,

and would also help to meet current gaps in the service, identified in the Palliative Care Services Review (Craft and Killen, 2007), which result in unplanned attendances to Emergency Departments and inappropriate hospital admissions. Planning end of life care for a child at home is often impossible without access to specialist advice.

In summary, the availability of 24/7 specialist children’s palliative care advice would benefit families by:

- supporting parents and professionals to care for children in the location of their choice
- reducing unnecessary and unwanted hospital admissions
- improving access to and quality of advice given and raising standards of children’s palliative care
- promoting emotional health and well-being of families living with a life-limited child.

This service development would also benefit providers by:

- improving collaboration between services
- providing improvements in infrastructure to support transfer of patient information and facilitate inter-professional communication
- promoting staff development and training to providing an expert knowledge base for the region and offer career progression in the specialty.

Project outcomes

The project, structured around five work streams, was funded by a grant awarded by the Department of Health.

Stream one: current best practice models and advice provision in the South West

The project identified five specialist 24/7 children’s palliative care telephone advice services in the UK, of which four were hospice based. None covered a region as large or as diverse as the South West peninsula.

Key professionals currently working in children’s palliative care in the South West confirmed that, although there are many services providing high standards of clinical care for children with palliative care needs, access to specialist nursing and medical advice 24/7 is not available as a planned or equitable service. In contrast with adult palliative care services, most children’s specialist telephone advice is currently provided on an informal/goodwill basis.
Stream two: parent/carer needs for 24/7 specialist advice.

Parents reported that they DO need access to specialist advice, and that this advice;

- is needed outside office hours
- is not consistently available from professionals who support them in the day
- could prevent unnecessary and stressful hospital admissions
- is needed to provide reassurance in decision making, particularly with respect to need for hospital admission.

Parents gave a clear message that;

- the difficulties of caring for a child at home at the end of their life are compounded by limited access to specialist advice
- they would like advice from someone who knows their child or at least has access to their up to date records
- families under the care of CHSW feel that we do know their child and therefore they will contact CHSW for advice.

Stream three: Professionals’ needs for 24/7 specialist advice

Professionals reported that they DO need access to specialist advice outside office hours. In addition;

- when they are supporting families outside normal working hours it is on a good will basis, especially during the end of life period
- current arrangements are unsustainable, both in the short term, when providing care for an individual family, and the long term, when planning overall service provision
- effective coordination of services and communication between professionals is needed to provide 24/7 advice.

Parents and professionals most need specialist advice regarding: Symptoms, medication: doses, End of Life care decisions and arrangements following death.

Stream four: technology and communication support structures, call handling and administrative back up.

Call Handling
Both parents and professionals stressed the need for one telephone number with minimal waiting. They would like a system that does not rely on a script of questions and they do not want to repeat their child’s story from the beginning. All parents and the majority of professionals said that both groups should be able to ring the advice line directly.

System for transfer of patient information
A robust system for communication of patient information between all settings is of vital importance to the development of a specialist palliative care telephone advice service. For children’s palliative care in the South West region the decision regarding a system for transfer of information will be key to the strategic development of services.
Stream five: staffing, training, governance, supervision

Expertise of staff was rated consistently as the most important feature in giving professionals confidence in using an advice line.

To be eligible to work as part of the 24/7 service, staff must have specified experience levels in a field of paediatrics which involves palliative care, defined levels of palliative care training and specific training in telephone advice and advanced communication skills.

Staff should be structured as part of a team with strong links to other services and regular supervision. Governance structures to be in place from the outset include audit of recorded calls, feedback processes form parents and professionals and development of guidelines for commonly encountered problems in line with the available evidence base.

Conclusions

- The project demonstrates the need for a 24/7 specialist telephone advice line in the South West that is available to both parents and professionals.
- The credibility of a 24/7 advice line will depend on the experience and expertise of the staff giving advice.
- A robust system for sharing information is key to the success of a 24/7 specialist telephone advice line.

Considerations for the existing CHSW service

- Families attending the hospices feel we do know their child; they trust us and contact us for advice.
- Parents are already confident in CHSW advice and want CHSW to continue to give advice as they feel CHSW knows their children and understands their needs.
- Whatever direction the strategic development of CHSW takes it is crucial to protect the valued work and reputation of the existing hospices.

Options for scope of service

<table>
<thead>
<tr>
<th>Hours of operation</th>
<th>A full 24/7 service model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Area covered</td>
<td>Regional service: for South west region to cover the nine Primary Care Trusts.</td>
</tr>
<tr>
<td>Referrals to service</td>
<td>Referrals accepted from parents, carers and professionals involved in the care of a life limited children in the South West.</td>
</tr>
<tr>
<td>Time frame for service delivery</td>
<td>The CHSW strategic plan proposes the development of a 24/7 service for 2013. If this time frame is to be achieved a significant investment would need to be agreed in the coming financial year to support the training for staff to work for the service.</td>
</tr>
<tr>
<td>Operational considerations</td>
<td>Staffing Models (see options below). Experienced nurses and Doctors with specific palliative care and communication training working as part of a team. Proactive call model.</td>
</tr>
</tbody>
</table>
Options for models of service:

Model A: Two-tier on call model for telephone advice only.
Model B: Three-tier model with potential for doctor to visit.
Model C: Mixed on call rota (nurses and doctors at tier one) for telephone advice only
Model D: Nursing on call rota with potential for nurse to visit
Introduction

In September 2010 Children’s Hospice South West (CHSW) was awarded a grant from the Department of Health for the 24/7 project.

Aim

The aim of the 24/7 project was to develop a proposal as to how the need for 24/7 access to specialist children’s palliative care telephone advice could be met across the South West region, in collaboration with existing services.

Rationale for project

A key part of the vision for children’s palliative care services for the future, as set out by the Department of Health (DH) in “Better Care: Better Lives (2008) ¹ and by The Association of Children’s Palliative care (ACT ) in the “Guide to development of children’s palliative care services” ² is the availability of 24 hour access for professionals and parents/ carers to specialist advice.

Nationally this was identified as a service gap in the Craft and Killen (2007) Palliative Care Services Review ³ resulting in unplanned attendances to Emergency Departments and inappropriate hospital admissions. It was also clear that planning end of life care for a child at home was often impossible without access to specialist advice.

Although there are many services providing high quality clinical care for children with palliative care needs across the South West, provision of specialist nursing and medical advice 24/7 has developed in an ad hoc manner, leading to wide variation between areas in provision and access arrangements.

Due to its geographical coverage and 24/7 care provision, CHSW is in a unique position to develop a specification for a telephone advice service, working in collaboration with other service providers, to provide genuine access to 24/7 specialist advice.
Project Plan

The project was structured into five work streams:

Stream 1: Existing best practice models and current provision in the South West.
- Review of literature and current policy context.
- Review of existing UK wide 24/7 specialist advice service models.
- Mapping existing paediatric palliative care services across the South West and their contribution to 24/7 specialist advice.

Stream 2: Exploration of parent/carer needs for 24/7 specialist advice
- Qualitative exploration via semi structured interviews.

Stream 3: Exploration of professional needs for 24/7 specialist advice
- Initial engagement with key professional stakeholders.
- Online survey to scope professionals views and needs.

Stream 4: Technology and communication support structures
- Investigation for provision of call handling structure and administrative back up for the service.

Stream 5: Staffing, training, governance, supervision
- Exploration of competency levels, training and governance needs for medical and nursing staff giving advice.

6: Summary, conclusions and recommendations
Project personnel

Steering Committee:

Mandy Robbins  Director of Care, Children's Hospice South West (CHSW)
Phil Jardine  Consultant Paediatric Neurologist and Trustee, CHSW
Bruce Hughes  Medical Director, Little Bridge House
Julie Stanway  Head of Care, Little Bridge House
Ruth Berry  Senior Team Leader (Care Team), Charlton Farm
Tamsin Lewis  Head of Care, Little Harbour
Project team.  (Listed below).

Project Team:

Mandy Robbins  Director of Care CHSW  Project Supervisor
Jo Frost  Paediatrician, CHSW  Project Leader
Antonia Beringer  Senior Research Fellow University of the West of England, Bristol (UWE)  Lead Researcher
Katherine Pollard  Senior Research Fellow University of the West of England, Bristol (UWE)  Researcher
Jan Randall  Care Admin: Charlton Farm  Project Administrator

Methods

A range of approaches was used to collect data across the five project work streams. The Research Ethics Sub-Committee of the Faculty of Health and Life Sciences at the University of the West of England, Bristol, approved the project.

Methods and findings for each stream are presented in the relevant section of the report.
1.1 Review of literature and current policy context

A review of the literature and the current policy context was conducted in order to understand more fully what is known in this field, specifically:

- What is currently known about, and what can be adapted from specialist telephone advice services in adult palliative care.
- What is currently known about specialist telephone advice services for children’s palliative care.

1.1.1 Key messages from literature on adult palliative care specialist advice services:

1. There are existing models for use of telephone advice. ⁴
2. Hospices have taken a lead in developing these services. ⁵-⁷
3. Service developments of this type should be guided by the voices of users. ⁸
4. Nurses with specialist experience and training in palliative care are key to the development of these services. ⁹
5. Training of staff in telephone consultation is vital in the development of such a service. ⁵, ⁶
6. Doctors and nurses working for such a service need specific palliative care training in order to be considered “expert” in advice giving. ⁴-⁶
7. Best practice models of service include staff working as part of a team, with regular team discussions for complex cases, debriefing and supervision. ⁶
8. Advice sought of such services is predominantly related to symptom control and for reassurance for families. ⁶
9. Models include the use of proactive telephone calls to patient and families. ⁸, ⁹
10. Good inter-professional communication systems are vital to support giving advice out of daytime working hours. ⁴
11. The use of “Telemedicine” (the remote monitoring of patients through information and communication technologies) in palliative care is an expanding field, particularly in the provision of services to large rural areas. ¹⁰
1.1.2 Key messages from literature on children’s palliative care specialist advice services:

There is only one published abstract relating to the development of a specialist telephone advice service for palliative care in children. The audit of this service confirmed that:

1. Community nurses and parents made the majority of calls to the service

2. One third of the calls are felt to be urgent “signifying the need for direct access to specialist advice.”

3. There is considerable demand for advice outside office hours, despite anticipatory planning.

1.2 Review of existing UK wide 24/7 specialist advice service models

Data were collected by an internet search and email survey of UK hospices. Telephone interviews were conducted with representatives of UK services reported to offer 24/7 children’s palliative care advice. Researchers also drew on their professional contacts for relevant information. Please see Appendix 1 for details of data collection.

The search methods identified only five organizations outside the South West systematically offering 24/7 specialist telephone advice for children receiving palliative care. These comprised four non-NHS hospices and one NHS Trust.

The main features of the services offered by these organizations were:

- There is considerable variation with regard to the number of children and families receiving care, which ranges from 20 – 350 per organisation.

- Members of staff answering phone calls include members of the general care team (not necessarily registered professionals), as well as specialist children’s palliative care nurses and experienced paediatric nurses. Onward referral is made either to senior nursing or medical staff. Consultant opinion is usually available if required.

- In some organisations, staff are available to answer the phone 24/7, whereas in others, cover is provided by staff on an on-call rota or from other organisations.

- The background of staff providing advice includes specialism/training in paediatric palliative care, oncology, neurology and PICU.

- In most cases, staff are also provided with training on communication, including skills needed for telephone consultations.
All the services receive phone calls, from both families and professionals, for advice about symptom control, medication issues and end of life care.

Parents also phone for psychological support, and for reassurance that what they are doing is appropriate.

(More detail about features of individual services can be found in Appendix 1.)

### 1.3 Mapping existing paediatric palliative care services across the South West and their contribution to 24/7 specialist advice

Telephone interviews were conducted with 11 professionals from existing palliative care services across the South West operated by both voluntary organisations and NHS Trusts, to identify how they manage the need for 24/7 specialist advice for children receiving palliative care. Respondents included medical consultants and specialist nurses from the following services:

<table>
<thead>
<tr>
<th>Voluntary organisations and NHS Trusts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Palliative Care</td>
</tr>
<tr>
<td>CLIC Sargent</td>
</tr>
<tr>
<td>Community Paediatrics</td>
</tr>
<tr>
<td>Diana Team</td>
</tr>
<tr>
<td>General Practice</td>
</tr>
<tr>
<td>Jessie May Trust</td>
</tr>
<tr>
<td>Lifetime Service</td>
</tr>
<tr>
<td>Oncology Services</td>
</tr>
<tr>
<td>The Compass Team</td>
</tr>
</tbody>
</table>

Eight professionals stated that their organisations provided advice outside normal office hours, although none had a formal system for doing so on an ongoing basis. In most cases, when a child was identified as being clinically unstable or in the terminal phase, telephone numbers were made available to relevant individuals. Across the organisations, the service included, variously; telephone advice, home visits and proactive calls.

In four organisations both doctors and nurses provided advice outside normal working hours, while in another four it was given only by doctors (registrars and consultants). This service appeared to be provided mostly on an ad hoc basis, usually depending on the goodwill and/or availability of individual professionals. In one organisation, professionals operating the service were paid overtime, but this was not so elsewhere. Back-up support appeared to be variable across the organisations, with some professionals reporting good documentation and regular multidisciplinary team (MDT) meetings to discuss issues, while others stated that there were minimal standardised communication mechanisms or strategies in operation.

In five cases, this service was available to both parents and professionals, but only to parents in the remaining three. Advice was sought mainly for symptom management, including pain, emesis and seizure control; and also for end of life care and bereavement support. The demand for telephone advice outside office
hours appeared to be low, with one professional stating that they only needed to provide it about three or four times a year. However, when it was required, families sometimes used the service daily.

The main advantage of the various systems in operation was identified as providing continuity of care for families. Disadvantages identified included the need to rely on individuals’ goodwill in order to keep a service going, and the risks associated with staff carrying an unsustainable workload.

Three professionals stated that their organisations do not provide advice to families outside office hours, and two did not know how families obtain advice at these times. In the third case, families are referred to CHSW if the child is on their caseload; if not, staff attempt to organise pre-arranged contact with families to discuss relevant issues during office’ hours. In all three cases, it appears that most families can only access advice through NHS Direct or their GPs’ out of hours provision.

1.4 Current telephone advice provision by CHSW

Telephone calls seeking advice were logged by hospice staff over a two month period. A summary of the calls is shown below.

<table>
<thead>
<tr>
<th>Number of calls logged</th>
<th>23</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calls received outside usual ‘office’ hours.</td>
<td>9</td>
</tr>
<tr>
<td>Calls relating to children known to CHSW</td>
<td>22</td>
</tr>
<tr>
<td>Calls received from parents</td>
<td>16</td>
</tr>
<tr>
<td>Calls made by professionals</td>
<td>3</td>
</tr>
<tr>
<td><strong>Type of advice sought:</strong></td>
<td></td>
</tr>
<tr>
<td>symptom control</td>
<td>14</td>
</tr>
<tr>
<td>emotional support</td>
<td>13</td>
</tr>
<tr>
<td>medicines</td>
<td>6</td>
</tr>
<tr>
<td>feeding</td>
<td>6</td>
</tr>
</tbody>
</table>

More detailed information in appendix 2.

Stream 1: Summary
Existing best practice models and current provision in the South West.

The project identified five specialist 24/7 Children’s palliative care telephone advice services, in the UK. Of these four were hospice based. None covered a region as large or as diverse as the South West Peninsula. There were a variety of models for service delivery.

Consultation with key professionals currently working in children’s palliative care in the South West and a professionals survey confirmed our belief that although there are many services providing high standards of clinical care for children with palliative care needs, access to specialist nursing and medical advice 24/7 is not available as a planned or equitable service.

The majority of the specialist advice currently provided is on an informal/goodwill basis.
Data were collected through 26 interviews with parents/carers of children with life-limiting/terminal conditions, two of which involved both parents. All the parents/carers who were interviewed had children who had received, or were receiving, care through CHSW. One bereaved parent was interviewed. This interview was conducted face-to-face, as were interviews with seven other participants, eighteen interviews were conducted by telephone. With individuals’ consent, 23 interviews were audio-recorded. One interview was not audio-recorded due to environmental noise, and in two cases, technical failure affected recording. In these cases, data were recorded using field notes. The interviews were transcribed verbatim and analysed thematically.

2.1 Findings

Themes that emerged from the data included: need for advice, including frequency; dealing with symptoms, including administering medication; reassurance and emotional support; characteristics of staff giving telephone advice. Findings also emerged about the CHSW hospices, other services that families use during ‘office’ hours, and issues not directly to the provision of a 24/7 telephone advice line. Parents/carers also spoke about technical aspects of a telephone advice line; these features are discussed in Stream 4 below.

2.1.1 Need for 24/7 telephone advice

Nineteen parents/carers reported needing 24/7 advice.

<table>
<thead>
<tr>
<th>Parent/carer</th>
<th>Need advice</th>
<th>Don’t need advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>22</td>
<td>16</td>
</tr>
<tr>
<td>Men</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Couple</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>19</td>
</tr>
</tbody>
</table>

Table: Parent/Carer Interviewees – need for medical/specialist advice

Of the seven who said they did not need advice, four said that they had needed advice at an earlier stage of their child’s illness, but that the child had been well for quite a while. These parents/carers also reported that they were now so used to dealing with their children’s condition that they knew more about it than most health professionals. Two other parents felt that they might need advice in the future, as their child’s illness progressed. One parent reported not needing advice because the child in question had disabilities, but had never been seriously ill.
Most of the parents identified a gap in provision, stating that NHS Direct staff, out-of-hours GPs and paediatricians were often not sufficiently knowledgeable about their particular child and their condition, to give them suitable advice over the telephone, and nearly always suggested hospital admission:

“One of the conditions child has no-one really knows anything about it ... if we see anything new we ring people up and they have to Google it.” (Respondent 7)

“They’ll just say ‘call an ambulance’ or ‘you should be in hospital’, where with our kids, you know, if you listen to a lot of people we would spend all of our lives in hospital.” (Respondent 4)

“Paediatricians’ experience of rare diseases is somewhat limited and I often end up taking my son to the hospital as a consequence because they have no experience of it therefore they don’t feel happy to make the call over the phone.” (Respondent 21)

In thirteen interviews parents stated that, had specialist advice been available to them outside ‘office’ hours, their child might have avoided a hospital admission:

“My wife’s a nurse and she understands everything that goes on with child and we are competent enough to cope and we have all the equipment here at home, it’s just somebody at the end of the phone to say well if you’re happy to do that, if you’re confident enough with what you’re doing and you feel you can ride it out then that’s the best course of action to take’. It’s just somebody at the end just to say ‘yes, what you’re doing is right.’”

“Oh, and you haven’t had that?” (Interviewer)

“No.” (Respondent 10)

“When the chest infections took hold in a way that meant she needed more intensive treatment, we’ve had a couple of times where we had to bring her into hospital because we just thought, ‘we can’t manage at home with the way she is’ and it might have been that somebody telling us ‘okay, yes’ well it depends, like if they’d been able to prescribe something, that might have been different.” (Respondent 15)

“Two weeks ago she had a chest infection – her heart rate was too high, her respiratory rate was too high, her sats were too low, her breathing was hard work, even on a ventilator. If I could have just called someone and said ‘what do you think?’” (Respondent 22)

“... by being able to talk that [child’s symptoms] through with somebody beforehand, to actually say this is the situation we’re in ... can we wait another four hours? ... you know, not that it’s life threatening, but it means we’re waiting at home for four hours to see what might happen versus waiting in A and E for four hours, it could have made all the difference.” (Respondent 25)

Even when children are admitted to hospital, parents reported that there was no guarantee that staff there would know how to deal with the child’s condition:

“I took [child] to the hospital when her feeding tube broke, it snapped right near her stomach and all the acid came out and she had a nasty rash ... they said ‘well, I think we need to do some chest x-rays first and then some blood tests’ and I said ‘I think I just need a bit of sticky tape round the tube, and you tell me when I can take her up to theatre for a new tube’; but the nurse had no idea about it all ... she said ‘well, I’ll have to ring up the registrar and ask him’; and each time I spoke to anybody I had a good half hour wait between times and all the time my child was in a bit of distress because she hadn’t had a drink for a while. Eventually they put a bit of tape round it and sent me home and said ‘we’ll phone you with a date for putting a new one in’. So I learned my lesson, next time I put tape round it myself and I didn’t go down there and do all that but I just booked in a time when I could have it replaced.” (Respondent 1)
In two interviews, parents described going to health professional friends (school nurses and GPs) who knew their children for advice, and in eleven interviews, parents said that they phoned one of the CHSW hospices for advice outside normal working hours.

Parents reported that they would probably use a 24/7 telephone advice line two to four times over a six month period, although there were a few who felt that they would use it as often as once or twice a week in some circumstances. However, it was very difficult for most of them to estimate the frequency of need with any precision. Different seasons appeared to be influential, with parents/carers of children prone to respiratory infections reporting that they required advice more often in winter months.

All the parents stated that they would like to be able to phone an advice line themselves. Reasons given were that it would be quicker, they knew most about their children, and that it would make them feel more in control:

“"You’re not wasting time, you’re not faffing about trying to go through somebody else.” (Respondent 8)

“I am the child expert, I might not be a medical expert but I know all of the things that have happened to him that might have some kind of bearing on any issues that flare up from time to time, so I know about all the different surgeries, I know about all the different medications that he’s on.” (Respondent 4)

“I can only can talk from the case of my own son and my own experience, but with children like that, because their conditions are... life limiting, I think you are out of control of that condition, you know what the end result is going to be of that condition and anything that you can do which makes you feel you have a control of caring for your child empowers you.” (Respondent 21)

There was concern expressed that some parents/carers may lack the confidence to phone the advice line personally, in which case accessing it through a health professional might be preferable. However, none of the individuals interviewed felt that this applied to them. It was also mentioned by some parents that anyone caring for their child should be able to access an advice line on the child’s behalf.

2.1.2 Dealing with symptoms

Twenty-one parents reported needing/ having needed 24/7 advice about dealing with symptoms, particularly respiratory problems (n=13) and seizures (n=8). Ten parents reported that their children suffered at times from a combination of problems:

“"She had a couple of episodes of problems with her breathing since then but we thought it had all settled down and then basically kind of out of the blue one night she ended up really struggling with her breathing as she went to sleep and her sats kept dropping.” (Respondent 15)

"When he was a bit younger and he had problems with breathing and was just going blue and things like that... and also he had epilepsy which wasn’t controlled.” (Respondent 16)
Managing pain was also an issue for some parents. This had particularly been the case for the bereaved parent:

“Child was crying out in pain and she needed the morphine, we had given her Calpol so we didn’t know how much morphine she could have.” (Respondent 17)

Other problems which occur involve administering other medication or using specialist equipment in the home:

“It’s difficult because, you know, she could have a massive seizure, she could be given the Midazolam, she could then sort of go to sleep for twenty minutes if that, wake up and have another massive one and it’s like ‘well I’ve already given her her emergency meds’ ... I phone them and say ‘look it was only twenty minutes ago I gave her Midazolam and she’s fitting again, what shall I do?’” (Respondent 8)

“We gave them too much medication, well we gave it again and thought oh ‘my god did we give it?’ And it was just really finding out what the side effects were, what to look for and you know whether to take them to hospital or whatever.” (Respondent 26)

“Well my daughter is ventilated and she has a tracheostomy now which is about eighteen months old, but before that she was progressively increasingly ventilated with a BPAP mask, until by the end she was twenty four hours on the ventilator. So things would go wrong with the ventilator.” (Respondent 12)

2.1.3 Reassurance and emotional support

One of the key issues for many parents/carers was knowing whether or not to take a child to hospital. Going to hospital could be quite difficult in the middle of the night:

“Often you know I’m at home thinking ‘well I don’t know if he’s bad enough to phone the hospital’ but I’m a bit worried and want to do something; so maybe something in between, someone to say ‘well yes I think you should phone the hospital’ or ‘why don’t you just give him a few hours and see what he’s like then?’, you know, sort of a middle man sort of thing maybe.” (Respondent 20)

“It’s difficult to phone the ward to ask for advice when all they turn round and say is just ‘bring him in’, and we’re not at that stage yet where we feel that we’re comfortable with taking him up to the hospital, because we have two other children, we can’t just drop everything and take him up, especially in the middle of the night time.” (Respondent 10)
In thirteen interviews, parents reported that what they wanted was reassurance that they were doing the right thing:

“We don’t go in very often because child’s nearly 17, we’re quite well practised and a lot of the stuff that he does is pretty much exclusive to him, it’s stuff that can’t actually be remedied by being in hospital and we’re generally, 99.9% of the time we’re okay to cope with it at home. Just every now and then you think, actually, even if they can’t do anything I want somebody to say it’s okay or carry on doing what you’re doing or we’d rather keep him on here.” (Respondent 4)

“Yesterday evening she had two fits within 20 minutes of each other, and then the next two hours, I couldn’t honestly say she wasn’t fitting, and I couldn’t honestly say that she was fitting ... sometimes it would be good just to say ‘look, this is what’s happening ... are we alright to stay at home until tomorrow morning?’” (Respondent 22)

Some parents were very direct about needing emotional support themselves:

“... just somebody to just sort of help you along and through the difficult sort of times when you’re exhausted and you haven’t had any sleep.” (Respondent 8)

“I would phone the hospice in the middle of the night ... purely because I’ve been feeling down because of tiredness ... it’s somebody to generally chat to and get advice from and there’s no end of me to be in tears on the phone talking to them. It can be over anything but mainly obviously about my son and things that are going on in the family that are all being affected and that sort of thing really.” (Respondent 9)

...[the mother] stated that, as most of her friends also had children with life-limiting conditions and complex needs, she felt that she could not phone them in the middle of the night when she wanted emotional support, as they might be enjoying a relatively rare good night’s sleep, which she did not want to disturb. (Notes of interview 11)
2.1.4 Characteristics of staff giving telephone advice

For all the individuals interviewed, the **most important characteristic of staff giving 24/7 telephone advice was whether or not they knew their child.** At the very least, parents/carers thought that staff should be familiar with their child’s condition, or be able to find out about it at very short notice:

“In order to give advice, especially in child’s case, you need to understand what is wrong with child without having to be on the phone for half an hour just explaining what is wrong with child and all of child’s needs ... when we phone during the daytime we speak to the community team, they know child, they’ve come out, they’ve seen him, we’ve gone through all of child’s needs and what he does, what he doesn’t do and they are in consultation obviously with his paediatrician so they fully understand child, yes. Speaking to a stranger about child is going to be completely different and they’re not going to know him, they’re not going to know his funny ways, you know they’ve never met him, so asking advice on what’s best for child is going to be difficult.” (Respondent 10)

“I think it’s important that whoever it is knows the child and knows the norm for them. You know her consultant knows that she can have three times the dose [of Midazolam] of any normal person and still be fine, but you know others would immediately go ‘oh gosh no she’s already had more than she should have’ ...” (Respondent 8)

“I would want would be that person could access child’s records and that that person knew about child’s equipment and about her … you know her illness, her situation. Now even if that person said ‘look okay fine, thank you very much, I’ll ring you back in half an hour’ but that that person was then armed with the knowledge to be able to answer my questions … if it was somebody who I had to go through from the beginning again, you know, describe her symptoms, you know how it is, when you take your child into hospital for the first time and you have to go back to square one, ..

Some parents went so far as to state that, **if staff answering the advice line did not know their child, they would not use it.** These parents felt that they received very good support from CHSW, and were of the opinion that the advice line should be set up and staffed by CHSW personnel, who would know their children.

Some parents thought that staff answering a telephone advice line should also have personal experience of caring for children with complex needs. One parent gave an example of how CHSW staff had been able to help her when her son was unable to pass urine:

“He was crying, crying, crying and he hadn’t been to the toilet ... they [staff at Little Bridge House] gave me little tips how to agitate the bladder and … allow him to wee because he was in pain by that point. ... I would have had to have gone to the hospital to get him catheterised in order to obviously relieve his pain, however they were able to say try this, try that, try the other, and it worked ... which was a reasonably simple solution.” (Respondent 21)
A few parents mentioned the need for the person answering the phone to be sympathetic:

“I think the person on the end of the line would need to be very understanding … someone who snaps at you is definitely not going to be a person you’re going to call on again.” (Respondent 18)

Most of the parents said that they would like follow-up contact from an advice line in the form of a telephone call, for which the time period ranged from two to forty-eight hours. A few parents stipulated that follow-up should be negotiated, rather than there being a routine system. These parents felt that they wanted some say in how follow-up would be managed, to increase their feeling of having some control over what was happening to them and their children.

2.1.5 Children’s Hospice South West (CHSW) feedback

In thirteen interviews, parents spoke spontaneously about how supportive and helpful they found their contact with Charlton Farm or Little Bridge House:

“When child first came out of hospital we went there [Charlton Farm] for two nights which was wonderful because you know I slept right through the night rather than being sleeping beside her in hospital. They’re just so good, they’re so tuned into you, there’s such a lovely atmosphere that you feel you can ask them anything ” (Respondent 1)

“ We know Charlton Farm are good and they have seen children with thousands of different needs, special needs, and we have actually rung them up for advice on health stuff before anyway … I can’t explain it, Charlton Farm’s like a family and we feel wanted and that there, rather than just another patient or something.” (Respondent 7)

“Without the hospice [Little Bridge House] I think I would have been well stuck when he was younger, because it was really hard and really tough going and to not have that person there to talk to, I don’t know what I would have done, I don’t know if I’d still be here to be honest with you, sometimes, because it was hard, very hard.” (Respondent 9)

2.1.6 Services available to families during ‘office’ hours

Parents were generally happy with other services available to them during normal working hours, whether these were NHS organisations or voluntary originations.

“We’re very lucky, our GP surgery is very good for home visits and things during their plotted working week.” (Respondent 4)

“ I mean they have a very good GP surgery, I think we’re very lucky.”

(Respondent 12).
2.1.7 Location of care

In eighteen interviews, parents stated that they tried to keep their children out of hospital, or had little confidence that they would always receive timely and/or appropriate care when they were admitted. Reasons given for this included the facts that many hospital staff were unfamiliar with caring for children with life-limiting conditions, and that their children did not always follow the normal patterns that staff expected to see in relation to symptom management. In these circumstances, some parents experienced staff being unwilling to accept that the parents' knowledge of how their child reacted to various situations was valid. Low staffing levels caused some parents to feel they needed to stay with their children at all times when admitted, which could impact negatively on the wider family unit.

2.1.8 Areas for further exploration

All the parents/carers who were interviewed had children who had received, or were receiving, care through CHSW. The original research design was to include interviews with parents/carers of children with life limiting conditions, NOT known to CHSW. Strategies to contact such parents were unsuccessful within the time frame of the project. It was also planned to speak to a number of bereaved parents/carers but only one such interview was possible within the time frame of the project. Both these groups of parents will be important to contact if there is a period of further exploration.

Stream 2: Summary

Exploration of parent/carer needs for 24/7 specialist advice

Parents tell us that:

- They need access to specialist advice outside office hours
- This advice is not consistently available from the professionals who support them in the day.
- Access to advice could prevent unnecessary and stressful hospital admissions.
- They need advice and reassurance in decision making, particularly with respect to need for hospital admission.
- The difficulties of caring for a child at home at the end of their life are compounded by limited access to specialist advice.
- They would like advice from someone who knows their child or at least has access to their up to date records.
- Families under the care of Children’s Hospice South West feel that we do know their child and therefore they will contact CSHW for advice.
3.1 Online survey for professionals

An online survey was developed to gather information and views held by professional staff about various aspects of 24/7 specialist children's palliative care telephone advice.

The survey questions were designed to gather information about three main topics.

3.1 Current provision of telephone advice.
3.2 Experience of seeking telephone advice.
3.3 Views on the nature and scope of a telephone advice line.

Distribution: The survey was distributed by email to 230 professionals known to be involved in children’s palliative care services across the SW region. A leaflet which gave information about the project, including a web link to the survey, was distributed by post.

Response: A total of 80 responses were received from a wide range of professionals representing organisations covering a large geographical area. (See Appendix 3 for a list of post titles of participants and Appendix 4 for the organisations represented.)

The findings of the survey presented below related to each of the survey questions (Q1 – Q16)

3.1 Current provision of telephone advice

Q1. Do you provide specialist medical and/or nursing advice to parents or carers of children with palliative care needs?

Yes 78.8% n=63
No 21.2% n=17

Q2. Do you provide this advice outside 9-5 working hours?

Yes 55.0% n=33
No 45.0% n=27
Q3. How do you provide out of hours advice?

![Bar chart showing how advice is provided out of hours]

Of note here was the high proportion of advice given on a ‘goodwill’ basis. The ‘other arrangements’ described involved individual arrangements at service level between staff and managers, involving reimbursement on a case by case basis.

“We provide a 24/7 service to terminal pts at home, we get paid on call and hourly for any visits but as far as I know it is not a condition in our contract as it is considered to be a service that we provide with a large sprinkling of goodwill as there are only 2 nurses covering 24/7”

Q4. When do you provide this advice?

![Bar chart showing when advice is provided]

When do you provide this advice?
Q5. What type of advice is sought by parents/carers?

Advice on clinical symptoms, medicines management and reassurance were named by professionals as being most frequently needed by parents/carers.

Q6. What are the advantages of your current system?

The advantages identified by the participants were, in order of frequency,

- Knowing the child and family well
- Flexibility
- Continuity of care
- Low cost
- Reduces hospitals admissions
- Allows choice of place of care

These features are succinctly presented in the response below.

"Parents have choice of place of care and can stay where they want, they can speak on the phone or ask for a visit. Parents can access someone with experience and knowledge of their child to get the answer to their query without having to repeat the events until their call."

(The full responses are listed in Appendix 5)
Q7. What are the drawbacks of your current system?

The drawbacks identified by the participants were, in order of frequency,

- Not knowing the child and family
- Reliance on goodwill
- Not adequately structured or resourced
- Exhaustion of staff when covering end of life phase
- Lack of skills and knowledge especially about symptom control

Drawbacks were most frequently related to care provision during the end of life phase, as this extract typifies.

“The main drawbacks are that it is only 2 nurses carrying out the on call. If we have a long period when we are on call it can be very draining both emotionally and physically. If one of us is on holiday we can ask one of our doctors to help but it can mean a long stretch on with no break.”

(The full responses are listed in Appendix 6)

3.2 Experience of seeking telephone advice.

Q8. Have there been occasions when you yourself have needed advice on the care of children with palliative care needs?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>82.9%</td>
</tr>
<tr>
<td>No</td>
<td>17.1%</td>
</tr>
</tbody>
</table>

Q9. Did you need this advice outside 9-5 working hours?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>62.1%</td>
</tr>
<tr>
<td>No</td>
<td>37.9%</td>
</tr>
</tbody>
</table>

Q10. How many times during the last year, if you had to estimate, have you a) accessed specialist advice, or b) would have accessed it if it were available?

<table>
<thead>
<tr>
<th>How many times during the last year;</th>
<th>None</th>
<th>Once</th>
<th>2 to 5 times</th>
<th>6 to 10 times</th>
<th>Over 10 times</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) did you access specialist advice?</td>
<td>3</td>
<td>4</td>
<td>18</td>
<td>3</td>
<td>8</td>
<td>36</td>
</tr>
<tr>
<td>b) would you have accessed specialist advice if it were available?</td>
<td>0</td>
<td>0</td>
<td>14</td>
<td>4</td>
<td>8</td>
<td>26</td>
</tr>
</tbody>
</table>

Between 2 and 5 times a year was the frequency of access indicated both by those respondents who had accessed advice and those who would if it were available.
3.3 Views on the nature and scope of a telephone advice line.

Q11. What type of specialist advice have you needed, are likely or unlikely to need if it were available?

As with parent/carer advice needs, the participants identified clinical symptoms and medicines management as the types of advice that had been most frequently sought. Decisions regarding end of life care, place of care and arrangements following the death were indicated as the aspects of advice most likely to be needed.
Q12. What features of an ‘out of hours’ advice line would give you confidence in using it?

What features of an advice line would give you confidence in using it?

<table>
<thead>
<tr>
<th>Feature</th>
<th>Confidence Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expertise of staff</td>
<td>100%</td>
</tr>
<tr>
<td>Knowledge of child</td>
<td>80%</td>
</tr>
<tr>
<td>Access to relevant health records/information</td>
<td>60%</td>
</tr>
<tr>
<td>Existing relationship with service</td>
<td>60%</td>
</tr>
<tr>
<td>Feedback on outcome of call</td>
<td>40%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
</tr>
</tbody>
</table>

‘Expertise of staff’ was perceived by almost all participants as the most important feature that would give them confidence in using an advice line. How this expertise would be measured or assessed was not declared. The ‘other’ features suggested by participants were:

- Knowledge of local provision
- Knowledge of specific conditions
- Ability to provide telephone assessment and advice on clinical management
- The ability to listen and provide emotional support
- A ‘user friendly’ system that doesn't involve too many questions and repetition
Q13. What would put you off using an advice line?

Reasons given in response to this question related to aspects of a) the advisor, and b) the system in which they would be operating.

a. **Advisor related concerns:**
   - Lack of perceived expertise. Not knowing the person(s) you are speaking to
   - If the person answering the calls lacked the relevant knowledge, or lacked sensitivity
   - Lack of clinical credibility of the advisor
   - I think this is a fabulous idea - but would need to feel confident with the knowledge and experience of the person on the other end of the line to be beneficial.
   - I don't think it is necessary for the advice line personally to know the child as I would expect already to know the child well myself but would be asking the advice line specific questions to help with comfort and symptom control.

b. **System related concerns:**
   - Inflexible algorithms - like call centre scripts
   - If there are lots of steps to go through before you get to speak to someone.
   - Length of time for call to be answered
   - Fine as long as there is a step up arrangement if child needs to be seen
   - Risk of adding additional service into already complex communication system unless very confident it was well integrated with other acute & community services
Q14. Which of the following do you think would be most useful? An advice line for professionals, an advice line for parents/carers or an advice line for both.

The vast majority (74%) of participants indicated that an advice line should be for both professionals and parents/carers.

Q15. In relation to the above question, can you give a reason for this?
The reasons given why participants thought an advice line should be for professionals, parents/carers or both are represented by the extracts below.

**Both professionals and parents/carers:**

- As a clinical psychologist, families sometimes ask medical questions of me and of course I have to direct them on to their consultant. It would be helpful if I could recommend an out of hours service for them to contact. It would also potentially be helpful if there was a service I could contact if a consultant was unavailable and I had concerns although I would probably seek the advice of a consultant at the hospital as they would have access to the medical records.

- Not all palliative care services provide 24hr cover. This type of help line would allow parents to contact staff with relevant experience for reassurance out of hrs. Clinical staff would have a support network of professionals for advice.

- Because there exists need for both in relation to 'what should I do' questions out of hours in particular. Would need to be careful to clarify whether it's a support line (re parents) or a clinical symptom management line.

- Carers, Parents and Professionals all accessing the same advice line would ensure that conflicting and differing advice was kept to a minimum.
Professionals only:

- Because in the event of advice needed, the nurses who know the child are usually best placed to give support and advice and feedback to other members of the team, but we sometimes need specialist info e.g. re suitable drugs and unexpected symptoms.

- I am relatively new to caring for a child who is receiving end of life care and I do have lots of questions to ask so would find it very helpful to have an advice line which could support me in making those decisions.

- In my view the families have already come into contact with many Professionals and having to get to know new people at this difficult time would make it harder.

- I think an advice line for parents run regionally would be swamped. I think it best for families to have local systems in place for accessing help and then an advice line be available to professionals if they have difficulty managing those problems. Local teams more likely to know the patients and the facilities available locally.

- The problem if it was for parents is they may get conflicting info from the child’s health team and the advice line and the last thing you need at this time is the parents having additional concerns.

Parents/carers only:

- Sometimes parents are the real experts in relation to the child and it may make more sense for them to get advice directly, rather than go through another professional. Also, may prevent unnecessary admissions and enable child to spend more time at home.

- Different advice needs for parents/professionals. Some parents might prefer the anonymity of an advice line as opposed to face to face.
Q16. Is there anything you can think of that would improve how specialist medical/nursing advice is provided?

Key factors that participants identified were:

- a) Training and education
- b) Feedback on outcomes
- c) Support for advisors (team meetings & supervision sessions)
- d) Recognition of timeliness of as well as content of information
- e) Increased funding & investment, commissioner support
- f) Strong links with other services to support effective coordination

Full responses are given in Appendix 7.

Stream 3: Summary
Exploration of professional needs for 24/7 specialist advice

Professionals tell us that:

- They need access to specialist advice outside office hours.
- When they are supporting families outside normal working hours it is on a goodwill basis, especially during the End of Life period.
- They recognise the current arrangements are unsustainable, both in the short term, when providing care for an individual family, and the long term, when planning overall service provision.
- Effective coordination of services and communication between professionals is needed to provide 24/7 advice.

Parents and professionals most need specialist advice regarding:

- Symptoms.
- Medication: doses, side effects.
- End of Life care decisions.
- Arrangements following death.
The following sources of information were used to investigate options for call handling and systems for transfer of patient information, in order to inform service design.

4.1 Key messages from Streams 1-3 relating to aspects of service design
4.2 Options for call handling (with advantages and disadvantages)
4.3 Further investigation for call handling.
4.4 Further investigation of systems for transfer of patient Information: ADAstra
4.5 Links identified to other projects/areas of tele-health development.

4.1 Key messages from Streams 1-3 relating to aspects of service design

Literature review and interview with existing UK wide 24/7 service providers confirmed the following:

Call handling models used in current practice:
- Hospital switchboard to pager carried by nurse or Doctor on call.
- Direct dial to hospice, on call nurse carries pager.
- Direct dial to mobile held by Doctor or Nurse on call.
- Call handling by contract with out of hours G.P co operative call handling service, message paged/ or call transferred to Doctor or nurse on call.

Systems used for transfer of patient information in current practice:
- Hand held paper records (telephone advice records)
- Secure email via nhs.net
- Secure fax
- On call Blackberry with patient information downloaded via encrypted USB memory stick
- On call lap top with patient information downloaded via encrypted USB memory stick.
- Hospice based data bases
- Specific information systems: for example Adastra.

Two key aspects underpinning advice line development were identified:

**Tele-health.** This is defined as “the remote monitoring of patients through information and communication technologies. Its most common application is in the support of dedicated out of hours specialist advice. Tele-health initiatives are an adjunct to clinical care not an alternative. It is particularly relevant across rural and remote areas.

**Information governance.** This has implications for the transfer of information to support a specialist telephone advice service and for CHSW in general. Details at: [http://www.connectingforhealth.nhs.uk/systemsandservices/infogov](http://www.connectingforhealth.nhs.uk/systemsandservices/infogov)
### Key messages from parent interviews and professionals survey

<table>
<thead>
<tr>
<th>Aspect of service design</th>
<th>Comments from parent interviews and professionals survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>One telephone number</td>
<td><em>I mean going into some kind of call centre scenario would be bad news.</em> (Respondent 13) (F)</td>
</tr>
<tr>
<td>No waiting or minimal waiting</td>
<td><em>Put on a call waiting listening to Greensleeves would definitely put me off.</em> (Respondent 13) (M)</td>
</tr>
<tr>
<td></td>
<td>Professionals commented on the following as potentially putting them off using the service:</td>
</tr>
<tr>
<td></td>
<td>If there are lots of steps to go through before you get to speak to someone.</td>
</tr>
<tr>
<td></td>
<td>Unacceptable length of time for call to be answered</td>
</tr>
<tr>
<td>Not a box ticking/ form filling approach</td>
<td>“…or having to go through a load of information before you talk to them about what’s going on, like effectively a form filling in process, we don’t want to do all of that”. (Respondent: 13)</td>
</tr>
<tr>
<td></td>
<td>“Inflexible algorithms - like call centre scripts would put me off using the service.” (A Professional survey respondent)</td>
</tr>
<tr>
<td>Not having to go through child’s story from the beginning</td>
<td>“… and I think the problem that most of us with children like this we know that a heck of a lot of it is repetition and time wasting you know because when actually you just want to get to the nub of what do I do, quick, quick something’s gone wrong, I don’t want her to have to go through and tell you about what happened when she was born, you know I just want to know what to do now”. (Respondent: 12)</td>
</tr>
<tr>
<td></td>
<td>“One of my biggest beefs about the NHS is they’re constantly … whenever I see anybody new they always ask you all these questions, … you have to go through the whole scenario again” (Respondent: 13)</td>
</tr>
<tr>
<td>Follow up calls to review the situation</td>
<td>“It would be good that they rang say the next day to find out you know whatever advice they got was obviously good advice or on the feedback.” (Respondent: 26)</td>
</tr>
<tr>
<td>Parent AND professionals to be able to ring the advice line</td>
<td>The response to this was unanimous from all parents interviewed. The majority (74%) of professionals completing the survey indicated that an advice line should be for both professionals and parents/carers.</td>
</tr>
<tr>
<td>Systems in place to ensure sharing of information with other professionals</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td></td>
</tr>
<tr>
<td>“I know if I rang that helpline or whatever on Saturday and then on Sunday I had say the courtesy call back and then an email or a fax or something to the GP just saying you know this family were under some kind of stress of some sort over the weekend, just to make you aware of it does give a GP a more holistic picture”. (Respondent: 25)</td>
<td></td>
</tr>
<tr>
<td>“What I would want would be that person could access child’s records and that person knew about child’s equipment and about her … you know her illness, her situation”. (Respondent: 12)</td>
<td></td>
</tr>
<tr>
<td>“It’s a massive thing and because none of them talk to each other but it doesn’t seem, even within the NHS, they don’t talk to each other even within the NHS so if they had a database that all of that would be on there it would be a massive, massive weight off peoples’ shoulders. I think that would be the biggest thing that the NHS could do to help.” (Respondent: 13)</td>
<td></td>
</tr>
<tr>
<td>Over 50% of professionals stated “access to relevant health records/information” would give them confidence in using the advice line.</td>
<td></td>
</tr>
<tr>
<td>“Risk of adding additional service into already complex communication system unless very confident it was well integrated with other acute &amp; community services”. (Professional Survey Respondent)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Likely call frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents: When asked how often they would need to contact a specialist advice line out of hours responses varied from once in six months to once or twice a week.</td>
</tr>
<tr>
<td>Professionals: Between two and five times a year was the most common frequency of access indicated both by those respondents who had accessed advice and those who would if it were available.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Variation in frequency of advice depending on child’s health</th>
</tr>
</thead>
<tbody>
<tr>
<td>It would vary dramatically, as she is at the moment I probably feel that I could do with it, I’d say over this last month I probably could have done with it once a week but I haven’t, you know I’ve held back. (Respondent: 8)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seasonal variation in advice.</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It all depends on … I mean during the summer time probably hardly ever because he’s very well and it’s only when we come into that autumn/winter period that we start having the admissions into hospital and probably when we would start using the service then.” (Respondent: 10)</td>
</tr>
</tbody>
</table>
### 4.2 Options for CHSW call handling for specialist palliative care advice line

Four options were identified:

<table>
<thead>
<tr>
<th>Option</th>
<th>Description</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Hospital switchboard to pager carried by nurse or Doctor on call.</td>
<td>Link to Hospital clearly establishes service as working with NHS providers. (Works for on call services where staff are predominantly working in the hospital)</td>
<td>No control over call handling process. Long wait for call to be answered. Call initially answered by person with no medical training.</td>
</tr>
<tr>
<td>2.</td>
<td>Direct dial to hospice, On call nurse carries pager.</td>
<td>Simple. Parents maintain confidence that call will be handled by hospice staff.</td>
<td>Difficulties for nurse on call in prioritizing calls. No system for call handling if multiple calls. Conflicts for nurse if shift busy.</td>
</tr>
<tr>
<td>3.</td>
<td>Direct dial to mobile held by Doctor or Nurse on call.</td>
<td>Simple system (works for hospices with outreach teams answering calls directly from parents)</td>
<td>Limited mobile reception at Charlton Farm. No system for call handling if multiple calls.</td>
</tr>
<tr>
<td>4.</td>
<td>Call handling by contract with out of hours G.P co-operative call handling service, message paged/ or call transferred to Doctor or nurse on call.</td>
<td>Contract with not for profit social enterprise company. Existing set up for call handling with person employed and trained to answer initial call. Call recording allows audit and training thereby enabling good clinical governance. Telephone advice training can be included in contract. Already linked in with G.P systems for communication of patient information.</td>
<td>Cost for purchasing this service. Call initially answered by person with no medical training.</td>
</tr>
</tbody>
</table>

### 4.3 Further investigation for call handling

Taking the above into consideration we pursued option four: for call handling by an existing out of hours call handling service. *(Detail available on request to lead author)*.

- Costings for contract for a not for profit social enterprise to provide this service
- Diagram for possible call handling structure.
### 4.4 Further investigation for system of transfer of patient information

The use of systems for transfer of patient information has been explored through discussion with current users and stakeholders.

Within this project the use of the system ADASTRA (A web based system for communication of information in Adult patients used in General Practice) has been explored.

#### Advantages:
- Already in use by G.P’s in Bristol and Devon
- Accessible in theory in all settings: (Devon Doctors using in Adult hospices, Hospitals, GP surgeries) url/N3 link for NHS, nhs.net email in community.
- Pilot of the End of Life register (a module within Adastra) for children and young people is due to be launched in Devon.

#### Disadvantages:
- In Bristol not yet accessible by Hospitals, Hospices or Ambulance control.
- Limitations on amount of patient information
- Is not accessed by patients currently.

### 4.5 Links identified to other projects/areas of development.

During the research for this work stream links to the following projects emerged which may be of benefit to the service design.

See Appendix 8 for summaries of these projects with possible benefits to CHSW and the 24/7 project.

1. Global virtual meeting centre (Web X platform) a system for regional multi-disciplinary case discussions.
2. End of life register for young people in Devon and use of Adastra for Young people and children.
3. Wiltshire project: Setting up “A community of practice” on line.
4. MY QOL-T: Measure Yourself Quality of Life Tool.
1. **Call Handling**

Both Parents and Professionals commented on a need for:

- One telephone number
- No waiting or minimal waiting
- A system not reliant on a script of questions such as are used in existing out of hours services.
- Not having to repeat the child’s story from the beginning
- Follow up calls to review the situation
- All parents and the majority of professionals said that both groups should be able to ring the advice line directly.

2. **System for transfer of patient information**

It is clear that a system for communication of patient information between all settings is of vital importance to the development of a specialist palliative care telephone advice service for the following reasons:

- Parents want to speak to someone who has access to up to date information about their child.
- Parents do not want to have to start “from the beginning” each time they ask for advice.
- Professionals recognise the need for better transfer of patient information and integration of services.
- Professionals giving advice need accurate up to date patient information in order to give safe, timely advice.
- Clinical Governance standards cannot be upheld without effective transfer of information for these complex patients.

For children’s palliative care in the South West region the decision regarding a system for transfer of information will be key to the strategic development of services.

**The following features are important for this system for transfer of patient information:**

- A system accessible in all settings where professionals assess and give advice regarding a patient: Hospice, G.P practice, Hospital, Community, ambulance control.
- A system that can be updated from all settings.
- A system fulfilling the standards of Information Governance.
- An Information sharing protocol agreed with all stakeholders.
Stream 5: Staffing, training, governance, supervision

This stream explores competency levels, training and governance needs for medical and nursing staff giving advice.

5.1 Current models staffing of 24/7 advice

Sources

a) Interviews with existing 24/7 advice line providers for children’s palliative care
b) Literature review on current provision of palliative care telephone advice
c) Interview about paediatric palliative care training with Dr Richard Hain: Lead Clinician Welsh managed clinical network for Paediatric Palliative Care.
The following models are used for staffing existing 24/7 specialist children’s palliative care telephone advice services (both contracted, planned services and informal advice):

<table>
<thead>
<tr>
<th>Staffing model</th>
<th>Nursing on call</th>
<th>Medical on call</th>
<th>Second tier medical on call</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contracted Hospice based 24/7 advice line</td>
<td>Experienced nursing staff at hospice take initial call.</td>
<td>Level 3 or 4 * trained doctor on for 24 hour period.</td>
<td>Level 4* trained doctor on for “week on” system</td>
</tr>
<tr>
<td></td>
<td>(reside within an hour of hospice so that can bring patient to hospice for review or visit if needed).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contracted Hospital based 24/7 advice line</td>
<td>Experienced nurses (Band 7 or 8) with previous specialty experience.</td>
<td>Paediatrician in Palliative medicine grid training post. (Either nurse or Doctor take initial call: Mixed first on call rota)</td>
<td>Level 4* trained Consultants in Paediatric Palliative medicine on “week on” rota</td>
</tr>
<tr>
<td>Informal Hospice based 24/7 advice with no formal Medical Tier</td>
<td>Experienced nurses as part of hospice care team take initial call.</td>
<td>Contract with local GP co operative but not for specialist advice</td>
<td>Goodwill arrangement with daytime hospice doctors to cover evenings, nights and weekends on a case by case basis.</td>
</tr>
<tr>
<td>(This is the type of system CHSW currently operates)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospice to home outreach team with on call advice as part of wider service</td>
<td>Experienced nurses. (8 years plus experience) and often specialist training in palliative care.</td>
<td>SLA with existing medical 24/7 services OR contact with local GP service OR goodwill arrangement with hospice.</td>
<td>Level 4* trained doctor if this is part of SLA with existing medical 24/7 service (or no tier 2 advice)</td>
</tr>
<tr>
<td>(Often only for end of life period)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table: Staffing Models

*Competency levels defined p42.
5.2 Experience and training levels of nursing staff

Nurses working for existing specialist 24/7 advice services are:

- Experienced paediatric nurses (often with 8+ years experience)
- Band 7 or Band 8
- Specialist in a field of paediatric nursing which involves palliative care (For example Oncology, Community, Paediatric Intensive Care, Hospice care)

Nurses working for existing specialist 24/7 advice services type of services have the following training:

- Modules or diploma in Paediatric Palliative care
  (Examples of training modules given were: Oxford Brookes, Cardiff, Bristol)
- Training in Advanced communication skills
- Training in Giving Telephone advice.
  For details of courses see Appendix 9.

The Royal College of Nursing has set out Core competencies/key aspects of training for nurses providing telephone advice to people with long-term conditions, which include:

- Good clinical decision-making skills, including sound knowledge of the disease area and treatment options
- Sound knowledge of potential risks related to the disease and treatments
- Communication skills—interview techniques (listening and questioning skills) and coping with difficult calls
- Skills to gain appropriate information without visual clues
- Limitations of telephone consultation and patient recall
- Legal implications of telephone advice
5.3 Experience and training levels of doctors

Background:

As paediatric palliative medicine has only recently emerged as a specialty in its own right, the experience and training of Doctors working in the field varies, according to their background.

ACT is currently defining the specialism of children’s Palliative care and its relationship to competencies in Paediatric training:
In one summary R. Hain defines these as:

| a. Generic: skills and competencies essential for good palliative care in children that are expected from anyone trained in the care of children. |
| b. Specialist: those skills that are expected from professionals who make palliative care their main area of training |
| c. Semi-specialist: skills that are more than would be expected from most professionals trained in the care of children but are not restricted to paediatric palliative care. |

Specialist Paediatric Palliative medicine grid training posts now exist in two centres. Progression through this system qualifies doctors to take up posts in Paediatric Palliative Medicine. ¹³

There is not currently such a post in Bristol, although this is being strongly advocated for as key to the development of a regional service.

Doctors providing advice as part of a specialist 24/7 advice in children’s palliative care require the following competency level and training:

- Level three or four competency in Paediatric Palliative Medicine.*
- Training in Advanced communication skills
- Training in Giving Telephone advice.

* Competency levels in Paediatric Palliative Medicine:

The Royal College of Paediatrics and Child Health defined competency levels in Paediatric palliative medicine.

Level three applies to Trainees in the sub-specialty of palliative medicine (ST6 -8) but can also be used by Doctors from different backgrounds (For example, General Practice, Oncology, Community Paediatrics) working in a hospice setting to measure their competency level.
Level three could be achieved by completing a diploma level qualification in paediatric palliative medicine (for example the Cardiff Diploma) and at least a year’s experience in a clinical setting where palliative care is the main area of work.

**Level four** applies to Consultants in Paediatric Palliative Medicine.

<table>
<thead>
<tr>
<th></th>
<th>Nurses</th>
<th>Doctors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinical experience</strong></td>
<td>- Experienced paediatric nurses, band 7 or 8</td>
<td>- Paediatricians with clinical experience in palliative medicine and a current post where the significant focus of their work is in palliative care.</td>
</tr>
<tr>
<td></td>
<td>- Specialist in a field of paediatric nursing which involves palliative care (e.g. Oncology, Community, Paediatric Intensive Care, Hospice care)</td>
<td></td>
</tr>
<tr>
<td><strong>Clinical training</strong></td>
<td>- Modules or diploma in Paediatric Palliative care</td>
<td>- Level three or four competency in Paediatric Palliative Medicine.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Communication training</strong></td>
<td>- Advanced communication skills</td>
<td>- Advanced communication skills</td>
</tr>
<tr>
<td></td>
<td>- Telephone consultation and advice giving.</td>
<td>- Telephone consultation and advice giving.</td>
</tr>
</tbody>
</table>

Table: Summary of staff experience and training.
5.4 Key messages from streams two and three.

5.4.1 Types of advice needed by Parents and Professionals:

- Advice regarding symptoms (most commonly, respiratory symptoms and seizures)
- Advice regarding medication: In End of Life care specifically advice regarding morphine; doses, frequency, side effects.
- Decisions regarding end of life care
- Place of care
- Advice after the death of a child
- Reassurance in decision making, particularly with respect to need for hospital admission.
- Emotional support.
- Advice regarding equipment.

5.4.2 Knowledge of child

An overwhelmingly strong theme emerged from parents for the need for professionals giving advice to know the child.

Ideally parents would like the professional to know their child directly, but if not, to have access to up to date records and information about their child and their condition.

This theme is reflected in professionals’ comments on the positive aspects of goodwill on call rota arrangements.

5.4.3 Expertise of staff

Expertise of staff was perceived by the majority of professionals participating in the survey as the most important feature that would give them confidence in using an advice line.
### 5.5.4 Relating types of advice needed to competency level of medical staff giving advice

<table>
<thead>
<tr>
<th>Type of advice needed</th>
<th>Highlighted by whom</th>
<th>Competency level*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Symptoms: Respiratory</td>
<td>Parents</td>
<td>Level 3: Practice of palliative medicine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom Control: Dyspnoea Page 35</td>
</tr>
<tr>
<td>Clinical symptoms: Seizures</td>
<td>Parents</td>
<td>Level 3: Practice of palliative medicine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom Control: Seizures and other neurological problems Page 36</td>
</tr>
<tr>
<td>Clinical symptoms: In General</td>
<td>Professionals</td>
<td>Level 3: Practice of palliative medicine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom Control. Page 34</td>
</tr>
<tr>
<td>Opioids: dose, frequency, side effects</td>
<td>Both</td>
<td>Level 3: Practice of palliative medicine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptom Control: Opioids Page 34</td>
</tr>
<tr>
<td>Decisions regarding End of life care</td>
<td>Professionals</td>
<td>Level 3: Practice of palliative medicine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The period immediately before death. Page 39</td>
</tr>
<tr>
<td>Arrangements following the death of a child</td>
<td>Both</td>
<td>Level 3: Practice of palliative medicine</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Practicalities after death Page 40</td>
</tr>
</tbody>
</table>

*Cross referenced with “A Framework for competencies for Level three training in Paediatric Palliative medicine”.

### 5.4.5 Structuring the staff to work as part of a team:

It will not be either desirable or safe for staff to work only on an on call rota without connection to a team providing the 24/7 service and to a post involving clinical work in paediatric palliative care.
An ideal service design would support teamwork by integration of service with a weekly meeting to discuss complex cases and new referrals to the service. This would also enable communication with key professionals and proactive symptom control plans. (This model is used in a number of the existing 24/7 services.) This could link to use of the WebX Platform for multi-disciplinary case discussions. (Appendix 8).

**Linked posts:**

Nurses: Link posts for on call to other posts or employ on one contract for both roles;

For example…

- CHSW Hospice nurse with linked post to 24/7 advice line.
- Community Nurse in another service with linked post to 24/7 advice line.

**Doctors:**

Doctors working for the on call service would need to have another post where a significant amount of the job was related to palliative care (in order that they maintain their expertise in the field)

For example…

- Consultant Paediatrician in Palliative Care (if appointment made in Bristol)
- Medical Director Hospice
- G.P with special interest and specialist training in Palliative care.
- Community Paediatrician with Special interest and specialist training in Palliative Care.

**5.5 Governance of a children’s palliative care specialist advice service:**

Clinical governance is "A framework through which NHS organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish" 16.
Summary of components of Clinical Governance and relevance to 24/7 service.

<table>
<thead>
<tr>
<th>Component of Clinical Governance</th>
<th>Relevance to 24/7 advice line</th>
<th>Suggested approach for 24/7 service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Audit</td>
<td>Need to monitor service against set standards to ensure standards met and improvements made.</td>
<td>From the start set standards in each area of service and develop a program of audit.</td>
</tr>
<tr>
<td></td>
<td>Service design to include some contracted commitment to audit.</td>
<td>Include audit of recorded calls (Doctors practice is to audit 10% of calls)</td>
</tr>
<tr>
<td>Risk Management</td>
<td>Possibility of critical incidents.</td>
<td>Culture of learning from experiences and mistakes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>System for reporting critical incidents.</td>
</tr>
<tr>
<td>Education and training</td>
<td>Need for staff to have Continuous development programme and yearly appraisal.</td>
<td>See training section of Stream 5</td>
</tr>
<tr>
<td>Using Information and Information technology</td>
<td>Need for patient information/records to be accessible and up to date.</td>
<td>See Stream 4 and Information Governance</td>
</tr>
<tr>
<td></td>
<td>Confidentiality and Data protection</td>
<td></td>
</tr>
<tr>
<td>Staffing and Staff management</td>
<td>Appropriate recruitment of staff in accordance with recommended experience and training levels.</td>
<td>Ongoing training as part of the role. Regular opportunity for debrief for clinical and emotional issues.</td>
</tr>
<tr>
<td></td>
<td>Ensure staff retention.</td>
<td>Set up service with opportunities for staff to operate as part of a team, with team discussions for complex cases and clinical supervision.</td>
</tr>
</tbody>
</table>
Patient and public involvement

Ensure service developed and provided suits patient/parent needs.

Use of patient/parent feedback to develop the service.

Feedback from parents/professionals accessing the advice line. A system is set up for “user feedback” through a not for profit social enterprise company.

Consider a steering group for the service with parent representation.

Clinical effectiveness and research

Use of evidence based approach where possible.

Development of guidelines for commonly encountered problems in line with evidence base.

Follow up research links identified in Stream four.

5.6 Legal issues

There are a number of professional and legal issues for practitioners to consider when providing any form of health care support, and these principles remain as relevant when providing telephone advice. These will include policies on:

- Documentation
- Confidentiality
- Risk management
- Statutory training
- Professional codes of conduct
- Prescribing practice
- Complaints and governance procedures
Expertise of staff was rated consistently as the most important feature in giving professionals confidence in using an advice line.

To be eligible to work as part of the 24/7 service staff must have the following experience levels:

Nurses:
- Experienced paediatric nurses.
- Band 7 or 8
- Specialist in a field of paediatric nursing which involves palliative care (For example Oncology, Community, Paediatric Intensive Care, Hospice care)

Doctors:
- Paediatricians with clinical experience in palliative medicine and a current post where the significant focus of their work is in palliative care.

The training level of staff eligible to work for the 24/7 service can be summarised as follows:

Clinical training:
- Nurses: Modules or diploma in Paediatric Palliative care
- Doctors: Level three or four competency in Paediatric Palliative Medicine.

Training in communication:
- Advanced communication skills
- Telephone consultation and advice giving.
Structure of staff team, support and supervision

Professionals tell us that it is essential that staff working for the 24/7 service have:

- Support in the form of team meetings and supervision
- Strong links with other services

Supervision: should be a planned part of service design. “Medical and Nursing staff should have access to clinical supervision to ensure that they are adequately supported and can cope with the stressors related to telephone consultations”.

Working as part of a team: It will not be either desirable or safe for staff to work only on an on call rota without connection to a team providing the 24/7 service.

Governance:
From the outset the following systems should be put in place:

- Audit of recorded calls as part of the service design for training and governance.
- Process for feedback from patients and professionals accessing the advice line.
- Development of guidelines for commonly encountered problems within the evidence base to enable consistency of advice.
Consultation with key professionals and parents/carers in the South West and a professionals survey confirmed that although there are many services providing high standards of clinical care for children with palliative care needs, access to specialist nursing and medical advice 24/7 is not available as a planned or equitable service.

Considerations for the existing CHSW service:

- Many comments from parents show that families attending the hospices feel we do know their child; they trust us and contact us for advice.

- Parents are already confident in CHSW advice and want CHSW to continue to give advice as they feel CHSW knows their children and understands their needs.

- It is crucial to protect the valued work of the existing hospices, whatever direction the strategic development of CHSW takes.

This section of the report contains information about:

- 6.1.1 The need for and benefits of 24/7 specialist advice.
- 6.1.2 Important features in design of a 24/7 service.
- 6.1.3 Important features in staffing a 24/7 service.
- 6.1.4 Conclusions
- 6.1.5 Recommendations
- 6.1.6 Options for scope of service
- 6.1.7 Options for models of service
6.1 The need for and benefits of 24/7 specialist advice:

6.1.1 Parents tell us that:

- They need access to specialist advice outside office hours.
- This advice is not consistently available from the professionals who support them in the day.
- Access to advice could prevent unnecessary and stressful hospital admissions.
- They need advice and reassurance in decision making, particularly with respect to need for hospital admission.
- The difficulties of caring for a child at home at the end of their life are compounded by limited access to specialist advice.
- They would like advice from someone who *knows* their child or at least has access to their up to date records.
- Families under the care of CHSW feel that we *do* know their child and therefore they will contact CHSW for advice.
6.1.2 Professionals tell us that:

- They need access to specialist advice outside office hours.
- When they are supporting families outside normal working hours it is on a goodwill basis, especially during the End of Life period.
- They recognise the current arrangements are unsustainable, both in the short term, when providing care for an individual family, and the long term, when planning overall service provision.
- Effective coordination of services and communication between professionals is needed to provide 24/7 advice.

6.1.3 Parents and professionals most need specialist advice regarding:

- Symptoms
- Medication: doses, side effects
- End of Life care decisions
- Arrangements following death

6.1.4 Demand for the service:

Most Parents estimated they would call such a line 4 – 8 times over a year period. This frequency increased to up to hourly in the end of life period and varied according to season, child’s condition and the time from diagnosis.

The majority of Professionals estimated they would need advice 2- 5 times over a year.
6.1.5 Benefits to the existing CHSW service:

The development of the service would have the following benefits:

- Formalise rota for medical cover for on call
- Promote consistent medical advice and training level of Doctors
- Promote career development within CHSW for experienced nurses.
- Support information governance with a consistent method of documentation, hand-over and inter professional communication of information and advice given.

6.2 Important features in design of a 24/7 service:

6.2.1 Call Handling

Both Parents and Professionals commented on a need for:

- One telephone number
- No waiting or minimal waiting
- A system not reliant on a script of questions such as are used in existing out of Hours services.
- Not having to repeat the child’s story from the beginning
- Follow up calls to review the situation
- All parents and the majority of professionals said that both groups should be able to ring the advice line directly.
6.2.2 System for transfer of patient information

It is clear that a system for communication of patient information between all settings is of vital importance to the development of a specialist palliative care telephone advice service for the following reasons:

- Parents want to speak to someone who has access to up to date information about their child.
- Parents do not want to have to start “from the beginning” each time they ask for advice.
- Professionals recognise the need for better transfer of patient information and integration of services.
- Professionals giving advice need accurate up to date patient information in order to give safe, timely advice.
- Clinical Governance standards cannot be upheld without effective transfer of information for these complex patients.

For children’s palliative care in the South West region the decision regarding a system for transfer of information will be key to the strategic development of services.

The following features are important for this system for transfer of patient information:

- A system accessible in all settings where professionals assess and give advice regarding a patient: Hospice, G.P practice, Hospital, Community, ambulance control.
- A system that can be updated from all settings.
- A system fulfilling the standards of Information Governance.
- An Information sharing protocol agreed with all stakeholders.
6.2.3 Setting up processes to provide governance for the service:

From the outset the following systems should be put in place:

- Audit of recorded calls as part of the service design for training and governance.
- Process for feedback from patients and professionals accessing the advice line.
- Development of guidelines for commonly encountered problems within the evidence base to enable consistency of advice.

6.3 Important features in staffing a 24/7 service:

6.3.1 Experience and training

Expertise of staff was rated consistently as the most important feature in giving professionals confidence in using an advice line.

To be eligible to work as part of the 24/7 service staff must have the following experience levels:

**Nurses:**

- Experienced paediatric nurses.
- Band 7 or 8
- Specialist in a field of paediatric nursing which involves palliative care (For example Oncology, Community, Paediatric Intensive Care, Hospice care)

**Doctors:**

- Paediatricians with clinical experience in palliative medicine and a current post where the significant focus of their work is in palliative care.
The training level of staff eligible to work for the 24/7 service can be summarised as follows:

**Clinical training:**

- Nurses: Modules or diploma in Paediatric Palliative care
- Doctors: Level three or four competency in Paediatric Palliative Medicine.

**Training in communication:**

- Advanced communication skills
- Telephone consultation and advice giving.

### 6.3.2 Structure of staff team, support and supervision

Professionals tell us that it is essential that staff working for the 24/7 service have:

- Support in the form of team meetings and supervision
- Strong links with other services

Supervision: should be a planned part of service design. “Medical and nursing staff should have access to clinical supervision to ensure that they are adequately supported and can cope with the stressors related to telephone consultations” 17.

Working as part of a team: It will not be either desirable or safe for staff to work only on an on call rota without connection to a team providing the 24/7 service.

### 6.4 Conclusions

6.4.1 This project demonstrates the need for 24/7 specialist telephone advice line in the South West to be available to both parents and professionals.

6.4.2 The availability of this advice would support parents and professionals to care for children in the location of their choice, reducing unnecessary and unwanted hospital admissions.

6.4.3 The credibility of a 24/7 advice line will depend on the experience and expertise of the staff giving advice.

6.4.4 A robust system for sharing information is key to the success of a 24/7 specialist telephone advice line.
6.5 Recommendations

6.5.1 The service design should take calls from BOTH parents and professionals.

6.5.2 There will need to be a commitment to and investment in the training and development of nursing and medical staff in line with CHSW’s strategic vision: “to be recognised regionally and nationally as a progressive centre of excellence in the care of children who are expected to die before adulthood and their families”

6.5.3 The development of a 24/7 specialist telephone advice line and the training of staff for this should be structured to provide a necessary progression and career development to retain senior nursing staff in CHSW.

6.5.4 Doctors working for the 24/7 service need to have reached competency level three in Paediatric Palliative Medicine in order to have the necessary expertise to give this advice

6.5.5 Staff providing 24/7 specialist telephone advice should be supported by, ongoing training, linked posts, clear team structures and supervision.

6.6.6 The choice of system for sharing information needs to be embedded within the strategic development of children’s palliative care across the south west region, with agreement from of all key stakeholders.

6.5.7 Steps should be taken to ensure that when a system has been agreed on, the necessary technology will be in place within the three CHSW hospices across the south west in order to link with this system.
### 6.6 Options for scope of service

<table>
<thead>
<tr>
<th><strong>Hours of operation</strong></th>
<th>A full 24/7 service model for the nursing on call tier (as opposed to a purely “out of hours” model) in order to support communication and planning needed to provide a safe and effective service. For medical cover, the development of the service would be linked to developments in daytime medical cover in order to provide a tier of level three competency Doctors in the 9-5pm period in addition to the on call Doctors required for the 5pm – 9am rota.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Area covered</strong></td>
<td>Regional service: For South west region to cover the 9 Primary Care Trusts (PCT) (Cornwall and the Isles of Scilly, Plymouth, Torbay, Devon, Somerset, North Somerset, Bristol, South Gloucestershire and Bath and NE Somerset). Consideration could be given to covering a wider geographical area in view of investment needed in staff in comparison to small numbers of children per PCT</td>
</tr>
<tr>
<td><strong>Referrals to service</strong></td>
<td>Referrals accepted from parents, carers and professionals involved in the care of a life limited children in the South West. (Referrals not restricted to families known to CHSW.) Two “levels of referral” according to colours of life. Green/yellow: Standard referral information Amber/Red: Enhanced referral information (appropriate for children/young people nearing the end of life period).</td>
</tr>
<tr>
<td><strong>Time frame for service delivery</strong></td>
<td>The CHSW strategic plan proposes the development of a 24/7 service for 2013. If this time frame is to be achieved a significant investment would need to be agreed in the coming financial year to support the training for staff to work for the service.</td>
</tr>
<tr>
<td><strong>Operational considerations</strong></td>
<td>Staffing Models (see Options for models of service, next page). Experienced nurses and Doctors with specific palliative care and communication training. Regular 24/7 Team meetings to discuss new referrals, complex symptom management and end of life situations for region. (Could link this to use of the Web X platform for Palliative Care Multi-disciplinary meetings for region and invite relevant professionals for each child to join meeting on line). Proactive call model Collaborative work with professionals involved in care during “office” hours to plan for proactive calls when needed (of particular relevance at end of life). Follow up call model To build in system for calling back parent/professional to review progress since advice given.</td>
</tr>
</tbody>
</table>
6.7 Options for models of service

6.7.1 Model A: Two-tier on call model for telephone advice only.

Tier one: One nurse one call from one of the three hospice bases at any one time. Rota* set up for one nurse to be on call for advice line 24/7.

Tier two: Doctor on call standard rota. Face to face assessment to be arranged with local G.P or hospital, if required.

For medical cover, the development of the service would be linked to developments in daytime medical cover in order to provide a tier of level three competency doctors in the 9 -5pm period, in addition to the on call doctors required for the 5pm – 9am rota.

6.7.2 Model B: Three-tier model with potential for Doctor to visit.

Tier one: One nurse on call from one of the three hospice bases at any one time. Rota set up for one nurse to be on call for advice line 24/7.

Tier two: Doctor on call from home (Doctor for the day for each hospice to cover “out of office hours” as standard on call rota.) Available to visit the hospice if required (i.e lives within 1 hour) or to bring in child/young person for assessment.

Tier three: Doctor on call for region for specialist advice: week on rota.

6.7.3 Model C: Mixed on call rota (nurses and doctors at tier one) for telephone advice only

Tier one: Nurse or Doctor first on call from hospice or home.

Tier two: Doctor on call from home for region, week on rota. Face to face assessment to be arranged with local G.P or hospital, if required.

6.7.4 Model D: Nursing on call rota with potential for nurse to visit.

Tier one: Nurse on call from each hospice base. Available to visit for end of life care or symptom assessment.

Tier two: Doctor on call 5pm to 9am, 24/7 weekends and bank holidays. Week on OR standard rota

*Note on rotas:

**Standard on call rota:** To cover on call from 5pm – 9am Monday to Friday and 24/7 weekends and Bank holidays.

**Week on rota:** A senior level doctor (more experienced Level three competency Doctor OR Level four competency Doctor) covers the whole week to give consistency of advice and decision making.
Options for models of service

Model A: Two-tier on call model for telephone advice only.
Model B: Three-tier model with potential for doctor to visit.
Model C: Mixed on call rota (nurses and doctors at tier one) for telephone advice only
Model D: Nursing on call rota with potential for nurse to visit

<table>
<thead>
<tr>
<th>Tier I</th>
<th>Tier II</th>
<th>Tier III</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse on call from one hospice base for region.</td>
<td>Doctor on call from home for region.</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse on call from one hospice base for region.</td>
<td>Doctor for day on call from home. (One for each hospice)</td>
<td>Doctor on call for region. Week on rota.</td>
</tr>
<tr>
<td>C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse or doctor on call from hospice or home for region.</td>
<td>Doctor on call from home for region. Week on rota.</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse on call. One from each of hospice bases.</td>
<td>Doctor on call from home for region. Week on or standard rota.</td>
<td></td>
</tr>
</tbody>
</table>
References


3 Killen S & Craft A. Palliative Care Services for Children and Young People in England, an independent review for the Secretary of State for Health. HMSO London. 2007


1. Review of existing UK wide 24/7 specialist advice service models

Internet search strategy and e-mail survey

The terms 'children’s palliative care' and ‘telephone advice’ were used as terms to search the internet. This process yielded 11 UK organisations (hospices and NHS Trusts) based outside the South West which appeared to offer 24/7 specialist telephone advice to parents/carers and/or professionals. Telephone follow-up with these organisations revealed that only two of these, both of them hospices, operated a formal specialist telephone advice line outside of normal office hours, as opposed to individuals giving advice ad hoc on a goodwill basis.

E-mails were also sent to 70 managers of UK children’s hospices, as identified by Children’s Hospice UK (CHUK), asking them if they offered 24/7 medical and nursing advice for parents or professionals caring for children with palliative care needs. Managers from ten hospices responded, five of whom confirmed that they offered some form of 24/7 advice. The research team carried out telephone interviews with three of the managers from these five hospices, and received email information from the other two. Only three of these hospices had a formal system for providing specialist telephone advice (one of these had already been identified by the internet search).

Data also came from a face to face interview with a specialist nurse who had recently been working with the symptom control team based in a large urban NHS Trust which also provided 24/7 specialist telephone advice for children receiving palliative care.

Features of the five services identified as systematically providing 24/7 specialist telephone advice are provided in the table below:
Features of existing UK wide formal 24/7 specialist telephone advice service models – summary of five organisations

<table>
<thead>
<tr>
<th>Organisations</th>
<th>4 hospices (A,B, C, D), 1 NHS Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>How many families on the books?</td>
<td>Considerable variation:</td>
</tr>
<tr>
<td>• NHS Trust and hospice D: 20-35 families;</td>
<td></td>
</tr>
<tr>
<td>• Hospice C: 90-100 families (including all oncology patients, regardless of stage of the disease);</td>
<td></td>
</tr>
<tr>
<td>• Hospices A and B: 300-350 families (one of these hospices is a regional centre).</td>
<td></td>
</tr>
<tr>
<td>Who provides the advice?</td>
<td>• In hospices A and B, the phone is answered by a member of the care team, who refers to a senior nurse, or on to medical staff. Consultant advice is available if necessary.</td>
</tr>
<tr>
<td>• In hospices C and D, advice is given by specialist children’s palliative care nurses or by experienced paediatric nurses.</td>
<td></td>
</tr>
<tr>
<td>• In the NHS Trust, there is a team of clinical nurse specialists and specialist registrars available, who can refer to a consultant if necessary.</td>
<td></td>
</tr>
<tr>
<td>How are staff organised to cover the 24/7 service?</td>
<td>• In hospices A, B and C the care team and/or nurses are on site 24/7, so there is always someone to answer the phone. Medical cover (registrar, GP or consultant) is provided via an on-call rota. In hospice C, this includes consultants from a local adult palliative care service. Hospice C also operates a home visiting service, where necessary.</td>
</tr>
<tr>
<td>• In hospice D, there is a nurse on call between 7.30 am and 8 or 9pm for telephone advice and home visits. Medical back-up for 24/7 telephone advice is provided by hospice A.</td>
<td></td>
</tr>
<tr>
<td>• In the NHS Trust there is a rota of nursing and medical staff for 24/7 cover.</td>
<td></td>
</tr>
<tr>
<td>What training do staff receive?</td>
<td>• In hospices A, C and D, phone advice is given by trained palliative care nurses, which in hospice C includes an oncology nurse specialist.</td>
</tr>
<tr>
<td>• In the NHS Trust, Band 6 or 7 nurses with a background in oncology, neurology and/or PICU deal with telephone calls. Registrars are in an RCPCH training post for paediatric palliative medicine. Clear guidance is given to staff about what queries can be answered in a telephone call.</td>
<td></td>
</tr>
<tr>
<td>• In-house training on communication, including skills needed for telephone consultations, is provided for staff in hospice B and in the NHS Trust.</td>
<td></td>
</tr>
<tr>
<td>• In hospice C, a key aspect of training for staff is communication skills.</td>
<td></td>
</tr>
</tbody>
</table>
### Who can use the service?

**Families:** All five services are available to families

- In hospices A and B, and in the NHS Trust, the service is technically only for families referred to it.
- In the NHS Trust, the caseload is managed so that the number of families who can access the service is limited to 25.
- The lead consultant in hospice A has other children on his books, so usually hospice staff know who they are.
- In practice, both hospices will try to answer queries from other families as well as those officially on the caseload.

**Professionals:**

All five services are available to other professionals. This includes staff from NHS Acute Trusts, community nurses, out-of-hours GPs and staff from other hospices.

### What is the demand for the 24/7 service?

This appears to be variable between the services:

- Hospice A – where children are receiving end of life care or active treatment in the community, demand is frequent.
- Hospice B – generally low demand.
- Hospice C – high demand.
- Hospice D – no details.
- NHS Trust – high demand, up to 36 calls per day over a weekend.

### What type of calls do you receive?

- All the services receive phone calls, from both families and professionals, for advice about symptom control, medication issues and end of life care.
- Parents also phone for psychological support, and for reassurance that what they are doing is appropriate.

### Do you phone families out of hours?

All five organisations call families out of hours to monitor progress/situations.

- Hospice A reported that this happens only rarely, as a community nurse usually phones when with the family.
- Hospice B has a system of pre-planned phone calls where staff and family are aiming to avoid active treatment.
| What back-up is there (technical and personnel)? | The manager from hospice A reported having robust systems both technically (large switchboard) and in terms of staff cover, so felt that additional back-up is not required.  
In hospices B, C and D, staff carry mobile phones and/or pagers.  
On-call nurses from hospice D carry telephone advice forms and copies of end of life plans.  
In the NHS Trust, on-call staff are paged via a hospital switchboard. On-call staff carry a Blackberry with updated symptom management plans. |
|---------------------------------|----------------------------------------------------------------------------------|
| What are the advantages of your current system? | **Advantages listed included:**  
Provision of a key worker (hospice A).  
Flexible system which increases accessibility for families, carers and professionals (hospice B).  
Provides support for GPs who attend a family during the night (hospice B).  
System linked to weekly team meetings, thereby allowing for proactive prescribing (hospice C) and symptom management planning (NHS Trust).  
Well co-ordinated access to expert advice (NHS Trust). |
| What are the disadvantages of your current system? | **Disadvantages listed included:**  
The service is quite localised (hospice A).  
Unrealistic demands by families, for example, not realising that staff cannot diagnose a new problem over the phone (hospice B).  
As the service expands, hospice C will not be able to offer home visits throughout the new area covered.  
The service cannot be sustained for all patients at all times, hence the need to limit it to 25 families (NHS Trust). |
| What would improve your current system? | The manager from hospice A felt that the service would benefit from being on a more regional basis, in order to support outreach teams, and to provide a more geographically joined-up service.  
In hospice B, criteria for using the services were currently being examined, with the aim of balancing families’ need with feasibility. The manager felt that it was important to keep the helpline low-key, as otherwise the service would not able to cope with demand. |
| Any other comments? | There was an awareness of the necessity of balancing families’ and professionals’ needs with the demands of a budget. In hospice B, it was noted that the need for the service is unpredictable, and on-call staff were frequently not used. This proved expensive for the organisation and demoralising for individuals.  
It was also felt to be important to share resources with other organisations across wider geographical areas. |
### 2. Telephone advice given by CHSW - current demand

The following calls were logged by staff during the project period. These data are likely to under represent the actual number of calls received.

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Date</th>
<th>Call time</th>
<th>Call duration (mins)</th>
<th>Known to CHSW?</th>
<th>Callers relationship to child/ prof role</th>
<th>Type of advice sought*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charlton Farm</td>
<td>02/12/2010</td>
<td>18:00</td>
<td>10</td>
<td>yes</td>
<td>father</td>
<td>CS, M</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>02/12/2010</td>
<td>19:45</td>
<td>5</td>
<td>yes</td>
<td>mother</td>
<td>CS</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>24/12/2010</td>
<td>18:00</td>
<td>15</td>
<td>yes</td>
<td>mother</td>
<td>CS, F, Em, Sl</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>29/12/2010</td>
<td>08:30</td>
<td>10</td>
<td>yes</td>
<td>mother</td>
<td>CS, F</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>29/12/2010</td>
<td>09:55</td>
<td>10</td>
<td>yes</td>
<td>father</td>
<td>CS, F</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>29/12/2010</td>
<td>15:00</td>
<td>10</td>
<td>yes</td>
<td>father</td>
<td>CS, F</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>not recorded</td>
<td>not recorded</td>
<td>not recorded</td>
<td>yes</td>
<td>parent</td>
<td>CS</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>not recorded</td>
<td>not recorded</td>
<td>not recorded</td>
<td>yes</td>
<td>parent</td>
<td>CS, Em</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>not recorded</td>
<td>not recorded</td>
<td>not recorded</td>
<td>yes</td>
<td>parent</td>
<td>CS, Em</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>not recorded</td>
<td>not recorded</td>
<td>not recorded</td>
<td>yes</td>
<td>parent</td>
<td>CS, F, Em</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>06/01/2011</td>
<td>16:45</td>
<td>25</td>
<td>yes</td>
<td>parent</td>
<td>Em, Sc, Sib</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>10/01/2011</td>
<td>19:04</td>
<td>3</td>
<td>yes</td>
<td>parent</td>
<td>Eq</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>17/01/2011</td>
<td>22:15</td>
<td>60</td>
<td>yes</td>
<td>mother</td>
<td>Em</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>18/01/2011</td>
<td>19:00</td>
<td>30</td>
<td>no</td>
<td>doctor</td>
<td>CS, M</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>28/01/2011</td>
<td>22:15</td>
<td>45</td>
<td>yes</td>
<td>mother</td>
<td>M, Em</td>
</tr>
<tr>
<td>Charlton Farm</td>
<td>17/02/2011</td>
<td>21:45</td>
<td>20</td>
<td>yes</td>
<td>mother</td>
<td>CS, Em, Eq</td>
</tr>
<tr>
<td>LBH</td>
<td>24/12/2010</td>
<td>16:00</td>
<td>15</td>
<td>yes</td>
<td>CCN</td>
<td>Em</td>
</tr>
<tr>
<td>LBH</td>
<td>31/12/2010</td>
<td>14:50</td>
<td>20</td>
<td>yes</td>
<td>Community Matron</td>
<td>M, F, Sib,</td>
</tr>
<tr>
<td>LBH</td>
<td>05/01/2011</td>
<td>12:00</td>
<td>10</td>
<td>yes</td>
<td>CCN</td>
<td>Em</td>
</tr>
<tr>
<td>LBH</td>
<td>21/01/2011</td>
<td>15:15</td>
<td>35</td>
<td>yes</td>
<td>mother</td>
<td>Sc, Sib, Em, Ss</td>
</tr>
<tr>
<td>LBH</td>
<td>10/02/2011</td>
<td>several 30 min calls</td>
<td>yes</td>
<td>prof role</td>
<td>CS,M</td>
<td></td>
</tr>
<tr>
<td>LBH</td>
<td>10/02/2011</td>
<td>13:30</td>
<td>20</td>
<td>yes</td>
<td>hospice nurse</td>
<td>CS, M</td>
</tr>
</tbody>
</table>

*key

<table>
<thead>
<tr>
<th>Cs</th>
<th>clinical symptoms</th>
<th>Em</th>
<th>emotional support</th>
<th>M</th>
<th>medicines</th>
<th>F</th>
<th>feeding</th>
<th>Sl</th>
<th>sleep</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eq</td>
<td>equipment</td>
<td>Sch</td>
<td>school</td>
<td>Ss</td>
<td>social support</td>
<td>Sib</td>
<td>siblings</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3. Post titles of online survey participants

<table>
<thead>
<tr>
<th>Title</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acting Director of Nursing and Patient Safety</td>
<td>Manager, Home Care Service</td>
</tr>
<tr>
<td>Associate Specialist</td>
<td>Matron</td>
</tr>
<tr>
<td>Associate Specialist Paediatric &amp; Adolescent Oncology</td>
<td>Neuromuscular care advisor</td>
</tr>
<tr>
<td>Care Team Manager</td>
<td>Oncology outreach nurse specialist</td>
</tr>
<tr>
<td>Child Development Group Co-ordinator</td>
<td>Paediatric Community Services Manager</td>
</tr>
<tr>
<td>Children's Community Nurse</td>
<td>Paediatric Doctor</td>
</tr>
<tr>
<td>Children’s respite carer</td>
<td>Paediatric Oncology Outreach Nurse Specialist</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>paediatric oncology outreach nurse specialist</td>
</tr>
<tr>
<td>Clinical Nurse Specialist</td>
<td>Paediatric Oncology Outreach Nurse/CCN</td>
</tr>
<tr>
<td>Community Nursery Nurse</td>
<td>Paediatric oncology Sister</td>
</tr>
<tr>
<td>Consultant</td>
<td>Paediatric oncology specialist nurse</td>
</tr>
<tr>
<td>Consultant Clinical Psychologist</td>
<td>Paediatric Respiratory Nurse Specialist</td>
</tr>
<tr>
<td>Consultant Paediatric Oncologist</td>
<td>paediatric/neonatal consultant</td>
</tr>
<tr>
<td>Consultant Paediatrician</td>
<td>Prof Lead Community Children's Nurses</td>
</tr>
<tr>
<td>Consultant PICU</td>
<td>Programme Lead Children and Young People</td>
</tr>
<tr>
<td>Consultant Respiratory Paediatrician</td>
<td>Senior Nurse for Children (Matron)</td>
</tr>
<tr>
<td>Diana Children’s Community Nurse</td>
<td>Special school nurse</td>
</tr>
<tr>
<td>Director of Care Services</td>
<td>SpR Paeds</td>
</tr>
<tr>
<td>Family Support Manager</td>
<td>Staff Nurse</td>
</tr>
<tr>
<td>group manager</td>
<td>Staff nurse. Oncology liaison nurse</td>
</tr>
<tr>
<td>Hospice Doctor</td>
<td>Team leader special needs- children</td>
</tr>
<tr>
<td>Lead nurse for paediatric oncology &amp; palliative care</td>
<td>Team Manager</td>
</tr>
<tr>
<td>Leukaemia Clinical Nurse Specialist</td>
<td></td>
</tr>
</tbody>
</table>
### 4. Organisations represented by online survey participants

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bristol Royal Hospital for Children</td>
</tr>
<tr>
<td>2</td>
<td>Children's Community Team Torbay</td>
</tr>
<tr>
<td>3</td>
<td>CHS</td>
</tr>
<tr>
<td>4</td>
<td>CIOS Community Health Services</td>
</tr>
<tr>
<td>5</td>
<td>Clic Sargent / R D &amp; E</td>
</tr>
<tr>
<td>6</td>
<td>Clic Sargent/RUH</td>
</tr>
<tr>
<td>7</td>
<td>COIS PCT</td>
</tr>
<tr>
<td>8</td>
<td>COMPASS team</td>
</tr>
<tr>
<td>9</td>
<td>Cornwall and Isles of Scilly PCT</td>
</tr>
<tr>
<td>10</td>
<td>Derriford Hospital</td>
</tr>
<tr>
<td>11</td>
<td>Gloucestershire Hospitals NHS Foundation Trust</td>
</tr>
<tr>
<td>12</td>
<td>Great western hospital foundation trust</td>
</tr>
<tr>
<td>13</td>
<td>Honeylands Specialist Child Development Centre</td>
</tr>
<tr>
<td>14</td>
<td>Lifetime service</td>
</tr>
<tr>
<td>15</td>
<td>Musgrove park Hospital</td>
</tr>
<tr>
<td>16</td>
<td>NHS</td>
</tr>
<tr>
<td>17</td>
<td>NHS Devon</td>
</tr>
<tr>
<td>18</td>
<td>NHS DEVON CCN service</td>
</tr>
<tr>
<td>19</td>
<td>NHS Gloucestershire</td>
</tr>
<tr>
<td>20</td>
<td>NHS Somerset</td>
</tr>
<tr>
<td>21</td>
<td>NHS South West</td>
</tr>
<tr>
<td>22</td>
<td>North Bristol NHS Trust</td>
</tr>
<tr>
<td>23</td>
<td>Plymouth Hospitals NHS Trust</td>
</tr>
<tr>
<td>24</td>
<td>Polkerris ward RCHT Truro</td>
</tr>
<tr>
<td>25</td>
<td>Rainbow Trust Children’s Charity</td>
</tr>
<tr>
<td>26</td>
<td>Royal United Hospital Bath</td>
</tr>
<tr>
<td>27</td>
<td>Social care</td>
</tr>
<tr>
<td>28</td>
<td>Special needs team Redditch/ Bromsgrove</td>
</tr>
<tr>
<td>29</td>
<td>The Jessie May Trust</td>
</tr>
<tr>
<td>30</td>
<td>The Lifetime Service</td>
</tr>
<tr>
<td>31</td>
<td>UH Bristol NHS Foundation Trust</td>
</tr>
<tr>
<td>32</td>
<td>Yeovil</td>
</tr>
</tbody>
</table>
5. **What are the advantages of your current system?**

- We know the children well and have a good relationship with the family.
- Very flexible arrangement at present. We have on average 2 - 4 deaths per year. Usually by the palliative phase our small team (core of 4 people) know the child and family extremely well. This relationship helps greatly in supporting those (the majority) who chose to die at home. Communication is greatly aided by this and the families have confidence in a small team that they know well.
- Advantages are that our families get good continuity of care. When their child is at the end of their life families receive care from professionals who have known them from the beginning of their cancer journey. We generally find that the child/parents/siblings really benefit from this as they are very vulnerable and it can be hard for them to have new people introduced to them at this time. We are a small team so there are not many new faces to get to know.
- Other advantages are is that they have 24 hour access to advice and we can visit as well. We also have access to the doctors in our team so they can come and do visits with us and are readily available for medical advice.
- I know the patients well and have access to their medical notes and Consultant out of hours. They know me and trust that I am familiar with their situation.
- Flexible Low cost Families receive continuity of care. We involve the GPs which may help in long term care for the families.
- Good continuity for families.
- Continuity of care.
- Flexible, relating to needs of the family and child.
- Flexibility of approach, knowledge and professional relationship established with the family.
- Have already established relationship with family and have access through hospital to Clic staff and consultants.
- Because end of life care is infrequent it is not burdensome.
- Personal, flexible. Family know us, we know them and their child. Good relationship, been with them all through child’s journey to this point. don’t always have terminal pt so service just starts when there is need. Team always discuss offering the service to families first, it is not a given that each family will receive this service. Nurse safety, child safety etc is always a primary consideration.
- As a service, we work frequently with families in their own homes and are ideally placed to provide on the spot support.
- Allows for a service to be offered to patients at end of life. Supports them and allows patient to stay at home.
• Our oncology team medical and nursing are contactable through the ward or the nominated person on call overnight. Parents will be given the correct contact number(s)

• Close knit team, family get to know who team from onset of referral. Working together with CCN team and Paed Onc Team

• Family usually known to me

• It is flexible

• Parents have choice of place of care and can stay where they want, they can speak on the phone or ask for a visit. Parents can access someone with experience and knowledge of their child to get the answer to their query without having to repeat the events until their call.

• Allows parent's and families a choice of place of care, enables quality of life for families to be in a setting of comfort and choice Enables hospital to keep costs down of inpatient hospital admissions and save money

• Knowledgeable staff, flexibility, all the senior sisters participate (Band6/7) Families feel supported. We involve the primary care team GP, district nurses etc. facilitates the child remaining at home if that is what the child and family want.
6. What are the drawbacks of your current system?

- May not know the child / family
- Not consistently available. Relies solely on goodwill unstructured and not resourced
- Sometimes we don’t know the answer and have to seek advice - have called hospice / general paediatricians. Also if we have a long terminal phase or two patients palliative close together we all get exhausted.
- The main drawbacks are that it is only 2 nurses carrying out the on call. If we have a long period when we are on call it can be very draining both emotionally and physically. If one of us is on holiday we can ask one of our doctors to help but it can mean a long stretch on with no break.
- Workload can be heavy at times
- If staff are on leave there may be times when people with less experience are being asked for advice. Can be intense on the few staff who do provide this advice. Staff not being remunerated accordingly.
- High work load for a few professionals
- On goodwill, no sustainable funding
- Very limited service available due to ongoing continued workload, families often feel they are bothering you despite assurances of on call process

- Difficult to manage if medical team on call do not know child well
- I do not have all the necessary skills esp around symptom control during end of life eg pain, nausea. At these times I do need further advice and support and have sometimes telephoned the hospices to seek advice from the Medical Directors.
- can be tiring if on call for long time ie months. No cover if one is on annual leave.
- Very small team without the security of always having expert specialist advice readily to hand - 24/7/365
- It is goodwill and we need more formal training
- Recognising the end of life is difficult and we are often caught out by a patient dying when we were not expecting it and hence were on call.
- Parents can often feel alone and isolated during out of office hours
- Limited knowledge of palliative care with ward nurses.
- A lot of Goodwill and having to convince management of needs of child and family
- No formal arrangement. can’t always provide cover as not in rota. Unwilling to take on to much uncontracted as have to do usual on call and have family of my own.
- If families need advice it will only be during office hours
- Limited to 2 members of the team, so caseload covering for the next day can be difficult if busy. Medical cover limited.
- Reliant on me! lack of proactive advance care planning disinterest by medical professionals lack of family/patient centred approach
- Staffing, only 2 members of the team and have a caseload to cover in working hours
- On call costs, staff don’t know when they could be called. Can be quite a distance for the team to cover when called from home eg live in oxford and have to go to Devizes
7. What would improve how specialist medical/nursing advice is provided?

- Ensure adequate training and expertise of professionals offering advice. Regular team meetings/supervision/CPD. Feedback of patient outcomes back to the advice line professionals. Specialist nursing and specialist medical advice should be available.

- 24 hour advice.

- Stronger links with adult services. On the occasions where children are transitioning to adult care there needs to be advice be that includes preparation for ending up in an ITU bed out of area, especially addressing the issues faced when they find themselves in an adult service led ITU.

- Ability to advise on symptom control.

- As suggested 24hr access to expert advice.

- More emotional support.

- Needs to be expert, easily accessible telephone or online service.

- The phone contact sounds great. Or how about a webpage that can be updated with new information much quicker than written guidance - eg we have had recent great success with astral fentanyl melts - this sort of info could be accessed via a webpage without disturbing someone out of hours.

- In my (vast) clinical experience as a paediatric palliative care community nurse, timing is as important as the content of the information. Professionals can't always know everything and a willingness to find out in a timely way is crucial to the family to allow them to make choices in the care they need for their child. I am therefore a great supporter of the development of this 24 hr access to advice service.

- I think that an advice line which is accessible 24 hours for both parents and professionals would be very useful, however I think parents might find it confusing as to who they should call for advice so think the help line would be better for professionals.

- Increased funding for the existing team to provide out of hours care.

- General training/education issues to ensure that staff, once they have taken advice, feel confident in taking that action (e.g. prescription of meds) and have/are familiar with the right equipment/protocols in order to be able to carry out that piece of advice.

- Follow up email so there is a record of advice given.

- Clear documentation of advice given that is communicated to all relevant professionals and family.

- Increase community nursing teams specialist in Palliative care who can provide 24/7 visits at end of life. Palliative care consultant for region Clinical network and regional service planning. Investment in training for One community Paediatrician for each area and allocated sessional time for this work. Service collaboration supported by communication of information on secure computerised system.

- To try and have one number throughout UK that can be accessed by all.
• A funded out of hours service

• A transparency and seamless working between different agencies is what most families want when going through a cancer diagnosis - established links such as integrated care and liaison with CLIC Sargent Nurse specialists have improved this - however until there is a 24 hour palliative care service that is available in Bristol and the surrounding area a help-line would certainly be of benefit. Communication pathways into and outwith this service would be critical though to ensure that seamless working is maintained.

• A coordinated approach rather than duplication of service - ie one stop shop

• 24 hr access, knowledgeable staff. FAQ on a website?

• Better liaison between the ward consultants and advice hospice doctors.

• Increase infrastructure and redevelop processes within health acute and community teams to enable reliable 24/7 advice to be available- look at first on call nursing support via lifetime with appropriate medical back up perhaps? Develop GP involvement (+/- GPs with special interest in palliative / end of life care) with integration with out of hours services via electronic record access ( like Adastra) Involve all community paeds through the on call system to have this as part of their work ( again backed by accessible e patient record system).

• Clear communication channels and access to records if needed or use of a profoma sheet with relevant information available and accessible for the advice line which we can update as needed. This would save having to go over everything at the time and give the person on the advice line up to date information. If any advice is given or changes made it would be useful for key professional identified to be notified of this i.e medication changes etc.

• TRAINING

• More money and staff! Regional education / sharing of problems.

• more courses available in paediatric palliative care

• electronic record system

• Skype calls

• I don't think it is necessary for family already to be involved with specialist service - often these situations come up at short notice or unexpectedly

• There is none! Therefore what would improve it...is investment and commissioner commitment.

• Designated Paediatric Palliative Care Team - including consultant, junior medical cover and specialist nursing cover Better and clearer communication methods for all
8. Linkage to other projects/ areas of telecommunication development

During the course of the project I have identified the following links to existing projects and developments in communication and technology in palliative care.

1. Global virtual meeting centre (Web X platform)

   A pilot project under the teenage and Young Adult (TYA) oncology group to facilitate regional multi disciplinary case discussions to improve patient care and inter professional collaboration.

   Contact: Deirdre McGuigan: Teenager and Young Adults (TYA) Lead Nurse, Cancer Services

   **Benefits for CHSW:** offer to host a pilot of the scheme for Palliative care for the region to enable multi disciplinary involvement in discussion about complex cases.

   **Benefits to 24/7 project:** would enable the 24/7 advice to be embedded in good liaison and planning with other professionals (and parents) across the region. Would enable Doctors and nurses working on 24/7 to be part of a team discussion and planning. Use of IT “platform” for weekly discussions and handover for complex cases.

2. End of life register for young people in Devon and use of Adastra for Young people and children

   Contact: Helen McLindon.

   The end of life register is a module within Adastra currently used for Adult patients who are expected to die within a year. This project is to pilot a Palliative care register for children and young people in Devon and to design specific Adastra pages for communication of information for these children and young people.

   **Benefits to 24/7 project:** provides a pilot for a system for transfer of patient information.
3. Wiltshire project:

Contact: Marla Forrest: Clinical Lead- Training and Development Children’s Specialist Services Wiltshire Community Health Service.

Project Looking at setting up “A community of practice” on line.

- To enable carers to look up answers to queries and ask questions on forums

- To set up Children’s information: including technical information, For example: feed pump information.

- Set up a system programme with alarms to keep you alert
  One of their concerns is the need for “someone to oversee and monitor system 24/7.

4. MY QOL-T: Measure Yourself Quality of Life Tool

Contact: Nicky Harris: Medical Director CHSW.

DH funded project to develop a patient-generated tool to assess symptoms and evaluate quality of life for children and families who require palliative care support.

Benefits to 24/7 project: Could enable remote monitoring of patient generated symptom assessment to support advice giving in a way that is timely and focused on patient and family quality of life.
9. Training courses:

Telephone advice training options:
- Included in contract with not for profit social enterprise company.
- Some aspects covered by telephone help lines association: www.helplines.org.uk

Paediatric Palliative care training options:
- Existing postgraduate courses in Paediatric Palliative Care: Cardiff: Diploma in Paediatric Palliative Medicine
  Cardiff Diploma in Paediatric Care.
- Oxford Brooks Modules in palliative Care
- Specific courses available in advanced communication skills for health professionals working palliative care.