

End of life care for infants, children and young people: planning and management

Appendix L: Together for Short Lives Report:

Exploring Palliative Care Needs and Provision
for Children and Young People with Life-
Limiting and Life-Threatening Conditions: a
Consultation with Young People

NICE Guideline

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Appendix A: Together for Short Lives Report

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1 **A.0 Abstract**

2 **A.0.1 Background**

3 A new clinical guideline for end of life care for infants, children and young people is currently
4 being developed by the National Institute for Health and Care Excellence (NICE) to inform
5 clinical practice in England. Patient experience is a NICE quality standard and one of the
6 three key components of quality in the English NHS. Ensuring that clinical guidelines are
7 informed by the views of those receiving care is therefore essential. This report presents
8 findings from a consultation with young people with life-limiting and life-threatening
9 conditions, which aimed to explore the views and experiences of young people on the
10 following topics: information and communication; care planning; place of care; emotional
11 care; and improving care provision. The consultation was commissioned by NICE, and
12 carried out by Together for Short Lives and Martin House Children's Hospice.

13 **A.0.2 Methods**

14 The consultation comprised qualitative thematic analysis of data collected from three
15 consultation groups and two individual consultations carried out between October and
16 December 2015. A total of 14 young people took part (seven male, seven female), ranging in
17 age from 12 to 18 years. Conditions included spinal muscular atrophy, cancer, cystic
18 fibrosis, and other rare degenerative and life-threatening conditions. A topic guide
19 comprising the pre-defined themes was used to structure the sessions, which consisted of
20 discussion points and activities using visual cues. Data collection and analysis were
21 informed by a pilot consultation group with five young adults (aged 19 to 24 years). Key
22 findings were shared with all participants; feedback received from seven young people was
23 used to help interpret the consultation findings.

24 **A.0.3 Findings**

25 Participants' experiences of care and care planning varied. Care plans were not always used
26 to share information with others or kept up to date, and in these cases young people had to
27 repeatedly explain their care needs to others. Participants were keen to be involved in
28 planning their care, although preferences for involvement varied across the sample.
29 Participants' needs for information also varied, and changed over time. Key information
30 sources included named specialists, other young people with similar conditions, and trusted
31 websites. Participants emphasised that quality of care was more important than place of
32 care, and although young people preferred being at home and or at their local hospice, they
33 explained that sometimes the hospital was the best place to be when they were unwell.
34 Participants identified features of good care that helped them to feel safe and looked after.
35 These included: access to specialists with knowledge of their condition; being treated as an
36 individual; carers taking the time to meet their personalised care needs; and continuity of
37 relationships. Having their own technologies and access to the internet while in hospital was
38 also important to young people, who used their devices to stay in touch with friends and to
39 distract them when they felt lonely or sad. Participants identified distraction and avoidance
40 as common strategies to manage negative feelings. Talking to others also helped, although
41 not all participants were able to do this and expressed unmet needs for emotional care that
42 for some young people were met through specialist provision. Transition to adult services
43 worried young people taking part, and was associated with the loss of known specialists and
44 other professionals.

1 A.0.4 Discussion

2 Having known and accessible specialists, and carers who take the time to get to know young
3 people and are aware of some of the challenges that young people with complex healthcare
4 needs and disabilities face helps young people to feel safe and looked after, and this is a
5 key feature of paediatric palliative care. Young people were keen to emphasise the
6 importance of raising awareness among hospital staff and other generalists or junior staff
7 they encountered to help improve quality of care. Providing young people with timely and
8 personalised information and involving them in planning episodes of care to the extent that
9 they desire, can reduce uncertainty about what will happen and when, minimise disruption to
10 everyday life, and help them to develop skills for the difficult transition to adult services. This
11 is borne out in other research, which shows the benefits of a shared decision making model,
12 although for young people, involvement in care planning needs to be balanced against their
13 developmental needs and the importance to them of living well with the condition, rather
14 than focusing on their deteriorating health and end of life care. Having access to specialist
15 psychological care helps young people to manage feelings about their illness and treatment;
16 however, there are barriers that mean few young people receive this.

17 A.1 Background

18 Paediatric palliative care is defined as ‘total care’ encompassing the physical, emotional,
19 spiritual and social needs of children whose lives are shortened due to a life-limiting or life-
20 threatening condition, and their families (World Health Organisation, 2016). Changing
21 patterns of childhood deaths and increased lengths of survival mean many children and their
22 families face prolonged uncertainty combined with significant need (Menezes 2010; Fraser
23 et al., 2012). Many children and young people with palliative care needs have complex
24 healthcare needs and degenerative disabilities. Others may have compromised immune
25 systems and partial organ failure, and may be supported by life-sustaining technologies like
26 enteral nutrition and assisted ventilation (Hain et al., 2011).

27 Palliative care in childhood can begin as early as point of diagnosis and continue,
28 sometimes in parallel with active treatment, for a significant number of years. Life can be
29 particularly challenging for some children and their families, and the provision of good
30 palliative care from medical and health professionals, children’s services, and other
31 organisations, including children’s hospices and charities providing specialist input, is
32 reported to enhance quality of life for children and their parents and for some families
33 becomes a lifeline of support in a changing and fragile world (Aldridge, 2007; Hain et al.,
34 2011; Hunt et al., 2013). However, despite the fact that in England paediatric palliative care
35 has been the subject of an independent review and policy improvements in the last ten years
36 (Craft and Killen, 2007; Department of Health, 2008), research continues to show that while
37 some families receive excellent care that enhances their quality of life, others experience
38 poor care co-ordination, conflict and misunderstandings from health and social care
39 professionals, and have unmet care needs (Hunt et al., 2013; Nicholson, 2013).

40 Evidence about the provision of paediatric palliative care in the main comes from clinicians
41 and parents, in part because of the challenges associated with recruiting children and young
42 people in this area of research (Crocker et al., 2014; Hunt et al., 2013). However, the
43 importance of including their voices is increasingly acknowledged, and studies that involve
44 children and young people themselves bring a depth of understanding that can better inform
45 care provision and clinical practice (Hunt et al., 2013; Kirk and Pritchard, 2010; Menezes,
46 2010; Noyes et al., 2013).

1 A.2 Methods

2 A.2.1 Consultation aims

3 This consultation was commissioned by the National Institute for Health and Care
4 Excellence (NICE) as part of their work to develop new clinical guideline for end of life care
5 for infants, children and young people. Despite adopting the term end of life in its title, the
6 new guideline is underpinned by the definition that includes care provided to children and
7 young people and their families / carers from first recognition of a life-limiting condition to
8 end of life and beyond. Main outcomes for the guideline include children and young people's
9 quality of life and psychological wellbeing, and their satisfaction with care (NICE, 2016).

10 This consultation aimed to ensure that the views and experiences of young people informed
11 the development of the new guideline, focusing specifically on particular review questions
12 provided by the committee, including young people's preferences for place of care;
13 information and communication provision; personalised care planning; and psychological
14 care (NICE, 2016). The consultation also aimed to find out from young people their views
15 about how care can be improved for children and young people with life-limiting and life-
16 threatening conditions.

17 A.2.2 Consultation design

18 The consultation adopted a qualitative exploratory approach using focus groups and
19 individual interviews to explore the views of young people about their experience and
20 opinions of care provision. Key principles of the Framework method underpinned this work,
21 which allows for a priori and emerging themes to be included, and involves a structured and
22 transparent process of analysis that moves between levels of abstraction and the raw data
23 (Spencer et al., 2003).

24 A.2.3 Sample

25 The sample included young people aged between 12 and 18 (inclusive) diagnosed with
26 either a life-limiting condition (defined as a condition which is likely to result in early death),
27 or a life-threatening condition (for example cancer, congenital anomalies leading to potential
28 organ failure) for which curative treatment options are no longer viable (Liben et al., 2008).

29 Other inclusion criteria included having capacity to consent, which was assessed by
30 researchers with the necessary skills and experience to assess capacity; being able to
31 communicate verbally, either individually to a researcher or in a group setting; and
32 understanding that they had been diagnosed with a potentially life-limiting or life-threatening
33 condition.

34 Drawing on methodological expertise (Carlsen and Glenton, 2011; Finch and Lewis, 2003;
35 Francis et al., 2010) and our own experience of conducting qualitative research in this area
36 (Nicholson, 2011; 2012; 2013), we aimed to recruit a minimum of 12 young people in the
37 consultation. A sample of this size would firstly allow us to explore the range and diversity of
38 experience among young people with life-threatening and life-limiting conditions, and
39 secondly help to ensure credibility of the consultation findings. In practice, this meant
40 continuing to recruit participants while new ideas were still emerging, applying a stopping
41 criteria of 1 until we reached data saturation, in other words when there were no new distinct
42 ideas still emerging (Francis et al., 2010).

43 Other published research in this area has recruited similar numbers of children and young
44 people; for example, Noyes et al. (2013) included 11 children and young people in their
45 study, although the level of participation varied from passive to active; Nicholson (2013)

1 recruited 12 young people; Menezes (2010) included 11 children and young people; Kirk and
2 Pritchard (2011) recruited 7 young people; and Hunt et al., (2013), being the largest of the
3 studies with a recruitment target of 50 to 80 families, included 18 children and young people.

4 Due to the short duration of the consultation, a convenience sample was sought in the first
5 instance, to include any young people meeting the above criteria. However, to explore the
6 views and experiences within what is a heterogeneous population, we purposively sampled
7 towards the end of the data collection period to include young people of different ages,
8 ethnicity, illness type, and experience of care, with reference to a recent study on the
9 prevalence and characteristics of life-limiting childhood conditions in England carried out by
10 Fraser et al., (2012).

11 **A.2.4 Recruitment**

12 To achieve our sample we aimed to conduct three consultation groups in different areas of
13 England (London, Bristol and York), each comprising no more than 8 young people to allow
14 for group discussion and individual participation. Although consultations were held in central
15 locations, we recruited from across each region to ensure participation of families in rural as
16 well as urban areas. We also planned, where necessary, to conduct a small number of
17 individual consultations with a) potential participants who expressed an interest in taking part
18 but who were not able to attend a group and b) to involve young people with conditions we
19 were not able to recruit for the group consultations.

20 The partner organisations (Martin House Children's Hospice and Together for Short Lives)
21 approached their membership communities and other organisations involved in supporting
22 young people with life-shortening conditions to recruit young people interested in taking part
23 in the consultation. An information leaflet (Supplement A) was provided to all potential
24 participants, which explained the consultation and what taking part would involve. All young
25 people (and parents where young people were under the age of 16) were asked to sign a
26 consent form, which included a series of statements to ensure they were providing informed,
27 voluntary consent (Supplement B).

28 Unfortunately, the limited time available for recruitment failed to yield enough participants
29 (only one) for the first group in London (26/09/2015), which was cancelled. For the Bristol
30 group (Group A), six young people expressed an interest in attending, however only three
31 took part on the day (10/10/2015). The York group (Group B) followed a similar pattern, with
32 11 young people expressing an interest and seven taking part on the day (28/10/2015).

33 Richard House Children's Hospice in London kindly agreed to host a third consultation group
34 (Group C), for which four young people expressed an interest and two young people
35 attended (12/12/2015). An additional young person receiving care from Richard House who
36 was not able to attend the group took part in an interview at home. One other young person
37 was recruited in the Yorkshire area, and was interviewed at home.

38 In total, three focus groups (of between two and seven participants) and two individual
39 interviews, with 14 young people in total, were carried out between October and December
40 2015.

41 **A.2.5 Data collection**

42 The pre-defined themes for the consultation (developed by the NICE Guideline committee)
43 were used to design a topic guide and materials to help structure the consultation groups.
44 This method is commonly used to help structure the collection of qualitative data, as a
45 means to ensure that topics of interest are covered while at the same time allowing for
46 qualitative exploration of participants' own experiences and understanding (Arthur and
47 Nazroo, 2003). Each topic consisted of discussion points and group exercises using visual

1 cues (for example, different emotions and care providers). Consultation tools used in health
2 services research were employed to stimulate discussion and engage young people in
3 conversations. These included mind maps / spider diagrams of information sources, pros
4 and cons for places of care, and affinity diagrams for care improvements (see
5 <http://www.servicedesigntools.org> for details).

6 A focus group was conducted with five young adults with life-limiting and life-threatening
7 conditions, age 19 to 24 years (four males, one female), in September 2015 to pilot the topic
8 guide. Participants were existing users of Martin House with an interest in research and
9 service provision, and were approached by JA about the consultation. As well as taking part
10 in the group discussions and exercises, these young adults were encouraged to provide
11 feedback on the questions and materials, which were then modified for the main
12 consultation. For example, places of care were reduced to three (home, hospital, hospice);
13 types of information were combined to create fewer statements to read; and young adults
14 liked to rank places of care by preference even though this was not achieved by the group.
15 The revised consultation group topic guide is provided in Supplement C.

16 The focus groups were designed to last 90 minutes (ranged from 83 to 91 minutes), and
17 were facilitated by JA and JT, who are both experienced qualitative researchers. The
18 interviews were shorter and included closed and open questions to allow for emergence of
19 new themes and enable participants to share their own experience if they wished. Individual
20 interviews ranged from 21 to 38 minutes, and were carried out by JT using the consultation
21 group topic guide. All groups and one interview were audio recorded and transcribed for
22 analysis.

23 A.2.6 Data analysis

24 A thematic analytic approach (Spencer et al. 2003) was used to structure and explore the
25 data. NVivo 11 software (QSR International Pty Ltd, Doncaster, Victoria, Australia) was used
26 to manage and code the transcripts and audio (the latter were used to help decipher words
27 and phrases that were not possible to transcribe). The process of analysis described by
28 Ritchie et al., (2003) was followed. This involved the following steps:

- 29 • Step 1: 'conceptual scaffolding' - identifying and extracting recurring themes from across
30 the data and developing a thematic coding framework which included the a priori topics
31 as main themes (that is, information and communication; care planning; place of care;
32 emotional care; improving care) and incorporated new themes identified in the data under
33 the main topic headings (that is, themes were placed into the best fitting topic) (carried
34 out by JT, JA and SM);
- 35 • Step 2: 'indexing' - testing and modifying the framework by labelling and sorting a
36 selection of data into the framework (carried out by JT);
- 37 • Step 3: 'coding' - coding the raw data to the framework in NVivo (carried out by JT);
- 38 • Step 4: 'descriptive analysis' - summarising and synthesising data by theme, and
39 detecting, categorising and classifying findings into higher order themes and phenomena
40 (carried out by JT, JA and SM);
- 41 • Step 5: 'explanatory analysis' - detecting patterns and examining linkages and
42 relationships between themes to develop a more in-depth understanding of the data
43 (carried out by JT and JA). As well as examining thematic patterns across the data,
44 deviant cases, for example participants with a different experience of care, were
45 examined to understand the variation within the sample, and to assess the level of
46 conceptual saturation reached in the study.

1 A.2.7 Quality

2 The quality of the consultation was ensured against several criteria, including dependability,
3 credibility, trustworthiness, and authenticity (Guba & Lincoln 1994).

4 To ensure trustworthiness and allow readers to make their own judgement about how to
5 interpret the findings, a full account of the consultation methods has been provided in this
6 report, including details about recruitment methods, study materials, sample characteristics
7 and group composition, and an explanation of how data were analysed and interpreted,
8 including sharing the conceptual framework to which data were coded. There is also an
9 assessment of the strengths and weaknesses of the consultation (see Discussion section) to
10 aid readers in their own assessment.

11 To create dependability (that is, consistency or reliability), a standardised approach to data
12 collection (topic guide) and analysis (thematic framework) was employed. Three researchers
13 (JT, JA and SM) were involved in the process of collecting and analysing data so that the
14 meaning of themes and interpretation of results, which further ensured dependability of the
15 findings, could be iteratively checked. In writing the report, the authors continued to check
16 with the raw data and coded framework to ensure that the weighting given to certain findings
17 (for example, the topics for discussion) were grounded in the data and not influenced by the
18 authors own experience and expertise in this area of clinical practice and research.

19 To assure credibility (truth value) of the findings, ‘member checks’ were used (what is often
20 referred to as respondent validation [Lincoln and Denzin, 2003]). This involved sharing a
21 summary of all themes to consultation participants and asking them to provide feedback on
22 our interpretation of the results against their own experience and understanding (see
23 Supplement D for the summary shared with participants). Five young people taking part in
24 consultation groups provided feedback about the findings; all young people felt that the
25 main themes discussed in their group had been captured. Two young people provided
26 suggestions about emphasis and weighing of different points raised in the summary; this
27 was incorporated into the final report.

28 To assure authenticity, which for Seale (2003) *“is demonstrated if researchers can show that*
29 *they have represented a range of different realities”* (p.173), three strategies were adopted.
30 First, the aim was to recruit a purposive sample of young people who varied by condition
31 type and progression, age, gender and ethnicity. Second, data were analysed alongside
32 data collection, and monitored recruitment to ensure that our sample varied by their
33 experience and understanding of receiving care as someone with a life-limiting or life-
34 threatening condition. This was as important as recruiting a sample varying in demographic
35 characteristics and illness profiles because their diverse experiences of care enabled the
36 authors to develop an understanding of the needs of children and young people across the
37 different consultation topics. Finally, the consultation findings (Supplement D) were shared
38 with young adults taking part in the pilot focus group who agreed to act as a service user
39 reference group for the consultation. Feedback was received from two young adults, for
40 whom the findings resonated well with their own experience of previously receiving care as a
41 young person under the age of 19.

42 A.2.8 Ethical considerations

43 This consultation was designed and conducted to assess current paediatric palliative care as
44 experienced and perceived by young people with life-limiting conditions, with an aim to
45 inform the development of new service standards. It involved the administration of
46 interviews, with participants recruited through third sector organisations. With reference to
47 Health Research Authority guidance (HRA, 2015), and through discussion with the NICE
48 guideline committee and the consultation team, the consultation was classified as service
49 evaluation and therefore not eligible for NHS ethical review.

1 To ensure high ethical standards throughout, the consultation team adhered to the
2 Economic and Social Research (ESRC) Framework for Ethics (ESRC, 2015). In particular,
3 principles of voluntary informed consent, confidentiality and anonymity, participant burden,
4 and study quality underpinned the consultation. All potential participants were provided with
5 written information about the consultation and were given an opportunity to ask questions
6 before deciding whether or not to take part. Capacity to consent was assessed by parents or
7 professionals known to young people who expressed an interest in taking part, and for all
8 young people under the age of 16, consent was taken from a parent or carer as well as the
9 young person.

10 At the beginning of consultation groups and interviews, consent was checked and further
11 information about the consultation and how their information would be used was provided
12 verbally. Consent and participant burden was checked throughout participation by the
13 consultation team, who have experience and expertise in conducting research in this clinical
14 area.

1 A.3 Findings

2 A.3.1 Participant characteristics

3 Participants of the main consultation included seven males and seven females, ranging from
 4 12 to 18 years of age. Three young people were from an ethnic minority background. Young
 5 people taking part had conditions in the following disease groups of life-limiting and life-
 6 threatening diseases: congenital and chromosomal, neuromuscular, cancer, and pulmonary
 7 and respiratory (Hunt et al., 2013). Conditions included spinal muscular atrophy, Duchenne
 8 muscular dystrophy, cancer, cystic fibrosis, and other degenerative conditions not listed
 9 because of the possibility of young people being identified by their condition. All participants
 10 lived at home with their parent/s, and all but one participant accessed services at a
 11 children’s hospice. Many of the participants had physical disabilities, and two participants
 12 had learning and communication difficulties. All but one participant had lived with their
 13 condition for several years.

14 A.3.2 Thematic framework

15 The thematic coding framework to which data were coded is provided in Table 1 (page 13-
 16 14). Theme names were chosen to reflect the data, for example using participants’ own
 17 wording where possible. Important sub-themes within each theme are provided in column
 18 two. These are discussed further in the presentation of findings in Section 3.3

19 **Table 1: Thematic coding framework**

	Theme	Sub-themes
1	Information and communication	
1.1	My consultant and others	Sources of information, named specialist key role
1.2	Knowing where to look	Trusting information online, different types of info
1.3	Choosing how much I want to know	We are all different, not wanting to know
1.4	Asking questions	Having an opportunity to ask questions
1.5	Talking to other young people	Experience of operations, advice about things
1.6	Knowing more than my parents	Young people become experts, parents still have a role
2	Care planning	
2.1	Ambiguity and variation	Different understandings, different / no / several plans
2.2	Sharing information about me	Repeating myself to others, not sharing plans
2.3	Getting on with it	Living life in the present, not always important to plan
2.4	Managing disruption and change	Updating care plans, planning hospital stays
2.5	Other	No mention about end of life care planning
3	Place of care	
3.1	It depends on how I am	Needing to be in hospital, choosing depends on context
3.2	Specialist medical expertise	Access to consultant and nurses, tests and medicines
3.3	Feeling safe and looked after	Regular checks, friendly carers, condition awareness
3.4	Knowing people	Continuity in relationships, staff understand me
3.5	Home comforts and technologies	Home comforts improve care, connecting with friends
3.6	Other	Dislike hospital stays, variation in care
4	Emotional support	
4.1	Care frustrations	Anger / frustration when things go wrong / mistakes

	Theme	Sub-themes
4.2	Having to ask and explain	Scared / embarrassed to ask, repeating self is frustrating
4.3	Overthinking and avoidance	Avoid feelings about future loss / overthinking distress
4.4	Distraction techniques	Art / friends / music / games / relax / reading / media
4.5	Talking it through	Bottling up, someone who understands, specialist care
4.6	Other	Unmet emotional needs, negative feelings
5	Improving care provision	
5.1	Good carers	Hard to find, understand care needs, flexible approach
5.2	Improving information	Personalising information / asking questions
5.3	Sharing and using care plans	One care plan, better sharing, updating when required
5.4	Treating us as individuals	We are all different, care needs / information needs / emotions
5.5	Better understanding and awareness	Disability, living in the present, training, young people
5.6	Preparing for transition	Skills for transition, help from children's services, scary
5.7	Improving access and equipment	Disability, wheelchairs, better access, information

1 A.3.3 Consultation findings

The findings for each consultation topic are presented below, using all themes and sub-themes within the framework to describe the results and select participant quotations to illustrate key themes. In sharing quotations, care has been taken to protect the identity of the young people who participated in this consultation (each quotation includes the participant unique identifier (for example y1, y2) to show that quotations are drawn from across the sample). Theme identification numbers (for example 1.1, 1.2) are provided to link the presentation of findings to the analytical framework. Although this is not common practice in qualitative research, it is hoped that this will aid the reader in their own interpretation of the study findings.

11 A.3.3.1 Information and communication

Participants identified their consultant as the key source of medical information about their condition because of their specialist knowledge and expertise (1.1). Other commonly reported sources of information included parents, hospital and community nurses, physiotherapists, occupational therapists and play therapists, charities supporting children and young people with life-limiting conditions (1.1), and other young people with similar conditions, although this was sometimes not possible for young people with extremely rare diseases or very individual needs (1.5).

Speaking to other young people was identified as important for nearly all participants, who reported that they met others mainly because of their connection to a children's hospice or condition specific charity. Some participants accessed online forums to link up with other young people. In particular, participants described asking other young people about treatments and procedures they had received to help them make a decision and to obtain information about other aspects regarding their condition that could only be answered because of their shared experience (1.5).

"I listen to other people with [my condition] ... I have a number of friends with [my condition], I've got three in [my area], so I talk to them quite a lot, because they're all older than me so they have the experience." (y3, age 14)

1 General practitioners (GPs) and social workers were not generally viewed as a source of
2 information because of their lack of specialist knowledge. A few participants reported using
3 their GP for *“a less severe thing, something small, a cough or a cold”* (y13, age 16), and
4 others identified good social workers who had helped to provide information about
5 equipment and other services they could access because of their condition (1.1). Many
6 young people acknowledged that their GP was not expected to have specialist knowledge
7 about their condition (1.2).

8 The internet was identified as an important source of information, although participants did
9 not always seek medical advice online because their needs and condition were so individual
10 (1.2).

11 *“Every disability is different so if you see on Google, people with feeding tubes, people with*
12 *trachees [tracheotomies], and proper wheelchairs with suction and everything, and I’m*
13 *completely different.”* (y1, age 14)

14 For most participants, asking their consultant or other trusted professionals was preferred to
15 using the internet for medical advice and information, although getting advice at the
16 weekend was sometimes difficult (1.2).

17 *“I ask like a professional, most likely, because we’ve been told these are professionals, we*
18 *can trust them, so we put our trust in them and we ask them, what is their advice, what do*
19 *they think is best for us.”* (y13, age 16)

20 Participants also described their efforts to avoid scary or inaccurate information online about
21 their condition, instead utilising official websites, for example NHS direct, or condition
22 specific charities, which were identified as more reliable, although they sometimes lacked
23 the information participants wanted about care and treatment (1.2).

24 *“I wouldn’t always recommend it because sometimes it does give you like big over*
25 *exaggerated information and that sometimes may cause panic.”* (y5, age 17)

26 Participants varied in how much information they wanted to know about their condition and
27 about possible treatments or procedures, and this varied by individual (1.3; 5.4); over time
28 as some young people became more involved in decisions about their care (1.6) – *“when I*
29 *was little I didn’t really care, to be honest”* (y3, age 14); and from decision to decision – *“I*
30 *think it depends on how important things are, or not”* (y5, age 17). Sometimes too much
31 information was seen as intimidating and caused participants to worry about what might
32 happen; for others, not receiving all the information could make them distrust the person
33 providing it (1.3).

34 *“If the doctor isn’t giving you all the information, the doctor’s not being honest. I think that*
35 *they should give you all the information.”* (y3, age 14)

36 Participants agreed that it was important to have time and opportunity to ask questions,
37 which helped them to learn and understand more if they wished (1.4). Some participants
38 were well connected to their care team and had a contact to arrange this for them (1.2).
39 Others asked parents to facilitate this, or would wait for their next planned consultation to
40 ask questions. Participants varied in how confident they felt to ask questions during
41 consultations, with some being actively involved at the time and others preferring to ask later
42 or to listen and then check other information sources to find out more (1.4).

43 *“Sometimes I don’t understand and I ask [gatekeeper to services] to contact the doctors and*
44 *consultants and try to explain it ... in a more easy way to understand ... I’ve become more*
45 *confident since I got diagnosed because I’ve needed to tell people, I need to tell school and I*
46 *need to tell my mates.”* (y14, age 12)

1 Many participants described knowing as much as or more than their parents now that they
2 were older. Some young people felt that their parents did not always know or understand,
3 and reported not asking them for information or advice (1.6).

4 *"You both know like fact stuff but you're the one actually experiencing it. So they can't know
5 what it is, if you know what I mean?"* (y10, age 17)

6 Researcher: *"Do you ever ask your parents stuff?"*

7 Participant: *"No ... I know a lot more than she does ... because obviously I have it."* (y1, age
8 14)

9 For others though, parents continued to be an important source of information and advice
10 and also helped young people to find out information and ask questions when they were
11 unable to find information themselves (1.2; 1.6).

12 *"He [my dad] does make them find the answer. They can't get away with not having the
13 answer because they're supposed to be the professionals ... I'm still learning to be an
14 advocate for myself so I don't really know what I'd do."* (y3, age 14)

15 A.3.3.2 Care planning

16 Participants varied in their understanding of 'care planning', with some young people
17 expressing uncertainty and asking questions about it (2.1). Through group consensus and
18 discussion, participants agreed that care planning is, *"when you arrange what treatment
19 you're going to get and when"* (y14, age 12), and a care plan, *"tells my carers and my
20 nurses, et cetera, about how I want to be looked after, what needs to be done to keep me
21 healthy"* (y3, age 14). Interestingly, no participants talked about advanced or end of life care
22 planning in discussing care plans, despite the use of sensitive prompts from group
23 facilitators (2.5).

24 Some participants explained in detail what their care plan was...

25 *"I have something called a care plan passport and it has like my photo, my name, my date of
26 birth, my condition and then it has like bullet points of who are my doctors and who
27 specialises in what area, who to contact in an emergency, and then it has a plan of what to
28 do in an emergency and what like meds to take and where to go and who to call and that
29 sort of thing."* (y10, age 17)

30 Others reported not having a care plan or not being aware of one and one participant
31 described her uncertainty about what a care plan was in relation to other paperwork (2.1).

32 *"I'm not sure which is care plans and which are other things ... I just know that there's like
33 always some sort of paperwork that needs to be filled in. So I'm not sure whether that's to do
34 with care plans or other things to do with care."* (y6, age 18)

35 Across the sample, care plans were described as being prepared by different organisations
36 and individuals, including community and hospital nurses, care agencies, children's
37 hospices, and sometimes by parents or named carers (2.1). For some young people,
38 parents were the care plan because of the limited involvement of other professionals or
39 carers in a young person's life.

40 *"We don't have carers, there's kind of no doctors really involved with us, we've got about
41 three doctors involved and that's about it."* (y7, age 18)

42 For some participants, care plans were updated regularly or when needed (2.4). For others,
43 care plans were out of date, or several care plans existing containing different information,
44 which meant having to repeatedly explain their care needs to others (2.2).

1 *“Whenever I read it, I just laugh at it because it’s not been updated at all ... I’ve got one at*
2 *the hospice and one at school but they’re completely different as well.” (y2, age 14)*

3 All participants liked the idea of having one care plan that contained, *“everything about you*
4 *in one place”* (y4, age 18). They agreed that care plans should be updated every 6 to 12
5 months, or when there were significant changes (2.4; 5.3).

6 *“I think everyone should have one care plan, because if you’re working from 50...that’s a bit*
7 *extreme, but let’s say 10, if you’re working from 10 different care plans, then which one are*
8 *you supposed to follow?”* (y3, age 14)

9 Care plans were not always used to share information with others (2.2), and participants’
10 opinions varied about who should have access to their care plan (5.4), with some preferring
11 an inclusive approach whereby everyone involved in their life should have a copy (including
12 friends and school staff), and others not wanting to share everything about their personal
13 care, just the important stuff (2.2). Participants in group B agreed that having a summarised
14 version like the ‘care plan passport’ described above would help...

15 *“So in an emergency you don’t have to read through the whole thing to find out a little bit of*
16 *important information, it’s just all there.”* (y10, age 17)

17 All participants wanted to be involved in care planning to ensure that their needs and
18 preferences were included (5.3), although the extent to which this happened and
19 participants’ own preferences for involvement varied across the sample (2.3; 5.4).

20 *“We should be involved with everything because even how someone should look after you*
21 *and what to do, otherwise if you don’t say it they won’t do it.”* (y1, age 14)

22 Many participants strongly emphasised that their condition was only one aspect of their life
23 and although care planning was identified as an important tool to plan care, and record and
24 share information, it was not a central feature of their lives (2.3). Some participants were
25 happy for their doctor or main carer to take responsibility for this, with their input.

26 *“I don’t need information referring to my disability all the time ... I’m involved with the*
27 *updates but halfway through I blank out and play games on the computer.”* (y3, age 14)

28 *“I think the doctor should do it first and bring it to you and see if you’re happy with it all.”*
29 (y14, age 12)

30 Care planning was identified as particularly helpful for managing the disruption caused by
31 new treatments or operations. Planning helped young people to know what was happening
32 and allowed them to plan where possible around school and other events (2.4). However,
33 this did not always happen and could cause young people to feel anxious about what was
34 going to happen and when (2.4; 4.1).

35 *“I’d like to have one [a care plan] when I was having my chemo because I’d know when I*
36 *was going to go in and how long I’d stay in.”* (y14, age 12)

37 *“They don’t really tell us what they’re going to do for care so we’re sent into hospital ... they*
38 *don’t really tell us how long they’ll do it for and what they are going to do ... they should tell*
39 *us what you should do out of hospital to make sure no complications happen.”* (y12, age 12)

40 **A.3.3.3 Place of care**

41 Most participants reported disliking hospital stays and preferred to be at home when
42 possible (3.6; 2.3). All but two participants had regular stays at a children’s hospice, which
43 was seen as having the best bits of home (such as home comforts, good food, *“lots of things*
44 *to do”* (y11, age 18), and flexibility around routines and activities) (3.5), but also good carers

1 who were known to them (3.4); other young people to spend time with (1.5); and in some
2 settings, access to specialist medical staff and equipment (3.2; 5.7).

3 *“The carers are good. They do exactly what you say and they understand what you say”* (y3,
4 age 14)

5 *The showers are accessible for me, whereas I have stayed in hospitals where the toilets are*
6 *way too far for me to walk and the shower is like a bath.”* (y1, age 14)

7 Several young people pointed out, however, that a hospice still wasn't home, which was
8 where participants felt the most relaxed and where equipment and facilities were adapted to
9 their specific needs (3.5; 5.7).

10 *“In a hospice, you have to cater for everyone and maybe everyone isn't you, if that makes*
11 *sense.”* (y3, age 14)

12 Having home comforts and technologies around them and things to do, were important to
13 participants, and this impacted on their experience of staying in hospital or at a hospice
14 (3.5). For example, not being able to speak to friends online or watch videos because of
15 poor wi-fi connection; not having food they would normally eat at home; not having access to
16 gaming equipment or to adapted controllers; having no games to play or things to keep busy
17 with; and not having other young people of a similar age to talk to. Most young people did
18 not watch regular TV and required other technologies with internet connection or satellite TV
19 for their entertainment.

20 *“Bad things about staying in hospital, your friends can't come and see you because there's a*
21 *lot of people who are in isolation ... they do have wi-fi but when I was in isolation ... I didn't*
22 *have a very good signal. It wouldn't work properly.”* (y14, age 12)

23 Despite not wanting to spend time in hospital, most participants explained that sometimes
24 hospital was the preferred place of care because of the specialist medical expertise (3.2),
25 tests, treatments, and medicines available around the clock, which reassured young people
26 when they were unwell (3.1).

27 *“The good things about being in hospital - doctors and nurses are always coming to check*
28 *on you and you know you're in safe hands.”* (y14, age 12)

29 *“At home though, you don't have medical professionals, you can't get much help ... that's*
30 *why people go to hospitals. People don't like going to hospitals but if you need medical help,*
31 *that's the only place you can go.”* (y12, age 12)

32 A few participants explained that going into hospital also eased the pressure on their parents
33 to look after them when they were unwell. For young people with compromised immune
34 systems, hospitals were identified as the preferred place of care because of the sterile
35 environment and isolation areas. Two participants also discussed not being discharged too
36 soon from hospital because of the risk of complications following a procedure (3.1; 3.3).

37 Participants expressed the need to feel safe and looked after when in hospital or at a
38 hospice or other place of care (3.3). For young people, this meant being cared for by
39 'friendly' people who took the time to check on them and help them feel well (3.3; 5.1), and
40 who treated them as an individual and tried to understand their condition and care needs
41 (5.1; 5.4). However, in hospital participants' experiences of care varied (3.6). A few
42 participants described very good care in hospital...

43 *“The doctors are always there for you and they always try their best to help you get through*
44 *everything ... the nurses, they come every half an hour to see if I'm alright ... it makes you*
45 *feel safe and you're in good hands and they know what they're doing.”* (y14, age 12)

1 Other young people described receiving very limited care compared to the care they
2 received at home or in their hospice, and some participants explained that their parents had
3 to stay with them in hospital to provide their care and help them to feel safe and looked after
4 (3.3). Participants also reported being woken during the night for treatments and by other
5 young children; receiving medication at the wrong times; an abrupt and sometimes
6 confrontational manner from doctors; and a lack of understanding about their condition and
7 the pain sometimes caused by treatments from hospital staff (3.3; 5.1; 5.5).

8 *“Obviously I was in a bad state and the doctor was very bad, he was very rude, he said,
9 right, if you’re not going to do this, you’re going to die.”* (y13, age 16)

10 *“Because I’ve got my disability it feels like I can’t really do things myself and I’m scared to
11 ask people I don’t know to do it for me, and sometimes my mum’s not there.”* (y2, age 14)

12 Visiting the same hospital ward for treatment over time enabled young people to get to know
13 the staff, which when staying in hospital or at a hospice was reported to help young people
14 feel relaxed, and reassured them that their care needs would be met without having to
15 explain their condition (3.4).

16 *“It depends on where you go but it depends if you’re going to the same hospital you’re used
17 to or not ... it’s been good that I’ve known the nurses because it feels more friendly rather
18 than just clinical people just looking at you.”* (y5, age 17)

19 Knowing people also gave young people confidence to ask for help if they needed it (3.4).

20 *“Sometimes I’m too shy to tell them but if I know the person, I will tell them.”* (y1, age 14)

21 A.3.3.4 Emotional care

22 Young people described a range of negative feelings that they experienced that were related
23 to having a serious health condition or a disability (4.6). For example, some young people
24 had been bullied at school or felt unsupported at school because of their disability (5.8);
25 others found it difficult to explain their condition to others and as a result bottled feelings up
26 (4.2); others worried about things that they might not be able to do in the future or about
27 what might happen to them in hospital; some young people felt lonely and missed their life at
28 school and their friends when they were receiving treatment; and many young people
29 described negative feelings that were caused by problems associated with the care they
30 received (4.1) or limited information about why they were receiving tests and treatments
31 (5.2).

32 *“I got loads of really bad infections in my ear, they said it could cause meningitis if I don’t
33 have surgery right away, and I was angry, disappointed at the doctors because they’d said
34 your ear’s fine for years ... I had depression over it and cried a lot because I couldn’t hear or
35 anything and the pain was really awful.”* (y2, age 14)

36 *“We have to ask why we are having this biopsy ... but they should tell us why because they
37 need to explain why they’re doing this... if they don’t tell us we’re going to be... worrying, oh,
38 is this going to happen, is this going to happen.”* (y12, age 12)

39 In particular, young people described becoming frustrated, angry, disappointed, scared and
40 feeling or acting mean when nurses or others did not take the time to understand their
41 needs, or when they were not provided with information about what was happening to them
42 (4.1). Having to repeatedly explain about their condition or care needs to different people
43 was also frustrating for young people and sometimes asking for help or having to explain
44 how care should be done made young people feel embarrassed, scared and nervous (4.2).

45 *“They [doctors] might just learn everything about your condition, about even like just home
46 stuff and everything that they need to know to help you, and then all of a sudden you get a*

1 *new one and they don't, so you have to start all over again with telling them about who you*
2 *are.” (y10, age 17)*

3 Young people explained that thinking too much about their condition and how it impacts on
4 their life could make them feel sad and stressed (4.3). For example, two young people
5 described feelings of loss about things they could no longer do, and worried about future
6 deterioration and loss of function.

7 *“Even if I compare myself to when I was younger like, say, my arms like I could lift them right*
8 *into the air, whereas now I can't. So it's like, well, what am I taking for granted now that I*
9 *won't be able to use in the future.” (y5, age 17)*

10 Most participants described their efforts to avoid thinking too much about their future (4.3),
11 instead “getting on with it” and trying to live their lives alongside other young people (2.3).

12 To avoid negative thoughts and overthinking, young people reported a range of distraction
13 and avoidance techniques they used, including reading, art, music, playing computer games,
14 talking to friends and carers, relaxation, and social media (4.3; 4.4).

15 *“When I'm just feeling bored and sad and I want a life, I'd go onto YouTube ... I watch, go on*
16 *Facebook, on YouTube and watch some funny videos.” (y14, age 12)*

17 *“My carer, he makes me laugh a lot ... we get to sit down and talk, have a laugh, make jokes*
18 *out of each other.” (y13, age 16)*

19 A few participants identified going to concerts, meeting celebrities and organising special
20 events or holidays as things that helped them to stop worrying, and be excited about life
21 (4.4). One participant kept a journal to, “*let out my feelings*” at times when other distraction
22 techniques failed to work. Talking things through with someone who really understands was
23 identified as important to many participants (4.5). This varied across the sample and
24 included friends, family, teachers, online forums, other young people with a similar condition,
25 carers and professional support from a psychologist, which for some young people provided
26 an opportunity to share feelings they would not discuss with others.

27 *“It's very useful having friends with the same condition because you can then swap*
28 *notes...Me and [friend] are always like talking to each other about different experiences that*
29 *we've had and, yeah, it's very useful.” (y10, age 17)*

30 *“I like online forums because you can be anonymous ... like if there's something you're not*
31 *comfortable talking about then you can speak to people but anonymously.” (y5, age 17)*

32 Not everyone reported having someone to talk to who understands (4.6), and while some
33 young people believed this would help them other young people were reluctant to seek
34 professional support for emotions (5.4). One young person explained that, “*there's a stigma*
35 *attached around it [therapy] but there shouldn't be*” (y10, age 17).

36 *“I do get upset because with just feeling judged or certain things with certain people, and*
37 *stuff like that ... My friends actually don't know me well enough, well they do know me but*
38 *not the disability, because I never really talk about it ... No-one's helpful. No one*
39 *understands anything.” (y2, age 14)*

40 Others did not want to worry others about their emotions, or to add to their parents' worry
41 and so chose not to talk about their condition and how it made them feel (4.5).

42 *“I think with feelings and emotions it's a lot easier to try and protect them [parents] from that*
43 *because you don't want them to feel guilty or anything.” (y5, age, 17)*

44 Some young people were concerned that other people might talk too much about their future
45 at the wrong time and that this would worry them more (4.5; 5.5).

1 *“Yes, we are in this state, possibly something will happen, but don’t try to scare us in a way*
2 *that we become upset and it pulls us away from trying to listen to you.” (y12, age 12)*

3 A.3.3.5 Improving care provision

4 As well as making suggestions for improvement, participants identified aspects of care that
5 were done well; for example, children’s hospice provision (3.6), having a good carer (5.1),
6 having a psychologist to talk through things with (4.5), and having access to someone who
7 would help to organise their care and provide information (5.2).

8 *“She’s the ward manager and she sorts everything out. If you ask her, she’ll get the doctors*
9 *to come, she’ll phone whoever you want ... she’s just there to help.” (y14, age 12)*

10 *“We call up the clinic because they’ve given us a special number for if anything happens,*
11 *they’ve told us to ask if we need any information, you should ask for it.” (y13, age 16)*

12 Most participants identified at least one improvement they would make if they worked for the
13 NHS, although some of these were about improving support from social workers (5.2),
14 amending the criteria for receiving care from social services to better reflect the needs of
15 children and young people with life-limiting conditions, and broader improvements and
16 information around access for wheelchair users (5.7). A small number of participants
17 reported being satisfied with the care they had received and could not think of how to
18 improve it. Others recommended care they had received to others.

19 *“Here the health system is already good ... It is not good in [country in which he previously*
20 *received care]” (y11, age 18)*

21 *“Get a psychologist to go and see the child, so they can express their feelings and [the*
22 *psychologist] can help them get over it.” (y14, age 12)*

23 Some participants wanted more help and information for finding carers with the right skills,
24 flexibility and attitudes, as having a good carer and continuity of carers enhanced their
25 quality of life (5.1). Some participants also wanted more allocated hours from their carer at
26 home, more stays at their children’s hospice, and for one or two participants to have their
27 carer with them during hospital stays due to their complex and individual care needs (3.3).

28 *“At night in hospital, my parents do have to turn me so usually at home I’d have carers come*
29 *out, but they’re not allowed to go into the hospital, so it would be good if they could come*
30 *into the hospital.” (y3, age 14)*

31 Direct payments could help to facilitate access to good carers; however, participants
32 described carers who were unreliable and inflexible, lacked understanding and expertise,
33 and explained that it was difficult and time consuming to find the right person (4.1). One
34 young person suggested establishing a resource containing details of individual carers that
35 were available so they were able to match carers to their needs (5.2).

36 Participants suggested better training of hospital staff, social workers, GPs and other carers
37 (at home and school) to ensure they have a good understanding about the care needs of
38 children and young people with life-limiting conditions and disabilities, so that young people
39 can access appropriate care from professionals other than their specialist team (5.5).

40 *“I think there needs to be some kind of extra training with them because I do really think that*
41 *they don’t really help as much as they should do. I think that’s why there’s a bit of a problem*
42 *with the health service because in my opinion there’s not much training on the small things*
43 *and the small things end up going to the big people [specialists] and ... the small things are*
44 *clogging those people up.” (y12, age 12)*

1 All participants wanted to be treated as individuals and viewed as a young person rather
2 than someone with a condition or a disability (5.4; 5.5).

3 *"We're just like a tiny handful of people as well, and we have already got so many*
4 *differences that how are they supposed to presume the young people's opinions when*
5 *there's such a massive scale of opinion. (y15, age 17)*

6 Participants wanted to improve the sharing and updating of care plans so that others would
7 know more relevant information about them and how to provide their individual care, thereby
8 easing the pressure on young people to ask for help and reducing their need to explain their
9 condition to others they do not know (5.3; 4.2).

10 Despite the fact that young people varied in the amount of information they wanted, many
11 participants wanted more information to be available, including having all the facts about
12 potential treatments and procedures, including drawbacks as well as benefits (5.2); more
13 information and time to plan episodes of care (5.3); better information about equipment and
14 care at home (5.7); and opportunities to ask questions from their consultant, their social
15 worker, and other people involved in their care (5.2).

16 Participants wanted the right equipment at home and in other places of care, and wanted
17 reductions in the time they had to wait for equipment. For example, having the right
18 wheelchair could greatly enhance quality of life for young people, increasing their mobility
19 and opportunities to socialise and get out and about (5.7).

20 *"I wouldn't be the person that I am today without the right wheelchair because I wouldn't be*
21 *as sociable, I wouldn't get out as much." (y3, age 14)*

22 Finally, participants wanted more support for transition, including help into young adulthood
23 to develop the necessary skills to manage adult services, as they expressed concerns about
24 how to adapt to the new processes, professionals and fragmented care provision. For young
25 people who had already transitioned to adult services, lacking a single point of contact (for
26 example consultant / specialist clinic) was described as a loss. Being accompanied by a
27 known professional from children's services during initial adult appointments was suggested
28 as one way to help young people transition into adult services, so that they were not having
29 to face it alone (5.6).

30 *"They just leave you to do it on your own ... even at the age of 16 they don't know whether*
31 *to class you as a child or an adult so you're stuck between the two." (y8, age 18)*

1 **A.4 Discussion**

2 Five over-arching themes emerged from the consultation, which were interwoven within the
3 data and raised by young people and identified during analysis across the topics of
4 discussion: seeing us as individuals; individual needs and preferences; quality of care;
5 emotional well-being; and living as a young person. These are outlined below, and are
6 followed by a summary of the strengths and limitations of the consultation, and a final
7 acknowledgement to recruiting organisations and study participants.

8 **A.4.1 Seeing us as individuals**

9 This over-arching theme centred on the importance of being seen as an individual person
10 first, rather than the condition or illness being their defining characteristic. The young people
11 emphasised the importance to them of living well with the condition, rather than the focus
12 being on deteriorating health and preparing to die.

13 **A.4.2 Individual needs and preferences**

14 Young peoples' needs and preferences for information and how they wish to be involved in
15 care planning (including preparing and updating care plans) vary. Preferences and needs
16 differ by individual, but can also change over time and vary depending on the specific
17 circumstances. Young people seek information from different sources, and vary in their
18 preferences about how much information they like to receive, from whom and when.
19 Individuals also have different preferences for the amount and type of information they wish
20 to receive about any treatments or operations they may need. Some young people can be
21 overwhelmed if they receive too much information; others require all the available
22 information in order to reach a decision.

23 The young people stressed that it is helpful to have information if they want it and they
24 appreciated opportunities to receive and discuss it, but they did not always want to know
25 everything. Examples they gave of good practice which made them feel better included
26 understanding what will happen to them when they have treatments, tests and procedures,
27 how long they might have to stay in hospital, and how they will be afterwards. They talked
28 about wanting information from reliable, helpful sources, but not wanting 'horror' or
29 inaccurate information. Parents were an important source of information and advice, but the
30 young people themselves also knew a lot as they had 'the lived experience' of their illness or
31 condition. The experience of other young people with similar conditions or who had
32 experienced the same treatments was also an important source of information.

33 The variation in needs and preferences for information and involvement in care planning is
34 not surprising, and is evident in the other patient populations too (Chewning et al., 2012).
35 Seeking preferences from patients about how much information they want to have and their
36 preferred level of involvement in decision making is a key component of the shared decision
37 making model (Coulter and Collins, 2011). Compared to medical paternalism, which
38 minimises the role of patients, and informed choice, which places responsibility for decision
39 making solely with patients, shared decision making is reported to increase satisfaction with
40 care, reduce decisional regret, and improve health outcomes including treatment adherence
41 and improved confidence and coping (Coulter and Collins, 2011).

42 **A.4.3 Quality of care**

43 This theme was around the broad topic of care. Both specialist expertise and continuity of
44 relationships were very important. 'Good carers' (as defined by attitude, sensitivity,
45 understanding and approach) made an enormous difference to quality of life for young
46 people, who expressed a need to increase awareness among health and social care staff

1 and carers about the challenges faced by children and young people with life-limiting
2 conditions and complex healthcare needs. Place of care was not seen as so important as
3 quality of care; although most of the young people preferred being at home or in a hospice
4 unless their medical needs were such that they needed to be in hospital.

5 Young people stressed the importance of feeling safe and looked after, and did not always
6 experience this in hospital. For young people with complex and personalised care needs,
7 this would be improved if parents or carers were allowed to continue their role during
8 hospital stays. Young people thought hospitals could be more aware of their needs,
9 including their technological needs to help them stay connected to their friends during
10 frequent or prolonged stays and, in some situations, their need for parents or carers to be
11 present. Family was important and they stressed the value of having better access to
12 appropriate medical care at home. Other studies also emphasise the importance of being
13 able to access appropriate and timely care at home, and the significant burden placed upon
14 families when this is not available (Hunt et al., 2013; Nicholson, 2013).

15 The young people talked about the value of having one care plan, with different aspects
16 shared across organisations, although they stressed that not every organisation and person
17 needed to see everything. Noticeably none of the young people focused on 'end of life
18 planning' or 'advanced care plans'. The focus was on living the life they had as well as they
19 could, what needed to be done to stay healthy, and managing any disruption that the illness
20 or condition caused as smoothly as possible.

21 **A.4.4 Emotional well-being**

22 The fourth theme was around the topic of better emotional care. The young people stressed
23 that living well and dealing in an emotionally healthy way with their illness or condition,
24 alongside their other developmental tasks, was a real challenge and they valued the
25 provision of a high standard of psychological care. They were critical of patronising or trite
26 approaches in this area.

27 Young people generally are at an enhanced risk of psychosocial problems (Patten and
28 Viner, 2007). There are currently significant concerns about mental health issues in young
29 people and poor provision of appropriate and specialist care (NHS England, 2016). Young
30 people with long-term conditions and complex healthcare needs are identified as a
31 particularly vulnerable group (NHS England, 2016). This is especially pertinent as more
32 young people with life-limiting conditions are living longer into adolescence and young
33 adulthood (Fraser et al 2012), and a recently published study in Scotland, 'Children in
34 Scotland requiring Palliative Care: identifying numbers and needs', strongly recommended
35 that "specialist psychological and emotional care should be available to children and young
36 people and all family members" (Fraser *et al.*, 2015).

37 In the present work, there were unmet needs for emotional care. The young people who had
38 specialist psychological input found it invaluable and recommended it for others, but many
39 did not have such help in place. They felt that they were often coping as best they could on
40 their own, largely using distraction and avoidance techniques to manage difficult feelings
41 and stop themselves from overthinking. Such techniques have a place but they are not
42 optimal coping strategies as they are avoidant rather than positive strategies. Having
43 someone who understands, to talk things through with, and with whom to explore emotional
44 issues and family concerns; and developing optimal ways to help manage the wide range of
45 challenges they could face was seen as important by the young people, but they were
46 sometimes reluctant to seek such help. Integrating specialist psychological input into the
47 care pathway at an early stage may help them to access such help and ensure that they
48 could benefit from this resource, and care pathways for paediatric oncology offer an
49 exemplar of increasingly good practice in this area (Kazak and Noll, 2015).

1 The young people also raised the important role of a peer group, to help address feelings of
2 difference and loneliness and also to help broadly with other aspects of development. This
3 was noted too by Kirk and Pritchard (2011), and Fraser et al., (2015), who recommended
4 that “services caring for children and young people with life-limiting conditions should also
5 find ways to provide opportunities for all family members to connect with and spend time
6 with their peers”.

7 **A.4.5 Living as a young person**

8 The present findings strongly emphasise the importance of a developmental perspective and
9 situating the work in an appropriate developmental context, and young people emphasised
10 the importance of ‘getting on with it’, and the central role of family, friends, school, and social
11 activities and other special events in their lives.

12 There is a well-established literature which looks at biological, psychological and social
13 development and the related developmental tasks and needs of young people, especially in
14 terms of developing their sense of self, their social, sexual and vocational identity (for
15 example, Erikson 1980). There is little research evidence but strong clinical evidence that
16 these developmental tasks are also important for young people with potentially life-
17 shortening conditions and complex disabilities (Beresford, 2004). Achieving them, however,
18 for this population can be a very particular challenge.

19 The present findings are consistent with this wider body of knowledge. Whilst aware of the
20 potentially life limiting nature of their lives, the emphasis of the young people was upon
21 wanting to make the most of the life they have got and living it as fully and richly as possible.
22 Some things were disruptive, and planning for them in order to minimise the disruption was
23 useful. Other things just had to be adapted to whilst they got on with life. Young people did
24 not focus upon end of life and preparing for death. The provision and delivery of
25 developmentally appropriate care is therefore essential. For example, the adult literature has
26 put strong emphasis upon the importance of advance care planning/ end of life care
27 planning (Singer et al., 1999). Professionals working in paediatric palliative care have also
28 emphasised advance care planning (Heckford and Beringer, 2014). However, this has not
29 been identified as a priority with children and young people themselves, nor was it identified
30 as such in the current work. As noted above, the emphasis was upon living well with the
31 condition or illness. This is further supported by the work of Doug et al. (2011), working in
32 the area of transition, stressing that plans should be “life, not illness” plans.

33 With regard to transition, the young people in the present work felt they were being expected
34 to start preparing for transition when they were too young, sometimes from as young as 14
35 years. Some of them felt too young at 15 or 16 years to start thinking about transition into
36 adult services, and stressed the value of support continuing into young adulthood, rather
37 than what they saw as the current emphasis on it starting younger.

38 The young people’s experience of care was enhanced by having a named consultant who
39 knew them and had specialist expertise in their condition; having care provided by people
40 known to them; and having parents who support them in hospital and enable them to access
41 information and care when it is needed. They were concerned that the transition to a more
42 fragmented system of adult services would be accompanied by a loss of these important
43 features, with many young people being left to manage this on their own. This was
44 confirmed by older young people taking part in the consultation who were beginning to make
45 the transition to adult services, and also by the service user reference group of young adults
46 and other research on the topic of transition (Noyes et al., 2014).

47 The young people taking part in the present focus groups argued for extending transition into
48 adult services for all young people with life-shortening conditions (as already happens in
49 some specialties, such as oncology and for some muscular degenerative conditions). This

1 would give time to develop the necessary skills, where appropriate, for interfacing with adult
2 services through greater involvement in personalised care planning and decision-making.

3 **A.4.6 Consultation strengths and limitations**

4 This consultation has been carried out by skilled researchers with experience and expertise
5 in conducting research in paediatric palliative care and in consulting with children and young
6 people. A rigorous and transparent approach to collecting and analysing data, and assuring
7 the quality of the research against appropriate criteria has helped to ensure that the findings
8 presented in this report are dependable, credible and trustworthy.

9 The pre-defined themes selected for exploration and the short timescale for data collection
10 set some limits on the study; restricting the sample size and recruitment strategy for the
11 consultation. As we were not recruiting a large sample and were limited to recruiting through
12 third sector organisations, the consultation focused on ensuring that the sample included a
13 range of experiences and diversity of views and opinion. However, despite best efforts to
14 engage young people to take part, only one participant was not receiving support from a
15 children's hospice, which from other research has been identified as one albeit a central
16 aspect of the care and support that children and their families receive (Kirk and Prichard,
17 2011; Nicholson, 2013). Additionally, the sample was limited to young people who could talk
18 about their experience (we did include several young people with learning and/ or
19 communication difficulties); and only one young person had been recently diagnosed. With
20 more time, we would have liked to recruit additional participants to explore this further,
21 targeting young people with a recent diagnosis and those not being supported by a hospice.
22 The consultation should therefore be interpreted with this in mind.

23 **A.4.7 Acknowledgements**

24 We would like to acknowledge the support of key individuals and organisations that helped
25 us to recruit young people for the consultation and to host and organise focus groups on our
26 behalf. In particular we would like to thank the staff at Martin House Children's Hospice,
27 Richard House Children's Hospice, and Together for Short Lives. Without their support, the
28 consultation would not have been possible. We would also like to acknowledge the work of
29 Sarah Murphy, a psychology graduate, who made detailed field notes during consultations
30 and assisted with data analysis.

31 More importantly, we would like to thank the 19 young people (and their families who
32 transported them to the focus groups) who took part in the consultation. Their commitment to
33 participate in this study and their willingness to share personal views and thoughts about
34 their own experiences of receiving care has enabled us to give young people with life-limiting
35 and life-threatening conditions a voice in the ongoing work to develop a new clinical
36 guideline for end of life care for infants, children and young people in England.
37

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1 **A.6 Supplements to Appendix L**

2 Supplement A: [A.6.1](#) Consultation information leaflet

3 Supplement B: [A.6.2](#) Consultation consent form

4 Supplement C: [A.6.3](#) Consultation group topic guide

5 Supplement D: [A.6.4](#) Summary findings shared with study participants

A.6.1 Supplement A: Consultation information leaflet

On the following pages, the leaflet that was distributed to recruit children and young people to the consultation focus group can be found.

The Consultation Team

Dr Jan Aldridge is an experienced clinical psychologist and researcher at Martin House. As part of her role Jan supports children and young people with life-limiting conditions and their families on a daily basis.

Martin House <http://www.martinhouse.org.uk/>

Lizzie Chambers is Development Director at Together for Short Lives, which is the leading UK charity for children with life-limiting conditions. Lizzie has experience of working with children and young people.

Together for Short Lives <http://www.togetherforshortlives.org.uk/>

Dr Jo Taylor is a research fellow at the University of York. Jo has worked on other research involving children and young people with life-limiting conditions, and has expertise in this area.

For more information

If you would like more information, please text or phone Jo on 07429 169147.

Or email Jo at jo.taylor@york.ac.uk

To learn more about the NICE Consultation, please visit <https://www.nice.org.uk/guidance/indevelopment/gid-cgwave0730>



YOUNG PEOPLE'S CONSULTATION

NICE Consultation: Guidelines for Children and Young People

INFORMATION LEAFLET

Can you help?

We are carrying out a consultation about how to improve care for children and young people with a life-limiting condition.

To take part, young people will attend a consultation group to discuss how children and young people like to be supported.

The information will be used to inform the development of new national guidelines for the care of children and young people.

About the Consultation

This consultation is being carried out for the National Institute for Health and Care Excellence (NICE). The findings will inform new national guidelines for the care of infants, children and young people with life-threatening and life-limiting conditions.

To understand how children and young people would like to be supported, we are running consultation groups with young people. During these consultation groups we will discuss topics including information, communication and care planning.

What will happen if I take part?

If you take part, you will attend ONE consultation group, depending on which is most convenient for you.

[INSERT VENUE DETAILS]

Around 5 to 10 young people between the ages of 12 and 18 (inclusive) will attend each consultation group. All young people who take part will have a life-limiting condition.

The consultation groups will last 1½ to 2 hours and will be run by experienced researchers and clinicians. Refreshments will be available if they are wanted.

You can bring a parent or carer with you. However, they will not take part in the consultation group itself.

If you can't attend a consultation but would like to contribute please contact us to see if we can visit you at home instead.

Do I have to take part?

You do not have to take part. If you decide to take part, you can change your mind at any time. You do not need to give a reason.

What are the drawbacks of taking part?

We may discuss topics that some young people could find upsetting. A member of the Consultation Team can offer support on the day, and afterwards by phone or email if you wish.

What are the benefits of taking part?

There are no direct benefits of taking part. However, you will have an opportunity to influence national guidelines. Doctors, nurses and other care professionals will use these guidelines to improve care for similar children and young people.

Will you tell anyone else what I say?

Only the Consultation Team and other young people attending the group will know your views. Your name and any information that may identify you will NOT be given to others or published in our reports.

How will the information I provide be used?

A report will be produced for NICE. This will include what we find out from the information provided by young people attending our consultation groups. The findings may also be used in other relevant publications.

A.6.2 Supplement B: Consultation consent form

**NICE Consultation:
Guidelines for Children and Young People**

Consent Form for Consultation Group

If you have any questions please contact [INSERT DETAILS]

FOR YOUNG PERSON TO COMPLETE

YES

Do you understand what the project is about and what taking part involves?

Do you understand that you don't have to take part and that you can change your mind at any time without giving a reason?

Do you understand that the information you share will be used to write a report for other people to read and that you will not be identified in this report?

Do you understand that your name and the information you share will not be given to anyone else?

Would you like to take part in the project?

Your name:

FOR PARENT / GUARDIAN TO COMPLETE

YES

Do you understand what the project is about and what taking part involves for your child?

Do you agree for your child to take part in the project?

Name of child

Child's date of birth

Parent/guardian's name:

Parent/guardian's signature:

Home address and postcode:

.....

.....

Home telephone:

Mobile telephone:

Email address:

How would you prefer to be contacted?

Landline Mobile Email

Which consultation group would you like your child to attend?

[INSERT VENUE DETAILS]

My child is unable to take part in a focus group but would like to contribute by taking part in an interview with a researcher at home

A.6.3 Supplement C: Consultation group topic guide

11:00 – 11:10	<p><u>INTRODUCTION</u></p> <p>Introduce facilitators and consultation:</p> <ul style="list-style-type: none"> • Inform new national guidelines to improve care for children and young people (C&YP) with a life-limiting condition. • NICE (National Institute for Health and Care Excellence) is developing these guidelines. They also do guidelines for other conditions. • NICE want to know what areas of care are being done well and what can be improved. • We will cover 5 topics today that NICE want us to talk about: information and communication; care planning; place of care; other support; and improving care. • Any questions?
11:10 – 11:30	<p><u>Information and Communication</u></p> <p><i>NICE would like to know what information C&YP need about their condition and care, and how that information should be provided.</i></p> <p>Group Discussion:</p> <ol style="list-style-type: none"> 1. When you want to know something about your condition or your treatment and care, who do you ask or where do you look for information? <p>You can use the cards on the table to help think about which people you might ask.</p> <p><i>(PROMPTS: good and bad aspects of different sources of information; quality of information)</i></p> <ol style="list-style-type: none"> 2. If you can't get the information you need, what do you do? <p><i>(PROMPTS: ask others?; talk about own experience; what sort of information)</i></p> <p>Group Activity:</p> <p>NICE and previous research has identified different information people may need when they have an illness. Look at these statements and discuss how relevant they are for you.</p> <p>PROMPT QUESTIONS: How useful is it to know this and when might you need it? Have you sought out this information for yourself and why?? Where would you look for this information or who would you ask? How easy has it been for you to find out for yourself? How might you use this information for making decisions about your care or treatment?</p>
11:30 – 11:50	<p><u>Care Planning</u></p> <p><i>NICE would like to know how C&YP would like to be involved in planning their care and who should help them with this.</i></p> <p>Group Discussion:</p> <ol style="list-style-type: none"> 1. What does a care plan mean for you and what is involved? 2. Tell us about your own involvement in planning your care? How could this be improved? <i>(PROMPTS: more involvement / less involvement / more time / being listened to)</i> 3. How often should you update / review your care plan? <i>(PROMPTS: how should this happen / why update?)</i>

	<p>Group Activity:</p> <p>Who would you like to help you plan your care and who should have a copy of your care plan? Use the cards on the table as prompts, and also try and identify other people we have not thought of who might be important to involve in care planning.</p>
11:50 – 12:10	<p><u>Place of Care</u></p> <p><i>NICE would like to know where C&YP would like to receive their care and why.</i></p> <p>Group Activity:</p> <ol style="list-style-type: none"> 1. We have identified home, hospital and hospice as the places where children and young people will spend time when they are unwell or need treatment. Are there other places you might stay? 2. In turn, can you identify three good things and three not so good things about staying at these different places? 3. Is there one place, if you had a choice, you would prefer to be when you are unwell? 4. Finally, is it possible to rank the places we have identified in order of preference? We will use the cards and try and put them in order as a group.
12:10 – 12:30	<p><u>Other Care and Support</u></p> <p><i>NICE would like to know what support would be helpful at times when you might feel upset or worried about your condition and any treatment or care you receive.</i></p> <p>Group Activity:</p> <p>Can you help us understand the range of feelings and emotions that come up for you? These can be about your illness or treatment, about home or school, or about other things in your life. Use the poster on the table to help – which are relevant and why, and which are not? What other feelings might come up? We have some blank cards to draw new ones!</p> <p>Group Discussion:</p> <ol style="list-style-type: none"> 1. When you have negative thoughts or feelings, what helps to make you feel better? 2. Is there anything that sometimes makes you feel worse? 3. If another young person asked for your advice about how to manage negative thoughts or feelings about your illness, what would you tell them to do?

<p>12:30 – 12:50</p>	<p><u>Improving Care</u></p> <p><i>NICE would like to know what areas of care are being ‘done well’ and what could be improved.</i></p> <p>Group Discussion:</p> <ol style="list-style-type: none"> 1. Thinking about everything we have discussed and about the care you receive, what do you think is being done really well? 2. And what do you think needs to be improved? <p>Group Exercise:</p> <p>Finally, imagine you are now running the health service and have to choose three things that would help to improve care for children and young people. You can each choose between 1 and 3 changes you would make or things you would introduce. We will come round and write each one on a post-it note for you, and when everyone has finished we will put them on the wall, and group them by changes that are similar. This is an affinity diagram, and will help us to identify particular aspects of care that need the most improvement.</p>
<p>12:55 – 13:00</p>	<p>CLOSE SESSION</p>

A.6.4 Supplement D: Summary findings shared with study participants

A.6.4.1 Introduction

This report presents findings from a consultation with young people with life-limiting and life-threatening conditions, which aimed to explore the views and experiences of young people on the following topics: information and communication; care planning; place of care; emotional support; and improving care provision.

A.6.4.2 Methods

The consultation comprised qualitative thematic analysis of data collected from three consultation groups (of between two and seven participants) and two individual consultations (a total of 14 young people), carried out in 2015. A topic guide comprising the pre-defined themes was used to help structure the groups, which consisted of discussion points and group exercises using visual cues. Data collection and analysis were informed by a pilot consultation group with five older young people, aged 19 to 24 years, who agreed to act as a service user reference group for the consultation and helped to interpret the study findings.

A.6.4.3 Main findings

Participants of the main consultation included seven males and seven females, ranging in age from 12 to 18 years. Young people taking part had conditions including spinal muscular atrophy, cancer, cystic fibrosis, and other rare degenerative conditions. All participants lived at home with their parent/s, and all but one participant used a children's hospice.

Key findings are grouped below, by consultation topic.

Information and communication

- A young person's consultant was identified as the key source of medical information about their condition. GPs and social worker were not generally viewed as a source of information because of their lack of specialist knowledge.
- The internet was identified as an important source of information, although participants did not always seek medical advice online because of the individual nature of their condition and to avoid scary or inaccurate information.
- Participants varied in relation to how much information they wanted to know about their condition and recommended treatments or tests and this also varied over time.
- For some, having an opportunity to ask questions was important and was reported to help them learn and understand more. Participants varied in how confident they felt to ask questions during consultations.
- Information and advice from other young people with a similar condition was identified as important for participants.
- Many participants described knowing more than their parents now that they were older. Nevertheless, parents continued to be an important source of information and advice for some and helped them to find out information when they had questions.

Care planning

- Participants varied in their understanding of 'care planning' and some reported not having a care plan. Care plans varied across the sample, although in the main participants agreed that a care plan tells others "about how I want to be looked after, what needs to be done to keep me healthy" (y3, male, age 14).
- Care plans were prepared by different organisations and sometimes by parents, as a young person's primary carer. Input from young people was not always included. Care

Appendix L: Supplement D. Draft executive summary

plans were not always used to share information or were not always up to date, which meant young people had to repeatedly explain their care needs to others.

- Participants emphasised that their condition was only one aspect of their life, and although care planning was identified as an important tool to plan future care and share information with others, it was not a central feature of their lives.
- Care planning was helpful for managing the disruption caused by new treatments or operations. Planning for these helped young people to know what was happening, and allowed them to plan where possible around school and other events.

Place of care

- Most participants reported disliking hospital stays, and preferred to be at home if possible, or in a children's hospice, which was seen as having the best bits of home and hospital, but was still not home.
- Participants explained that sometimes hospital was the preferred place of care because of need, the specialist medical expertise, tests, treatments, and medicines available around the clock, which reassured young people when they were unwell.
- Participants expressed the need to feel safe and looked after when in hospital or at a hospice. For young people, this meant being cared for by people who knew them, who take time to care for them and treat them as an individual and understand their condition and needs.
- Knowing the medical staff and carers when staying in hospital or at a hospice was reported to help young people feel relaxed and reassured them that their care needs would be met without having to explain their condition or ask for help.
- Having home comforts and technologies around them was important to participants, and this impacted on their experience of staying in hospital or at a hospice. For example, not being able to speak to friends online or use gaming equipment.

Emotional support

- Some participants expressed feelings of anger, disappointment and distress after receiving poor care, or when care professionals did not take the time to understand their needs or problems.
- Participants expressed frustration at having to keep explaining their condition or their care needs to others. Asking for help or having to explain how a task should be done was, for some young people, embarrassing and scary.
- Some participants tried to avoid thinking too much about their condition and what it means for their lives, for example, future loss of function.
- Participants described a range of distraction and avoidance techniques to avoid feelings such as sadness and frustration, for example music, reading, playing games, speaking to friends.
- Having someone to talk to about emotions who really understands (for example a psychologist) was important to some participants. Not everyone reported having the right person to talk to, some described bottling it all up and some did not want to worry others about their feelings and emotions, including their parents.

Improving care provision

Participants made the following suggestions for improving care provision for children and young people with similar conditions:

- More help for finding carers with the right attitude, skills and flexibility, as having a good carer can enhance quality of life. Participants also wanted more time from carers at home and in hospital, and more time at their children's hospice.

- Information to be available if and when they want or need it, including more information and time to plan episodes of care, better information about equipment and wheelchair access, and opportunities to ask questions when they need to.
- Improve the sharing and recording of relevant information about young people, so that carers and hospital staff know relevant information about the young people they look after and how to provide their individual care.
- To be treated as an individual and viewed as a young person, rather than someone with a condition, illness or disability.
- Better training of hospital staff, social workers and carers (at home and school) to ensure they have a good understanding about the lives of children and young people with life-limiting conditions and people with disabilities.
- Support for transition, including extending the period of transition into young adulthood and help and advice from a known professional to develop the necessary skills to manage adult services, including how to adapt to new processes, professionals and more fragmented care provision.
- The right equipment at home and in other places of care, including reducing the time young people wait for the equipment that they need. Some participants also wanted to improve general access for wheelchairs users.

A.6.4.4 Recommendations for policy and practice

Recommendations for policy and practice are drawn from the study findings and will be further validated through on-going consultation with study participants.

1. Improve training for medical, nursing and care staff in hospitals, and for other carers who support children and young people with life-limiting conditions, to increase understanding about this population and their care needs.
2. Expand access to specialist medical care in the community to enable children and young people to feel safe at home when they are unwell and to manage episodes of illness at home that may otherwise end in a hospital stay.
3. Establish standards for personalized care planning, including having one care plan, aspects of which are shared across organisations, and allowing young people greater ownership about what is included in their care plan and who has access to their information.
4. Work in partnership with young people to plan episodes of care (for example future treatments and surgeries) to help minimise the disruption in young people's lives and ensure that young people know what will happen and when.
5. Ensure that young people's preferences for how much and what type of information they would like are explored when they are planning care or making decisions, and create opportunities for young people to ask questions and obtain other information.
6. Improve hospital stays by introducing appropriate comforts and technologies to help young people feel safe and comfortable and enable them to connect to their friends; and make better use of care plans to familiarise staff with young people's care needs.
7. Integrate psychological care (for example psychologist) into the care pathway at an early stage to reduce any stigma around accessing professional help and ensure all young people can benefit from access to the right person to talk things through with and with whom to explore feelings, concerns and difficulties.
8. Extend the transition into adult services so that young people can continue to benefit from the continuity of relationships and specialist expertise in children's services as they develop skills to manage their care package and negotiate adult services.