

# An Options Appraisal for obtaining feedback on the experiences of children and young people with cancer

Final Report to NHS England

Word of Mouth Research and Point of Care Foundation

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Contact: [adam.crosier@womresearch.org.uk](mailto:adam.crosier@womresearch.org.uk)

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## 1. About this report

This is a report of a study to explore different methods of obtaining feedback relating to the experiences of children and young people with cancer.

## 2. Background

NHS England commissioned this study to address a recommendation, 'to develop a methodology to collect patient experience data for under 16s': recommendation no 54 in the national cancer strategy, 'Achieving world-class cancer outcomes: A strategy for England 2015-2020'. The study sought to help NHS England to understand how feedback can best be captured to understand how current services are meeting the needs of children and young people with cancer.

## 3. Study objectives

The broad aim of the study was to identify and assess different methods currently used by NHS cancer treatment services to capture the experiences of children and young people with cancer, and to explore the views of professionals and children and young people and their parents/carers about how to improve the collection and use of patient experience information.

Detailed objectives were as follows:

- Exploration and evaluation of a range of different approaches to capturing the experiences of children and young people with cancer
- Evaluation of the suitability of the different feedback approaches for different age ranges of children and young people
- Evaluation of feedback methods for capturing parent and carer experiences
- Assessment of the extent to which the data produced by each of the different feedback approaches will meet the data needs of stakeholders across the health system, including evaluation of the different potential uses of the data for each feedback approach e.g. national metrics, local service improvement
- Evaluation of the usefulness for the health system of the data collected for 16-24 year olds through the [National Cancer Patient Experience Survey](#) (NCPES)
- Consideration of the appropriateness of the topic areas covered by the adult NCPES for children and young people
- To identify good practice relating to the capture and use of feedback on the experience of children and young people across healthcare, at local, national and international levels

## 4. Methodology

The study involved three main elements: a review of literature from the health and social care sectors from the past 10 years, including published peer reviewed articles and so called 'grey literature', interviews with health professionals working with children and young people with cancer, professionals concerned with healthcare and social policy and the use of patient or service user experience, and interviews with children and young people who had experience of cancer and their parents and carers.

The fieldwork was conducted between November 2017 and April 2018, and interviews with professionals and children and young people took place in Leeds, Birmingham and London. Interviews with both professionals and young people were conducted in person (face to face) and by telephone.

## 5. Findings

A summary of key findings from the literature review and interviews/focus groups with both professionals and children and young people are reported below. Following the summary findings is a table of the feedback approaches identified during the course of this study. The supporting evidence that informs the findings is contained in the annexes at the end of this report (see Annex 1 for the literature review; Annex 2 for the professionals' report; and Annex 3 for the children and young people's report).

### 5.1 Literature review

A literature review was conducted to identify approaches and methods used to collect patient experience information among children and young people with cancer. The review was concerned with understanding the types and uses of various research methods to explore patient experience.

#### Key findings

The main types of study identified from the review were as follows:

- reviews of existing research, cross sectional surveys of children and young people with cancer (typically small numbers) and secondary analysis of longitudinal surveys of children and young people in hospital settings where cancer was a sub-set (mainly US based studies), mixed method studies, involving qualitative (mainly group discussions) and survey research and qualitative research, including a range of activity based (e.g. puppet and play, storytelling/making and draw and tell) methods for younger children.
- the uses to which the research was put included exploring the experience of children and young people's pathway to diagnosis, reasons for delays in diagnosis, failure to correctly interpret signs and symptoms, and the complexity of factors that lead to delays in both diagnosis and treatment.
- the role of emerging digital technologies (including benefits in treatment and support and patient experience research) for children and young people with cancer.
- methods to identify better ways of engaging with children and young people with cancer to improve patient experience research in this area. Engagement was identified as being important, achievable and beneficial to developing research instruments for patient experience, and more likely to increase participation rates. Some authors commented on the difficulty of engaging with the patient group, poor levels of response to surveys and high attrition rates. For quantitative research, shorter surveys were better for children with cancer.

Some research methods were found to be better than others at eliciting children's experiences (e.g. of enduring discomfort) and at identifying important lessons, including young children's inability to voice preferences, and older children's dislike of parents leading communication with health professionals.

## 5.2 Interviews and focus groups with professionals

A total of 35 professionals were interviewed as part of this study. Respondents included paediatric oncologists, nursing staff, service managers, play specialists, social and youth workers in NHS children and young people's cancer treatment services, research/data managers (also in CYP cancer services), staff responsible for the adult NCPES, respondents with methodological expertise from market research companies, staff working for charities supporting children and young people with cancer and NHS staff responsible for the children's patient experience programme. The professionals were interviewed in three focus groups (London, Leeds and Birmingham) and individually in person and by telephone.

### Key findings

#### 5.2.1 Patient experience is central to CYP's cancer services

- Understanding and responding to patient experience was identified as being integral to the functioning of services for children and young people with cancer. The quality of life of patients receiving treatment was ranked as equally as important as the tasks of saving lives and treating cancers with the most effective medicines. For children with a terminal diagnosis, understanding and responding to the patient's experience of care was just as vital as patients without a terminal diagnosis.
- Staff in children's cancer services reported that patient experience information is more valued than in other areas of healthcare, and that children and young people's cancer services are very patient centred as a result. This was felt to be due to the additional investment of resources in this area, made possible in many cases by the involvement of charitable funding (CLIC Sargent, Teenage Cancer Trust and Macmillan were the main sponsors identified).
- Patient experience information has a range of purposes: to inform everyday activities of staff to enable them to respond to the needs of patients in 'real time', to inform planners and service managers periodically about how to improve the services and make them more responsive to the needs of patients, and to enable an independent assessment of the quality of services.
- Asked what staff need from patient experience information, most reported that they want to know 'what is working well', 'what is not working well' and 'what is not known'.

#### 5.2.2 Acknowledgement of the need for better patient experience information

- Respondents reported that at present there was a lack of a national, systematic and consistent method of collecting patient experience information. This was acknowledged to be a current failing and gap to be addressed. Respondents also acknowledged disappointing findings from national surveys (both the NCPES and [the CQC Children and Young People's Inpatient and Day Case survey](#)) that identified significant shortcomings in care.
- There was a strong desire for a standardised, national and age appropriate feedback mechanism that can be used to both identify strengths and weaknesses of services and to provide quality assurance. Views on how this should be done varied. Most respondents felt that no single method was capable of providing a solution. They argued instead for a mix of both qualitative and quantitative approaches.

- Existing national surveys and feedback tools were considered ineffective and inappropriate to the needs of children and young people with cancer. The Family and Friends Test (FFT) was felt to be designed for an acute and single event, and the single quantifiable question was described as inappropriate and insulting by many, for children with cancer. The FFT feedback tool was not liked and not well used by most respondents, who felt it offered few insights into how cancer services for children and young people could be improved. Few respondents were aware of the CQC Children and Young People's Inpatient and Day Case survey. Local surveys, designed, administered and analysed by clinical staff or staff working in patient experience, were used in all services, but it was felt that these could benefit from greater research expertise, particularly in the data collection and analysis and interpretation stages.

### 5.2.3 Support for a national survey of children and young people with cancer

- Several respondents felt very strongly that there was a need for a national survey of children and young people with cancer, (in effect an extension of the adult NCPES to a younger age group). They argued that the absence of this was 'ageist' against the interests of children and gave the impression that the NHS did not take seriously the rights of children in their care and treatment. Several respondents cited the UN Convention on the Rights of the Child article 12, regarding children's rights to have a voice about the care they receive, and argued that under the current arrangements, these rights were not being respected.
- There were well documented methodological difficulties expressed over how such a survey could be delivered, especially by those with survey methodological expertise and experience of conducting surveys of children and young people in healthcare settings. Key issues included the (thankfully) relatively small number of children with cancer, the problems associated with low response rates to surveys among this age group, and the problem of analysis at small level (e.g. Principal Treatment Centre) that if published would risk identification of respondents. Despite this, many respondents felt that with creative thought and careful planning, such concerns could be overcome, and that regardless of the challenges, the NHS should be collecting information from children and young people in a standardised and systematic manner.
- Respondents felt that any new survey should be developed in consultation with children and young people, as well as NHS staff. Initial views as to domains for investigation were communication, respect and dignity, being treated with kindness and compassion, having the opportunity to ask questions, having access to key workers and feeling comfortable in a suitable physical environment. A small number of respondents mentioned the National Voices, 'I Statements' and suggested these would be valuable as a basis for exploring patient experience among this group. There was agreement that any survey should consider the possibility of different iterations for older and younger children, and that questions should be ordered in such a way as to capture the most important information in the first few questions as few children will be willing to complete a long survey.
- Respondents emphasised the importance of developing a method or range of methods that could capture the whole 'cancer journey', and not just provide a 'snapshot' at one point in time. Several respondents commented on the need to reflect the lives of children and not just what was important to the health service. This included experience of health care at home and in the community, experience of school and college and of home and social life.

#### 5.2.4 Qualitative methods (including social media)

- Frontline staff in cancer treatment services currently use a very wide range of age appropriate qualitative methods to engage with children in order to understand their experiences of care. These range from observation of pre/non-verbal children, the use of parents and other advocates including specialist healthcare providers for young children, creative play with young children to 'trigger' discussion, informal groups discussions, formal research groups and interviews, surveys, video-based techniques and the use of social media.
- There were concerns, recognised by NHS service providers, about the representativeness and potential for the lack of inclusion of various approaches to collecting patient experience. Where possible this was addressed through making efforts to use accessible methods including translation and interpreting services for non-English speakers and non-written (drawing/art based) methods for younger children and patients who do not speak English.
- Social media were felt to offer exciting opportunities for capturing patient experience information from children and young people with cancer. However, at present this method has not been exploited fully due to a number of concerns, including a lack of training and skills in how to use these media. Respondents reported worries about safeguarding online and some negative experiences. Effective use of social media for improving the patient experience dialogue with children and young people will require protocols/rules for engagement, proper training of staff and resourcing, management and coordination. In addition to maintaining NHS-owned accounts, some respondents argued that services should be passively 'scanning' the private social media accounts of parents and children on a periodic basis, as these were places service users would report most honestly their views and experiences. There was a call for NHS England to provide training, support and guidance on how to better use social media for improving patient experience information.

#### 5.2.5 Values and principles that underpin patient experience research

- Asked about values and principles that inform (and should inform) the collection of patient experience information, most respondents identified the following: being clear about why they would ask questions, about what would be done with the information, and that the service should communicate to the patients and their families what had been done (or not) as a result of having received this information.

#### 5.2.6 How patient experience information is used and reported

- Mechanisms for reporting patient experience information in order to effect change were variable across treatment centres, and also varied according to the nature of the information obtained. Several frontline respondents reported that they typically informed service managers of key insights obtained from qualitative interactions with patients and families, in order to improve service provision. More formal research findings, including survey information, were typically shared across relevant sites and settings, with small teams of service managers and/or senior nursing staff determining how to respond. In most instances, respondents reported that services took seriously the need to demonstrate to service users that they valued the information provided, and made efforts to report back to patients and families both what had been said, and what the service was doing as a result. This took a range of forms including 'You Said, We Did' boards, 'Graffiti Walls' and 'Tops and Pants' displays.
- A small number of respondents discussed the role of financial incentives and management processes that were used to encourage the recording of certain forms of patient experience



information. These included payments for hospital attendance avoidance, and the use of IR1 and IR2 forms (poor and good practice forms).

#### 5.2.7 The limited role of independent bodies and routine data

- There was very little mention by professionals of the role of Healthwatch, PALS, Care Opinion, NHS Choices or any other independent organisation whose role is to collect and record patient experience. When asked directly about these organisations, most respondents felt they were important, but in practice they appeared not to currently be very present in the working of most staff in this area.
- Similarly, routine data were not mentioned spontaneously as sources of patient experience information. When asked directly, respondents who were aware of the different sources felt that most did not include the kinds of measures that would be valuable for this patient group.

#### 5.2.8 Views on NHS England and its role in coordinating patient experience information

- NHS England's reputation as a 'command and demand' organisation was considered a potential barrier to the effective establishment of a national method for collecting patient experience information. It was felt that NHS England should communicate its desire to support and facilitate services in this venture, and that branding, promotion and administration of research tools should be undertaken by services, with NHS England being responsible for analysis and reporting.
- Respondents felt that NHS England had an important role to play in general in this area, in terms of supporting and enabling services to improve their collection and use of patient experience information. This included providing training and guidance in the area of local surveys, and on the management and use of social media in particular and generally in terms of sharing of good practice, through special events, publications and via existing professional networks.

### 5.3 Interviews and focus groups with CYP with cancer and their parents/carers

The recruitment of children and young people with cancer was a significant challenge for this study. Despite the support from CLIC Sargent and three Principal Treatment Centres and careful planning to ensure that times/dates of proposed groups were convenient to school aged children, very few children and young people volunteered to participate. After much effort, a total of 13 children and young people engaged with the study. The parents/carers of three children (the youngest group aged under 10) were also interviewed. Two small group discussions were held in Leeds (with children under 10) and Birmingham (with children aged 13-17). The remainder of the interviews were conducted by telephone, which proved to be a very valuable and rich source of information. Respondents ranged in age from 7 to 17 years. There was a wide range of types of cancer reported and of duration of treatment, ranging from only a few days in hospital to many months and repeat episodes. Telephone respondents were recruited via staff at Birmingham Children's Hospital and lived predominantly in the West Midlands region and Wales.

#### Key findings

##### 5.3.1 Challenges to conducting patient experience research with CYP with cancer

- Based solely on this study, recruitment of young people with experience of cancer may be more challenging than imagined. This fact should be considered in the design of any methodology for collecting patient experience information. The use of telephone interviews was found to be the most effective method for this study, following several abortive and disappointing efforts at

recruiting groups both in person and online. This study found that small financial incentives (£5-£10 per person) may be effective in encouraging completion of a survey and larger sums (£20-£25 per person) for participation in qualitative research.

### 5.3.2 Views on the collection and use of patient experience information

- The study found overwhelming support for the collection and use of patient experience information to improve the care and treatment of children and young people with cancer.
- Respondents were keen that the voices of young people should be heard and used to inform both the delivery of care and treatment to individuals questioned AND that this information should be used to improve the design, planning and delivery of services for others.
- Respondents felt that a mixed method approach to collecting patient experience information would be preferable. All suggestions for how this should be done involved both qualitative (group discussion or one-to-one interviews) and survey methods.
- All except one of the teenage respondents reported that their personal preference would be to be interviewed either face to face or in a group discussion, as this would enable more information to be collected, and to hear others' experiences that may trigger thoughts and memories that would be of benefit. The one person who did not agree with this reported that she would not have been able to contribute to a discussion group or interview while on treatment because she had felt too ill to participate. Surprisingly, no respondents volunteered a telephone interview as a preferred method, but this approach should be considered given the success of this method in this study.
- Several respondents said that it would be important that any qualitative interviewing of this type should be conducted by an independent person, not connected with the hospital or NHS. There was a fear that anyone connected with the NHS would not be impartial, and young people may feel intimidated or reluctant to be completely honest about their experiences. Some respondents reported the potential for possible repercussions of saying something negative to those providing care.

### 5.3.3 Views on a national survey of children and young people with cancer

- While respondents felt that it was important for local services to collect information about the experiences of patients they treated through a series of regular qualitative approaches (group discussions and/or individual interviews with children and young people with cancer), all respondents agreed that a survey was an important additional research method that should be used. All felt that the survey approach was the most democratic of methods, giving all patients the opportunity to respond, in contrast to qualitative methods which would only involve some patients.
- Based on this small study, age appropriate survey methods, including adjustments to survey instruments (e.g. use of child friendly language and the use of symbols rather than words or numbers for scoring/rating for example), would be required to ensure younger children are able to contribute meaningfully. Similarly, the range of question areas may need to be restricted for younger children to immediate (non-abstract) aspects of care and treatment such that the time frame for questions would need to be focused on the 'here and now' rather than days and weeks in the past.
- Older respondents (from age 12/13 upwards) demonstrated the ability to participate fully in the collection of patient experience information. Many of the themes and questions used on the adult NCPES would be appropriate for children aged 12 and over.
- There were several suggestions about WHEN would be best to collect information from respondents. All agreed that qualitative research should be undertaken some time after the start

of treatment, so that responses could report on both the experience of diagnosis and treatment. However, one suggested it should be done periodically (once every few months) during treatment, another suggested 'about half way through' treatment, so that there would be an opportunity for the hospital to make adjustments in response to the patient experience information provided. Others suggested it should be collected towards or at the end of treatment.

#### 5.3.4 Views on the content and administration of a national survey

- All respondents felt that a survey should include open ended (free text) question(s) to enable respondents to elaborate responses to closed questions.
- There was agreement among all respondents aged 13 and over that the following themes/question areas, (many of which are used on the adult NCPES) should be asked of children and young people:
  - ✓ whether they felt they were treated with respect
  - ✓ views on the quality of communication with medical and other staff
  - ✓ views on the friendliness of staff
  - ✓ whether they felt fully informed about the care and treatment, including side effects of medications
  - ✓ whether they were fully involved in decision making
  - ✓ whether the environment was clean and hygienic

In addition, the following were identified by respondents as additional themes to include on a child and young person's cancer survey (in no particular order of importance):

- ✓ whether young people felt they were treated as an autonomous and independent person, or whether medical staff spoke about them (with parents etc. or other healthcare professionals) rather than to them
- ✓ whether young people were able to see family and friends whenever they wanted
- ✓ whether there were other children/young people of a similar age on the ward/unit (and opportunities for socialising and making friends)
- ✓ whether there were adequate facilities to alleviate the boredom/tedium of being on treatment, including electronic gaming/devices and Wi-Fi etc. as well as DVDs/books and traditional games
- ✓ views on the school hospital service and on the support provided by the hospital with education more broadly (including working with respondents' schools to address uninformed 'teasing' and bullying related to cancer)
- ✓ views on the quality of food provided
- ✓ whether there was sufficient privacy (including noise)
- ✓ whether they were able to regulate the temperature of their room/environment
- There was a range of responses to the question about how respondents would like to receive and complete a survey. Based on the findings from this study, a method that enables respondents to reply by either postal questionnaire or online would be required. In addition, there was a reported preference for online invitations to be sent via email rather than text or a social media application.

#### 5.3.5 Summary of reported experiences by respondents

- In addition to asking about views and preferences regarding how patient experience feedback methods should be conducted with children and young people with cancer, the study asked about respondents' own experiences. While most respondents reported that their experience of

the NHS had been generally positive, several reported elements that were not positive and that could have been improved. These included for one respondent not being permitted to be treated at a hospital of her/her parents' choice, not being fully informed about side effects of treatments, the quality of food, the school hospital service and matters concerning privacy, opportunities for social relationships with children of a similar age, and environmental/comfort factors including control of temperature in hospital, the quality of pillows/bedding materials.










- An important finding was that for several respondents, the presumption that young people would want to have control in relation to the decision making about their treatment and care, was in fact, not a significant concern. These respondents explained that the reality of the cancer for them, was such that they were happy to entrust the decision making to their parents and the medical staff, and that they were, in any case, simply not well enough to engage with these matters. Similarly, some respondents reported that their recollection of time spent 'on treatment' was very hazy, as they had chosen to seek medication that had enabled them to sleep through much of the treatment, because the alternative would have been a very painful and unpleasant prospect.

#### 5.4 Options appraisal: summary of feedback approaches






The tables that follow provide information on the various feedback approaches identified by this study. Most of these methods were identified through interviews with professionals, although some examples of 'play and talk' activities and of the 'inspection' approaches were reported more extensively in the research literature.

Each group of feedback approaches reflects different purposes and address different stakeholders' interests in patient experience information. The 'routine' activities (purple) are designed to inform 'real time' or 'in the moment' service provision. 'Inspections' (in yellow) and 'interviews with service users' (blue) are designed to inform service managers working within NHS trusts about how to develop and improve services and may be conducted at regular intervals, often weeks or months. 'Social media and feedback apps' (grey), 'passive feedback' (green) and 'third party feedback' (red), are all methods that provide feedback to service managers and NHS Trusts on a more or less constant basis, but that can be reviewed periodically. Some of the 'survey/quantitative methods' (in beige) are also designed to inform service managers and front line staff about how to improve service provision.








#### 5.4.1 Routine (everyday) real time activities







Method	Description	Level of reporting	Frequency 	 Strengths	 Weaknesses
<b>Play and talk</b>  <b>AGE: 3/4 to Teens</b>	Activity-based 'play and talk' techniques designed to be age appropriate and development stage appropriate. Includes baking/cooking clubs, play, art (drawing, construction, painting and talking) writing and story-telling. Provides opportunity to talk about concerns while engaged in a fun/pleasurable activity.		Continuous	Vital techniques that are used to assess 'in the moment' experiences of children and young people. Particularly valuable for eliciting information from younger children.	Excellent for learning and responding to immediate needs, but not designed to assess patient experiences over a longer period.
<b>Professional observation</b>  <b>AGE: 0 to 6</b>	Active assessment of patient wellbeing by trained professionals (clinical staff and allied health professionals) to assess comfort/pain etc. especially among young and non-verbal patients.		Continuous	Important means of assessing very basic experiences (pain/discomfort etc.) among non-verbal and younger children.	Excellent for learning and responding to immediate needs, but not designed to assess patient experiences over a longer period. Limited range of experiences collected.
<b>'Open door' methods</b>  <b>AGE: All</b>	The senior member of staff communicates that s/he is available to discuss any matter of concern to patients or their families. Examples include 'Speak with Sister'.		Continuous	A very basic means of ensuring staff make themselves available to learn of patient experiences.	Excellent for learning and responding to immediate needs, but not designed to assess patient experiences over a longer period.

#### 5.4.2 Inspections of services by children and young people

Method	Description	Level of reporting	Frequency	 Strengths	 Weaknesses
<b>Inspection, 'journey mapping' and 'mystery shopping'</b>    including NHS England's '15 steps' approach to assessing services    <b>AGE: 7+</b>	<p>Young people inspect and assess a ward or department using a structured assessment tool. May include interviews with staff and patients. An immersive assessment that is designed to assess the 'feel' of a ward or department from a young person's point of view. Should include features that include the look and smell of the environment, whether the physical surroundings are welcoming, as well as whether staff are friendly and welcoming.</p> <p>May include assessment of issues of concern to children and young people with cancer: quality of food, privacy and noise, opportunities for socialising, games and activities to alleviate boredom, visiting times for family and friends etc. May also include observations about whether there are methods available for reporting patient experience, and whether these are displayed (such as 'You Said, We Did' boards).</p>		Every 3-6 months	<p>The 15 Steps is a structured approach, developed and tested by NHS England.</p> <p>Simple and easy to implement.</p> <p>Offers clear opportunities to address both physical and cultural (human) factors that impact patient experience.</p>	Relies on motivation of service managers to organise and implement, and to take action as a result of findings.







### 5.4.3 Interviews with patients and parents/carers






Method	Description	Level of reporting	Frequency 	 Strengths	 Weaknesses
<b>Formal group discussions</b>    <b>AGE: 7+ but grouped by meaningful age bands</b>	<p>Focus group discussions, to explore views and needs of young people who use the service. May focus on specific themes or plans, or may be unstructured and open time for feedback.</p> <p>Children and young people expressed a range of views about WHEN focus group discussions should be carried out. Should be after the start of treatment, to cover diagnosis experience and treatment. Some recommended every couple of months, others at the end of treatment and some time after the end of treatment.</p>		Every 3-6 months	<p>Excellent method to explore patients' experiences in depth. Will identify unknown areas of concern. Respondents can 'trigger' thoughts and memories that can be elaborated.</p> <p>Important that groups are conducted by independent researchers wherever possible. Respondents will not be critical of staff or services if they fear their treatment may be compromised as a result</p>	<p>Only a small number of people will be able to take part. Their views may not be representative of the whole patient population. Some young people may find the group dynamic intimidating, some may be too ill to feel able to participate.</p>
<b>Informal group discussions</b> 'Chomp n Chat', 'Pizza Club' and outings  	<p>Similar to a formal groups, but involves more observation by staff of informal conversations. Young people relax over a meal and are prompted to discuss issues relevant to the service.</p>		Every 3-6 months	<p>A relaxed atmosphere and informal setting help to encourage sharing of information that may not be discussed in a more formal setting.</p>	<p>Requires careful reflection by staff immediately after the event, as it is not possible to record responses in the moment. Important to communicate to participants the fact that their views are being</p>








AGE: 7+					sought.
<b>Narratives and depth interviews</b>  AGE 7+	One to one interviews with children and young people, conducted in person or by phone. An alternative to group discussions.		Every 3-6 months	Some young people will find talking easier one to one than in groups, especially where there are sensitive issues.	More labour intensive than group discussions.
<b>Video based techniques</b>  AGE: 7+	A range of approaches involving video testimony, including 'video booths' on hospital wards to record the experiences of children and young people.		Continuous	Video records of patients' experiences can be more emotionally engaging than the written word.  Video testimony is valuable for helping new patients and parents to know what to expect from the hospital/ward.	Involves costs for purchase and maintenance of equipment and production of edited videos.
<b>Coffee mornings</b> (for parents and carers) 	Informal (but usually scheduled) opportunities for parents/carers to discuss views and concerns with service managers and senior staff.		Every 1-2 months	An important means for service managers to hear views of parent/carer group. Can be used by service managers to explore themes and issues of concern, or to allow respondents to raise their own concerns – or both.	Risk of the same people attending regularly, and not reflecting the experiences of a broad group.



#### 5.4.4 Survey/quantitative methods and feedback tools









Method	Description	Level of reporting	Frequency 	 Strengths	 Weaknesses
<b>NHS Friends and Family Test</b> 	<p>NHS feedback tool to collect quantitative and qualitative feedback on care or treatment from healthcare services, designed to be a real time feedback tool rather than a comparable feedback tool, involves the following question, 'We would like you to think about your recent experience of our service. How likely are you to recommend to friends and family if they needed similar care or treatment?' And an open question.</p> <p>The following two child friendly versions of the FFT are currently available.</p> <p>'I would say this is a good service for my friends and family to be looked after in if they needed similar treatment or care to me' (5 or 6 response options).</p> <p>Would you tell your friends that this is a good hospital to come to? (4 response options).</p>	 	Continuous collection with monthly national reporting.	One of very few methods to provide opportunity for all NHS service users to report their experiences.	Not valued by children's cancer healthcare professionals. Inappropriate wording of question and not well suited to complex and chronic conditions like many cancers. Age and condition specific data is not nationally reported but could be collected at local level.

<b>CQC Children and Young People's Inpatient and Day Case survey</b>  	A professionally managed survey, run by the CQC that surveys patient experiences of children and young people to age 15.	 	Biennial	Enables assessments of individual trusts' performances. May be used as a monitoring tool to drive improvements.	Not well known among children's cancer healthcare professionals because it does not focus on cancer services or report cancer specific data due to small numbers.
<b>Local surveys of Children and Young People with Cancer</b>  	Ad hoc surveys conducted by Principal Treatment Centres.		Once per 2-3 years	Usually developed by staff in cancer treatment services. As a result question areas usually cover issues of direct relevance to staff in services.	Requires research expertise as well as resources to administer and analyse which are not always readily available.

	<b>Recommendation: New national survey of Children and Young People with Cancer</b>				
<b>Method</b>	<b>Description</b>	<b>Level of reporting</b>	<b>Frequency</b> 	 <b>Strengths</b>	 <b>Weaknesses</b>
 <b>AGE 7 to 16+ with separate questionnaires for parents/carers as advocates for children 0 to 7</b>	<p>Survey content to be developed with children and young people. This study indicates that while some question areas included in the adult NCPES would be appropriate for young people aged 12+, additional areas specific to children and young people should also be considered. Some adjustments to wording and use of response symbols would be needed for younger respondents (aged 7 to 12). Consideration should be given to the most important items being placed at the start of the survey.</p> <p>For children under 7, the questions may be asked as part of play/activities and recorded by parents/carers or advocates but care needs to be taken not to introduce bias into the results which would impact on the quality of the data for comparison</p>	 	<p>Annual/Biennial (frequency will depend on available sample size e.g. to achieve a sufficient sample size, data may need to be used over more than one year)</p>	<p>Young people considered a survey to be the most inclusive and democratic method of obtaining patient experience feedback.</p> <p>Such a survey would be capable of providing comparisons between NHS settings as well as identifying local achievements and areas for improvement, assuming robust methods are used. However, consideration would need to be given to how best to engage younger children to ensure that bias is not introduced into the results. Professionals are strongly supportive of a national survey of</p>	<p>With around 1,600 cancer diagnoses per year among children and young people, the number of people for potential inclusion in a national survey is small. Depending on response rates there is a risk that data cannot be published or would need to be published at a very high level in order to comply with data protection rules to ensure confidentiality. Careful assessment of whether this concern can be addressed will be required and if so, what impact that might have on the data. For example, it may be possible to combine one or more years of patient data to create a large enough sample but this would mean that some of those included in the survey may have received</p>










	<p>purposes.</p> <p>Survey should be administered by post, by phone, online (via email/text and via social media platforms). Professional respondents favoured branding and administration by the PTC. Collected data to be sent to NHS England to undertake analysis and reporting at national and local levels.</p> <p>Small incentive (£5-£10) may increase response rate.</p>			<p>children and young people with cancer.</p> <p>Branding, administration and analysis of the survey requires close collaboration between PTCs and NHS England. Guidance by NHS England will be required to address data protection and confidentiality concerns.</p>	<p>treatment some time ago. There may be consequent concerns about recall and relevance. NHS England will need to collaborate further with PTCs and Shared Care services to consider the sampling methodology.</p>
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#### 5.4.5 Social media and feedback apps






Method	Description	Level of reporting	Frequency 	 Strengths	 Weaknesses
<b>Social media and Feedback Apps</b>     <b>AGE: 13+</b>	<p>Involves NHS owned or managed accounts that invite disclosure and discussion about patient experiences from young people and families. Social media tools enable staff to learn of needs and to respond accordingly. NHS monitoring of 'private' content of service users and of user forums, to learn what patients and parents/families think and feel about services.</p> <p>Social media tools represent an emerging and important opportunity for collecting and engaging with patient experience. Currently, NHS cancer services lack a clear strategy for how to develop and exploit these technologies.</p> <p>Apps invite feedback on service provision. May be embedded on NHS Trust website and/or made available as a stand-alone app.</p> <p>A clear role exists for NHS England to assist services with developing strategies, identifying 'boundaries and rules' and training of staff.</p>		Continuous	<p>Social media tools are widely used and easily accessible. Information posted on social media pages and sites is likely to be detailed, honest and unfiltered in a way that is like no other feedback method.</p> <p>Patients and families can share information to learn what to expect from services without the intervention of the NHS.</p> <p>Apps have potential to act as either a direct feedback method, or to open up a conversation with staff and others. Staff can use the information to learn what is being done well and where improvements are</p>	<p>Requires trained staff to review content on a regular basis and to moderate and manage content of NHS social media accounts.</p> <p>To be used by CYP these tools require access to smart phones or tablets. This may be a concern regarding accessibility for some groups and ages. There are also considerations about privacy and data protection relating to social media.</p> <p>There is potential for social media to inflame inaccurate and unproven allegations against NHS staff and services. Examples exist of NHS social media accounts being shut down due to misleading and inaccurate posts alleging misconduct and negligence by bereaved families. As with all social media, there is a risk that the</p>

				required.	content is driven by more vocal participants and is not representative of most people's experiences.
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#### 5.4.6 'Passive feedback': comments cards, books, letters and complaints

Method	Description	Level of reporting	Frequency 	 Strengths	 Weaknesses
<b>Comments cards on wards</b>  <b>AGE: All</b>	Comments cards are made available to all Can be used for young children to draw rather than write. Given to staff, or posted in box for staff to review and respond.		Continuous	Simple to implement and easy and cheap to analyse.	Some children and young people will not want to use the method or to draw attention to themselves. Requires ability to organise thoughts and feelings. Some patients will be too unwell to complete cards.
<b>Comments books on wards</b>  <b>AGE: All</b>	Comments books are made available on the ward for patients and families to use.		Continuous	Important tool for some patients who want to thank staff. May be helpful to new patients to see positive comments from previous patients. Helpful for staff morale.	Tend to be used only to report positive comments.
<b>Letters of complaint to NHS Trusts and independent agencies</b> 	<p>Written letters (and emails) of complaint sent to hospital staff, including management.</p> <p>Written letters (and emails/online posts) of complaint sent to organisations such as the CQC, Healthwatch, Care Opinion.</p>		Continuous	Provide information about serious areas of concern to individual patients and families.	Very few patients or families write letters of complaint. Not a good indicator of patient experience overall.

#### 5.4.7 Third party feedback

Method	Description	Level of reporting	Frequency 	 Strengths	 Weaknesses
<b>Third party feedback</b> 	<p>Seeking feedback from advocates, third parties, including healthcare professionals, community advocates and parents/family members.</p> <p>Methods may include many of the approaches described above (e.g. groups, interviews, surveys, telephone calls). The key is actively seeking the feedback.</p>		Continuous	Third parties may have important information about patient groups and individuals that can be used to inform service design and how to respond to patient needs.	Third parties may have a partial or special interest. They may sometimes unwittingly misrepresent the needs and interests of the patient.



## 5.5 Comment on the feedback approaches

The study found that all of the methods identified above (with the exception of the national survey of course) were used to some extent by professionals interviewed. However, an important finding was that many of these methods were used only occasionally, and often relied on the motivation of a single individual to make them happen. Furthermore, there were often limitations in some aspect of the process (mainly due to the availability of methodological skills), be it in the design of the study, flawed/inappropriate questions, problems with the collection of data, delays in the analysis and reporting or the interpretation of information, all of which meant that patient experience information was frequently not used to best advantage.

The study found two desired purposes for a new national survey of children and young people with cancer: to provide standardised information about services and also to provide the opportunity to compare the views and experiences of children and young people between services. However, there are well documented concerns about the feasibility of such a survey which need to be explored fully before a survey is commissioned. The table on page 27 sets out some of the initial key considerations. Following initial feasibility considerations, any such survey would require appropriate developmental research and piloting to ensure its viability. However, despite the concerns, all respondents to this study supported the development of such a survey, regardless of potential limitations imposed by the main concern, which was the (thankfully) small numbers of children and young people with cancer.

## 6. Recommendations

### 6.1 NHS England should promote the full range of feedback approaches

As the tables in this report demonstrate, there is a wide range of possible feedback approaches each with their own strengths and weaknesses, providing data for different purposes. NHS England should promote the full range of feedback approaches described in this study and highlight the different purposes they serve. In doing so, as the policy holder for the Friends and Family Test, NHS England should seek to address the related weaknesses identified in this study such as the inappropriateness of the wording of the FFT for children with cancer.

Promotion of the feedback approaches identified would enable NHS England to better understand the performance of NHS cancer treatment services for children and young people, and ensure that opportunities for local service improvement are maximised. Notably, only one of the approaches identified above has the potential to provide robust comparable data for benchmarking across PTCs (a national survey). NHS England should clearly communicate the different uses of the data collected through the different approaches and provide training, guidance and support where necessary, to ensure that information gleaned from these approaches is used to inform service development and practice.

### 6.2 NHS England should explore the feasibility of a new national survey through development and testing

NHS England should consider the commissioning of a new national survey of the patient experience of children and young people with cancer. This should be developed by NHS England in consultation with professionals working in children's cancer treatment services and children and young people with cancer and tested appropriately, with piloting, to ensure it is administered effectively. A key consideration in the frequency of the survey will be the assurance that the achieved number of respondents is sufficient to allow for meaningful analysis and not compromise patient data. It should be understood that there will be compromises over the quality of the data should the number of respondents not be sufficient. For example, it may only be possible to provide national level data and where PTC level data can be produced, confidence in the reliability for comparison purposes may be affected. Some of the question areas used on the adult NCPES would also be appropriate for this survey. However, consideration of survey length and modification according to age group would need to be taken into account. Additional question areas for the children's survey should also be considered. The developmental work and piloting should assess the feasibility of administration of the survey via as many routes as possible (online, postal, within services) to encourage a high response rate. It should also assess the feasibility of making small financial incentives to encourage participation. NHS England and survey providers will need to assure themselves of concerns relating to data protection and confidentiality. Analysis of data will need to be reported in line with other patient experience surveys and at a level which supports patient confidentiality. As part of the developmental work, NHS England should consult with stakeholders over the option of a 'core' standardised survey with the flexibility for providers to adapt sections to local areas and/or type of cancer. A key concern will be the avoidance of identification of individual

respondents. None of the potential risks identified should be a reason for not further exploring the feasibility of a survey and developing and testing an approach piloting this methodology.

### 6.3 NHS England should extend any new survey to young children, to be completed by parents/carers or advocates.

For young children who may not be able to complete the survey (i.e. those aged under 7 and those who are not able to complete a survey without assistance), NHS England should assess the feasibility (and pilot where necessary) approaches that rely on a third party (parents/carers and advocates including healthcare professionals and allied professionals) to ask questions and record the information on behalf of the child or young person. This may be done through more qualitative approaches, including during play activities.

### 6.4 Considerations arising from the recommendations

The study found that both professionals and children and young people with cancer were in favour of a standardised survey about cancer experience. Below are a series of questions for NHS England to consider in taking forward this recommendation, with suggested answers and considerations.

<b>QUESTION</b> <b>What did the professionals and children and young people who participated in this study want the feedback approach to provide?</b>	<b>ANSWER/CONSIDERATION</b> <b>How will this work practically?</b>
Separate age appropriate child questionnaires as well as for parents/carers as advocates for younger children	How many different questionnaires should be used? Testing is required to ensure the questionnaires are age appropriate. It is important to note that separate age appropriate questionnaires, while necessary, will mean that small numbers are likely to make reporting of results difficult.
Question areas that are appropriate for children and young people. Adjustments to wording and use of response symbols needed for younger respondents (aged 7 to 12)	Will question areas cover the whole cancer patient experience, home/hospital, treatment phase or focus on a snapshot at one point in time? Development work required to ensure that questionnaires include questions that are important to children and young people. Consideration will need to be given as to which questions will be comparable across the different age ranges.
Consideration to length of survey, with most salient questions placed at the beginning	Testing will be required to help determine questionnaire length. It might not be possible to cover all of the topics requested. There will need to be a balance between length to encourage response and meeting stakeholder requests.
Consideration to method of administration of survey (post, phone, online – email, text, social media platforms)	The feasibility of each method will need to be considered. Will a social media policy need to be put in place? It may not be possible to obtain mobile numbers and email addresses etc.? Data protection concerns? Will children need to have

	access to a smart phone? Having to borrow from a parent may create privacy concerns? Testing required?
Different suggestions for timing of administration – after start of treatment, half way through, end of treatment	Will the best timing depend on what the survey covers? Is it different for different cancers? Testing required? Maybe pilot different options?
Branding and administration by the Principal Treatment Centres (PTC)	What support should NHS England provide? Considerations around data protection and confidentiality? Consideration around resource in PTCs e.g. printing and postage costs? Need to be clear with respondents who the survey is from and who has access to their data.
Collected data sent to NHS England/third party on behalf of NHS England to undertake analysis and reporting at national and local levels	How will the PTC and NHS England best work together to achieve this?
Small incentive (£5-10) to increase response rate	How feasible is this? Would it work?
Comparable data; suggestion to maximise sample size by using an appropriate sampling period for a standardised national survey	What are the potential challenges of using a lengthy sampling period? Recall bias for patients who may have received care some time ago? Relevance of findings two years on from care received?
Data that can be used for local service improvement (standardised survey with the flexibility for providers to adapt it to local area by adding their own questions)	What about risk of identification at a local level?

## **Annex 1 – A rapid review of literature on patient experience among children and young people with cancer**

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## Summary

Studies included in the review were mainly, but not exclusively, of children and young people with cancer. Some studies drawn from other areas of healthcare and some from other policy areas.

The findings were assessed in relation to methods used to elicit patient experience information, and key findings from studies.

Overall, the main purposes (aims and objectives) of studies were as follows:

- to document the experience of children and young people with cancer, in order to identify areas for improvement
- to describe the experiences of children and young people with cancer, with a specific focus on their use of cancer treatment services
- to develop new and improved methods for conducting patient experience surveys among children and young people with cancer
- to describe the use of non-survey research methods for capturing patient experience information among children and young people with cancer.

The main research approaches reported included the following:

- Reviews of the research literature/evidence in relation to key research questions (including how to best conduct patient experience research among children and young people with cancer, and the value of age appropriate cancer services).
- Cross sectional surveys of children and young people with cancer. Here the main finding was that such surveys tended to be small in size, to involve patients drawn from cancer treatment services, to involve a range of methods of administration and to include open ended (free text) questions that were analysed separately using thematic analysis methods.
- Mixed method studies (including surveys, analysis of 'free text' questions using content analysis, and separately focus groups and surveys) that were used to develop and test new patient experience survey measures.
- Qualitative research methods. Here a range of approaches were identified, including the use of puppet and play, drawing and writing, workshops, group discussions and online focus groups. There were fewer reports of qualitative methods compared with surveys and quantitative research methods. Qualitative methods were more often discussed in terms of age appropriateness.

Findings from the studies. These were broadly reported under the following headings:

- The pathway to diagnosis, reasons for delay, failure to correctly interpret signs and symptoms, complexity of factors that lead to delays.
- Digital technologies important for children and young people with cancer that can have benefits in treatment and support.
- Engagement of children and young people with cancer. Engagement was identified as being important, achievable and beneficial to developing research instruments for patient experience, and more likely to increase participation rates. A number of authors commented on the difficulty of engaging with the patient group, poor levels of response to surveys and high attrition rates. A key finding was that shorter surveys are better for children with cancer.
- Some research methods were found to be better than others at eliciting children's experiences (e.g. of enduring discomfort) and identify important lessons – young children's inability to voice preferences, older children's dislike of parents leading communication with health professionals.

## 1. Purpose of review

This review of published and unpublished literature was conducted as part of a larger study to explore how best to collect patient experience information among children and young people with cancer. The overall study aimed to provide NHS England with an 'Options Appraisal' of different methods for national guidance.

The aim of this review was to identify approaches and methods used to collect patient experience information among this group. The scope of the review included the collection of patient experience from other areas of healthcare for young people, in addition to cancer services, and also from other public policy areas, with a focus on social care. It was hoped that by extending the scope of the review beyond cancer treatment services for children and young people, it may be possible to identify relevant approaches that could be adapted for use in cancer treatment services.

## 2. Methodology

This was not a systematic literature review. It did however, include elements of a systematic review, including a pre-defined search strategy, with identified search terms, inclusion criteria based on the date of publication, sources (databases) searched and a structured method for reviewing the information included. A detailed strategy for the how the search was conducted is provided as an appendix to the review.

Key search areas included feedback from children and young people with cancer, feedback from children and young people with other conditions and feedback from children and young people from other public services.

The search covered the period 2007 to 2017 and was undertaken by the King's Fund's Information Service.

## 3. Findings

A total of 81 papers or reports were identified. Each of these were reviewed and assessed and the findings compiled under the following headings

Method involved:

- Review
- Survey
- Mixed method
- Qualitative/other

Also reviewed were the purpose (aims and objectives) and key findings. These are included within the review where relevant.

### 3.1 Methods of assessing patient experience

The focus of the review for the present study was the different research methods used to elicit patient experience information among children and young people with cancer. The studies identified were grouped into four distinct areas, as follows:

- Reviews of literature/evidence to assess patient experience among children and young people with cancer
- Surveys (and secondary analysis of surveys) of children and young people with cancer (and without)
- Combination of focus group and survey research to develop and test new survey instruments
- Qualitative methods

#### 3.1.1 Reviews of evidence to assess patient experience among children and young people with cancer

A small number of studies identified in the literature were review level studies involving an assessment of approaches to the collection of patient experience among children and young people, or reviews of the evidence on a specific question (such as the value of age specific treatment services for children and young people with cancer).

Robertson et al 2014 reviewed a range of methods to collect patient experience among children and young people in the design and delivery and improvement of care. The methods for involving individuals and families include questionnaires and innovative ideas such as feedback Apps. Other methods include the 15 Steps Challenge which helps an organisation to view the care it delivers through a patient's eyes and includes a 'walk around' involving a patient, carer, staff member and board member. The Experience Based Design approach is another method of reviewing a service and involves assessing how staff and patients feel when delivering and receiving care. Involving patient groups can be facilitated by working with schools and children's centres. The type of involvement will vary, but if carefully designed can allow meaningful participation and improvement of services.

Taylor et al 2013 conducted a systematic review of the literature to explore the association between specialist cancer care and quality of life for young people with cancer. Nine common themes were identified: psychosocial function, importance of peers, experience of healthcare, importance of support, impact of symptoms, striving for normality, impact of diagnosis, positive experiences, and financial consequences.

Marris et al 2011 conducted a systematic review of literature 1996-2008 to assess the value of age appropriate care for teenagers and young adults with cancer. They reported that the recent literature describes that teenage and young adult cancer patients have specific care needs, and gain benefits from an age-appropriate environment of care, including peer group support, age-appropriate information, recreational and vocational support, and staff expert in both the cancer and care of their age group.



### 3.1.2 Surveys (or secondary analysis of surveys) of children and young people with (and without) cancer

The most frequently reported method for conducting patient experience research involved surveys of children and young people with cancer identified in the literature tended to be relatively small in size (range N=102 to 301). Surveys tended to have been conducted online, or by using paper and pen or a combination, and to have included free text that was analysed using thematic analysis. Age ranges tended to be 8 years and above for self-completion and by parents for children aged 0-7 years. Also included in this section are surveys of CYP with other conditions (of which cancer may be a sub-category) and secondary analysis of larger (not cancer specific) surveys of CYP.

CQC 2014 and Picker 2016 reported on the National Children and Young People's Inpatient and Day Case survey (NHS) first conducted in 2014 and again in 2017. This is not a cancer specific survey and involves CYP aged 8-15 and parents and cares of CYP aged 0-15.

Furness et al 2017 undertook a review of existing National Cancer Patient Experience Survey (NCPES) data among TYA (Teenagers and Young Adults). The aim of the study was to understand the current cancer patient experience for this patient group. Findings highlighted that a prolonged pathway to diagnosis remains an issue for the TYA group and identifies areas on which quality improvement measures for TYA services should focus, including communication and involvement of the patient in treatment decisions. Positive experiences for the TYA group such as involvement in research were also highlighted.

Sizmur et al 2015 conducted secondary analysis of the NHS Friends and Family Test (FFT) to assess influence of age, sex and mode of administration of the survey. This was not limited to cancer patients. They concluded that FFT is vulnerable to bias from demographic factors and mode of administration – comparisons between organisations should be avoided.

Abrol et al 2017 conducted a cross sectional survey of 102 cancer treatment service users (teens and young adults TYAs) in the UK to explore the potential for digital technologies and support within cancer treatment services.

Taylor et al 2016 described their experience of using a confidentiality waiver (Section 251) in the National Health Service (NHS) Act to increase participation in NCPES among 16-24 year olds. The authors describe how they used a confidentiality waiver to identify and recruit potential research participants to a cohort study and consider its use in a wider research context. The method was implemented in 98 trusts; 75 supplied patient details.

Taylor et al 2015 reported early work undertaken to develop and validate a descriptive patient experience survey for AYA (Adolescents and Young Adults) with cancer that encompasses both their cancer experience and age-related issues. They aimed to develop, with young people, an experience survey meaningful and relevant to AYA to be used in a longitudinal cohort study (BRIGHTLIGHT), ensuring high levels of acceptability to maximise study retention.

Smith et al 2013 reported a study that involved secondary analysis of AYA HOPE study (N=523 AYA patients with cancer aged 15-39) vs healthy groups.

Klassen et al 2015 sought to develop and test a validated short survey questionnaire (Give Youth a Voice 56) on patient experience among children with cancer. Qualitative interviews were conducted

with 38 childhood cancer survivors. GYV-56 data were collected from 200 paediatric cancer patients and survivors.

Phillips et al 2010 aimed to develop Patient Reported Outcome Measures (PROM) using fewer questions among adult outpatients who were long term childhood cancer survivors – from 16 to 3 item questionnaire.

Wray et al 2017 sought to develop and test patient-reported experience measures (PREMs) for children and young people in paediatric settings.

Jones et al 2017 reported on a cross sectional survey with free text responses analysed using a thematic approach (N=301 across 11 European countries).

Schepers 2017 conducted a cross sectional survey online among CYP and parents in outpatient paediatric cancer care. N=205. Age groups 0-7 conducted by parents, 8-18 self-completion.

Wolfe et al 2014 undertook a trial (N=51 and N=53) where feedback was collected from CYP or parents aged 2+ with advanced cancer, and fed back to providers and families (and not)

Phillips et al 2010 undertook a survey to reduce a 16 item Patient Satisfaction with Communication questionnaire to a 3 item questionnaire. N=93 respondents at outpatient adult cancer clinic.

Waters 2016 used the POET survey of practitioners, CYP and parents/carers: N=2,989 responses (1879 from parents/carers and 906 from CYP with EHCPs).

### 3.1.3 Mixed method studies: survey and qualitative research

Several studies involved the use of a combination of qualitative and survey research. Most frequently, the purpose was to develop a new or a better (shorter, more accessible) survey or to test and validate items on patient experience surveys. Included also in this category are surveys that included open or free text question(s) that were analysed using qualitative techniques (content analysis).

Taylor et al 2015 reported on a multi-method study to develop and test a new survey design with AYAs with cancer (13-25). Involved focus group research with young people, parents and siblings, followed by convenience survey (N=23). Total of 238 questions. BRIGHTLIGHT survey.

Doukkali et al 2013 conducted a survey (N=59) of 11-22 year olds interviewed by telephone (RR 55%) analysed using qualitative content analysis. The aim was to assess the impact of childhood cancer on survivors' lives.

Klaassen et al 2015 used qualitative research among 38 childhood cancer survivors and 200 survey respondents to develop a new PE survey (GYV-56).

Rosenberg et al 2016 conducted semi structured interviews and paper and online survey with AYAs at two large hospitals (N=47).

Zabreck et al 2014 analysed open ended survey item among (N=296) AYA with cancer.

Farjou et al 2014 conducted a survey that included several open-ended questions to learn about the following: (1) what teenagers liked about the cancer care they received; (2) what they disliked about the cancer care received; and (3) what they would include if they could design the perfect cancer

centre for teenagers. The survey was completed by 200 teenagers (aged 12-20 years) from three paediatric hospitals in Canada.

Wray et al 2017 used focus groups and survey testing to develop a PREMs survey for CYP in specialist hospital setting. (N=543) 8-16 year olds with cancer attending out and inpatient services.

### 3.1.4 Qualitative and age specific research methods

This group of studies included reports of the use of puppet and play, drawing and writing, narrative interviews focus groups, online focus groups and one day workshops. Qualitative methods were designed to be age-appropriate (puppet and play for younger groups (4-5 years), drawing and writing for slightly older and groups/interviews for 12/13 plus. Samples tended to be small and drawn from treatment centres. Areas for investigation included 'Appreciative Inquiry (AI)' about cancer services, with a focus on family, friends, school, environment, also 'an ideal service' model.

#### Puppet and Play, Drawing and Writing

Gibson et al 2010 aimed to assess whether children's cancer services meet children's needs, using play and puppets, draw and write and interviews and activities day. They reported that little is known about whether children's cancer services actually meet children's needs, as the majority of previous research has sought the views of parents as proxies. Thirty-eight participants at different stages of the cancer journey (e.g. on treatment, near end of treatment, up to 18 months following treatment) were grouped for data collection by age: young children (4-5 years), older children (6-12 years) and young people (13-19 years). Data were collected concurrently over 6 months using age-appropriate, participatory-based techniques. Techniques included play and puppets, the draw and write method, interviews and an activities day. Some findings confirmed previously reported issues, such as, young children's inability to voice their preferences, and the importance of familiar environments and parental support for all ages. New findings suggested children worry about the permanence of symptoms, and older children are unhappy about their parents leading communications with health professionals. The authors proposed a conceptual model of communication roles of patients, their parents, and health professionals to illuminate communication patterns. The model suggests children (aged 4-12 years) reside in the background of information sharing with health professionals until they gain autonomy as young people (around age 13). They then move into the foreground, and their parents transition into a supportive background role. Reviewing this model may help younger children realise their abilities to voice their preferences and older children to move into the foreground.

Gibson et al 2013 undertook a series of narrative interviews with 24 young people aged 16-24, 2-4 months from the diagnosis of a solid tumour, to explore pre-diagnosis cancer experience in young people. The main themes, which included a group narrative concerning perspectives of delay, included the impact on an individual's everyday life by symptoms; the role that significant others in young peoples' lives played in the interpretation of symptom significance; the negotiation of entry into, and experiences of, generalist health care; entry into specialist care; and the threshold points that exemplified when events shifted and a diagnosis was eventually obtained.

Horstman et al 2008 explored the potential of draw and write technique for children with cancer – exploration of the method. The authors explored the issues for the child and researcher of using the draw and write technique as a participatory research methodology. Reflections on the technique are

drawn from experience of using it with children aged 6 to 12 years. This was part of a larger study undertaken to enable children aged 4 to 18 years with a diagnosis of cancer to give their views about hospital care. The participating children's verbal and artistic contributions illustrate how children are able to convey their opinions when there is an enabling climate created.

Angstrom-Brannstrom et al 2014 used analysis of drawings to investigate how children, aged 3 to 9 years, undergoing cancer treatment describe their experience of comfort. Data were content analysed and four themes were constructed--enduring discomfort, expressing discomfort, finding comfort, and comforting others.

Johnson et al 2012 reported on the use of drawing techniques to document oncology treatment.

Aldiss et al 2009 explored young children's (aged 4-5) experiences and views of cancer services, using play and puppets. The study involved interviews conducted with 10 children aged four and five years old. The themes elicited reveal important aspects of hospital care for young children, such as having 'lots of toys' available and that 'mummy and daddy are near'. The use of play and puppets as a data-collection method is discussed, along with the implications of findings for the care and support of young children who have cancer.

Burns-Nader 2017 examined children's anxieties of healthcare experiences through drawings. Fifty children, either experiencing a doctor's appointment or hospitalization, completed a drawing of a person in the hospital. Drawings were scored on individual items which were summed for a total score of projected anxiety. The drawings of hospitalised children displayed significantly more anxiety than that of the children attending a doctor's appointment.

#### Observation and 'walk arounds'

Thomas et al 2015 reported on the '15 Steps Challenge' that involved a ward 'walk around' to see the ward through the eyes of children and young people and parents/carers. The aim is to improve service delivery, and was developed in the light of the Mid Staffs failings.

#### Workshops

CLIC Sargent 2010 developed a method for working with 7-13 year old cancer survivors to identify needs and how service provision can be developed to meet these needs. The research model for this project was developed by a group of professionals working in the field of child health and research. An appreciative inquiry (AI) model was used throughout the study to identify the needs of young cancer survivors. Fundamental to this approach is the desire to discover 'what works well' and 'what could work better'. Children were invited to contribute through key questions relating to home and family life, school and friendships. They were also asked to express what was important to them and what others need to know about children living with and beyond cancer.

Fern et al 2013 explored whether benefits exist from specialist age appropriate care for teenagers and young adults with cancer. Using participatory research, 11 young people aged 13 to 25 years at diagnosis, participated in a 1-day workshop consisting of semi-structured peer-to-peer interviews. Eight core themes emerged: impact of cancer diagnosis, information provision, place of care, role of health professionals, coping, peers, psychological support, and life after cancer.

#### Online focus groups

Tates et al 2009 explored the potential of online focus groups within paediatric oncology. Online discussion groups were held with 7 paediatric cancer patients (aged 8-17), 11 parents, and 18 survivors of childhood cancer (aged 8-17 at diagnosis). All three participant groups could be actively

engaged over a one-week period. Respondents highly valued the flexibility and convenience of logging in at their own time and place to join the discussion. Adolescent patients and survivors emphasized that the anonymity experienced made them feel comfortable to express their views in detail. The findings indicate a 'strong preference' for online group discussions across all participant groups.

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### **British Nursing Index (BNI)**

The BNI is a database of journal articles, most of which come from 250 UK nursing and midwifery titles with only a small number coming from non-UK specialist journals. The articles date from 1994, with abstracts included from 2004 onwards, and cover areas such as accident & emergency nursing, breast cancer, evidence based practice, learning disabilities, midwifery, nurse practitioners, orthopaedic nursing, perinatal & neonatal mortality, psychiatric nursing, reflective practice, student nurses, theatre nursing, and wounds.

### **CINAHL (Cumulative Index to Nursing and Allied Health Literature)**

CINAHL aims to provide information for all allied health professionals by offering complete coverage of English-language nursing journals and publications from the National League for Nursing and the American Nurses' Association. As well as journal articles some books, book chapters, dissertations, and conference proceedings are offered. The database goes back to 1982 and also offers some technology journals, as well as articles on consumer health, health promotion, and legal issues within health care.

### **HMIC**

This database combines resources from the Library and Information Services of both the Department of Health and The King's Fund.

- **The Department of Health Library and Information Services database:**  
With a focus on the NHS and health service quality, and including data from 1983 onwards, the DH database covers areas within health service policy, management and administration. It also holds information on planning, design, construction, and maintenance of health service buildings, as well as occupational health, control and regulation of medicines, medical equipment and supplies, and social care and personal social services.
- **The King's Fund Information and Knowledge Services database:**  
Also with a UK focus, this database covers health management and services, social care, service development, and NHS organisation and administration. Resources include journal articles, books, reports, and pamphlets and cover the years from 1979 onwards.

### **PsycINFO**

Focused on the interdisciplinary aspects of the worldwide behavioural and social science research and literature, PsycINFO is a resource for locating scholarly research findings in psychology and related fields across a host of academic disciplines.

### **PubMed**

Covering clinical medicine, biomedical sciences, nursing, dentistry, preclinical sciences and health-care systems, PubMed has over 20 million citations from scholarly journals dating back to 1950. Citations are provided from MEDLINE, life science journals and online books, and links to full-text articles are provided where possible.

### **Social Care Online**

Provided by the Social Care Institute for Excellence (SCIE), Social Care Online makes use of journal articles, web sites, research reviews, government documents and legislation, and service user knowledge in order to provide information on all aspects of social care. Its content dates back to 1960 and is widely used by academics, researchers, information professionals, practitioners, service users and carers, social care managers, policy makers, and students.

## **Search strategies**

### **PubMed**

Title/Abstract: (adolescents or young people or teenagers or young adults or children) and (patient experience or views or satisfaction or patient survey\*) and cancer

MeSH: (surveys & questionnaires OR personal narratives as topic OR interviews as topic OR focus groups OR qualitative research OR Community-based participatory research OR research design) and MeSH: (adolescent OR child OR young adult) and MeSH (no explosion): neoplasms AND MeSH: (patient satisfaction OR patient preference)

MeSH: (adolescent OR child OR young adult) AND MeSH (no explosion): neoplasms AND MeSH (major term): (patient satisfaction OR patient preference)

MeSH (major terms): (adolescent OR child OR young adult) AND MeSH: (surveys & questionnaires OR personal narratives as topic OR interviews as topic OR focus groups OR qualitative research OR Community-based participatory research OR research design)

### **The King's Fund and DH Data [Department of Health library database]**

su: (children or young people or young adults) and su: (patient views or patient experience or patient satisfaction or patient surveys) and su: cancer

su: (children or young people or young adults) and su: (patient views or patient experience or patient satisfaction or patient surveys)

### **BNI**

Subject: cancer/children AND ((subject: consumer satisfaction OR Patients: attitudes and perceptions) OR (Title/Abstract: (patient experience OR patient views)))

Subject: (children or young people) AND Subject: research OR (Title/Abstract: (patient experience OR patient views))

Title: (adolescents or young people or teenagers or young adults or children) and Title: (patient experience or views or satisfaction or patient survey\* OR feedback)

### **CINAHL**

Title/Abstract: (adolescents or young people or teenagers or young adults or children) and Title: (patient experience or views or satisfaction or patient survey\* OR feedback) AND Title/Abstract: cancer

### **PsycINFO**

Title: (adolescents or young people or teenagers or young adults or children) and Title: (patient experience or views or satisfaction or patient survey\* OR feedback) AND Title/Abstract: (survey method\* OR measur\*)

### **Social Care Online**

Subject: (children OR young people OR young adults) AND Subject: user views AND Subject: research methods

## **Annex 2 – Report of research with professionals: Patient experience among children and young people with cancer**

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## Summary

- Understanding and responding to patient experience was identified as being integral to the functioning of services for children and young people with cancer. The quality of life of patients receiving treatment was ranked as equally as important as the tasks of saving lives and treating cancers with the most effective medicines. For children with a terminal diagnosis, understanding and responding to the patient's experience of care was just as vital as for other patients.
- Staff in children's cancer services reported that patient experience information is more valued than in other areas of healthcare, and that children and young people's cancer services are very patient centred as a result. This was felt to be due to the additional investment of resources in this area, made possible in many cases by the involvement of charitable funding.
- Patient experience information has a range of purposes: to inform everyday activities of staff to enable them to respond to the needs of patients in 'real time', to inform planners and service managers periodically about how to improve the services and make them more responsive to the needs of patients, and to enable an independent assessment of the quality of services.
- Asked what staff need from patient experience information, most reported that they want to know 'what is working well', 'what is not working well' and 'what is not known'.
- However, at present the lack of a national, systematic and consistent method of collecting patient experience information was acknowledged to be a failing and gap to be addressed. Respondents acknowledged disappointing findings from national surveys (both the adult National Cancer Patient Experience Survey (NCPES) and the Children and Young People's Inpatient and Day Case survey) that identified significant shortcomings in care provided by NHS staff.
- There was a strong desire for a standardised, national and age appropriate feedback mechanism that can be used to both identify strengths and weaknesses of services and to provide quality assurance. Views on how this should be done varied. Most respondents felt that no single method was capable of providing a solution. They argued instead for a mix of both qualitative and quantitative approaches.
- Existing national surveys were considered ineffective and inappropriate to the needs of children and young people with cancer. The Family and Friends Test (FFT) was felt to be designed for an acute and single event, and the single quantifiable question was described as inappropriate and insulting by many, for children with cancer. Local surveys, designed, administered and analysed by clinical staff or staff working in patient experience, were used in all services, but it was felt that these could benefit from research expertise, particularly in the data collection and analysis and interpretation stages.
- Several respondents felt very strongly that there was a need for a national survey of children and young people with cancer, (in effect an extension of the adult NCPES to a younger age group). They argued that the absence of this was 'ageist' against the interests of children and gave the impression that the NHS did not take seriously the rights of children in their care and treatment. Several respondents cited the UN Convention on the Rights of the Child article 12, regarding children's rights to have a voice about the care they receive, and argued that under the current arrangements, these rights were not being respected.
- There were well documented methodological difficulties expressed over how such a survey could be delivered, especially by those charged with conducting surveys of children and young people in healthcare settings. Key issues included the (thankfully) relatively small number of children with cancer, the problems associated with low response rates to surveys among this age group, and the problem of analysis at small level (e.g. Principal Treatment Centre) that would risk identification of respondents. Despite this, respondents felt that with creative thought and

careful planning, such concerns could be overcome, and that regardless of the challenges, the NHS should be collecting information from children and young people in a standardised and systematic manner.

- Respondents felt that any new survey should be developed in consultation with children and young people, as well as staff. Initial views as to domains for investigation were communication, respect and dignity, being treated with kindness and compassion, having the opportunity to ask questions, having access to key workers and feeling comfortable in a suitable physical environment. A small number of respondents mentioned the National Voices, 'I Statements' and suggested these would be valuable as a basis for exploring patient experience among this group. There was agreement that any survey should consider the possibility of different iterations for older and younger children, and that questions should be ordered in such a way as to capture the most important information in the first few questions as few children will be willing to complete a long survey.
- Respondents emphasised the importance of developing a method or range of methods that could capture the whole 'cancer journey', and not just provide a 'snapshot' at one point in time. Several respondents commented on the need to reflect the lives of children and not just what was important to the health service. This included experience of health care at home and in the community, experience of school and college and of home and social life.
- Frontline staff in cancer treatment services currently use a very wide range of age appropriate qualitative methods to engage with children in order to understand their experiences of care. These range from observation of pre/non-verbal children, the use of parents and other advocates including specialist healthcare providers for young children, creative play with young children to 'trigger' discussion, informal group discussions, formal research groups and interviews, surveys, video-based techniques and the use of social media.
- There were concerns, recognised by service providers, about the representativeness and potential for the lack of inclusion of various approaches to collecting patient experience. Where possible this was addressed through making efforts to use accessible methods including translation and interpreting services for non-English speakers and non-written (drawing/art based) methods for younger children and patients who do not speak English.
- Social media were felt to offer exciting opportunities for capturing patient experience information from children and young people with cancer. However, at present this method has not been exploited fully due to a number of concerns, including a lack of training and skills in how to use these media. Respondents reported worries about safeguarding online and some negative experiences. Effective use of social media for improving the patient experience dialogue with children and young people will require protocols/rules for engagement, proper training of staff and resourcing, management and coordination. In addition to maintaining NHS-owned accounts, some respondents argued that services should be passively 'scanning' the private social media accounts of parents and children on a periodic basis, as these were places service users would report most honestly their views and experiences. There was a call for NHS England to provide training, support and guidance on how to better use social media for improving patient experience information.
- Asked about values and principles that inform (and should inform) the collection of patient experience information, most respondents identified the following: being clear about why they would ask questions, about what would be done with the information, and that the service should communicate to the patients and their families what had been done (or not) as a result of having received this information.

- Mechanisms for reporting patient experience information in order to effect change were variable across treatment centres, and also varied according to the nature of the information obtained. Several frontline respondents reported that they typically informed service managers of key insights obtained from qualitative interactions with patients and families, in order to improve service provision. More formal research findings, including survey information, were typically shared across relevant sites and settings, with small teams of service managers and/or senior nursing staff determining how to respond. In most instances, respondents reported that services took seriously the need to demonstrate to service users that they valued the information provided, and made efforts to report back to patients and families both what had been said, and what the service was doing as a result. This took a range of forms including 'You Said, We Did' boards, 'Graffiti Walls' and 'Tops and Pants' displays.
- A small number of respondents discussed the role of financial incentives and management processes that were used to encourage the recording of certain forms of patient experience information. These included payments for hospital attendance avoidance, and the use of IR1 and IR2 forms (poor and good practice forms).
- There was very little mention by professionals of the role of Healthwatch, PALS, Care Opinion, NHS Choices or any other independent organisation whose role is to collect and record patient experience. When asked directly about these organisations, most respondents felt they were important in theory, but in practice they appeared not to be very present in the working of most staff.
- Similarly, routine data were not mentioned spontaneously as sources of patient experience information. When asked directly, respondents who were aware of the different sources felt that most did not include the kinds of measures that would be valuable for this patient group.
- NHS England's reputation as a 'command and demand' organisation was considered a potential barrier to the effective establishment of a national method for collecting patient experience information. It was felt that NHS England should communicate its desire to support and facilitate services in this venture, and that branding, promotion and administration of research tools should be undertaken by services, with NHS England being responsible for analysis and reporting.
- Respondents felt that NHS England had an important role to play in general in this area, in terms of supporting and enabling services to improve their collection and use of patient experience information. This included providing training and guidance on the management and use of social media in particular and generally in terms of sharing of good practice, through special events, publications and via existing professional networks.



## 1. Aims and objectives

This study sought the views of a diverse range of professionals who work with children and young people with cancer and their families, as well as others with an interest in patient experience, to identify views on how patient experience information is collected and used currently, and views on how this may be improved in future.

The study was commissioned by NHS England and forms part of a larger research project that identifies an 'options appraisal' of alternative methods for collecting patient experience information from children and young people with cancer and their families. NHS England commissioned the project to address a recommendation, 'to develop a methodology to collect patient experience data for under 16s': recommendation no 54 in the national cancer strategy, 'Achieving world-class cancer outcomes: A strategy for England 2015-2020'. The study intends to assist NHS England to develop its response.

## 2. Methods

The study involved a combination of telephone interviews and group discussions with professionals. Three group discussions were held in Leeds, London and Birmingham.

Most respondents were professionals who work directly with patients and their families (including siblings, parents and carers, extended family and friends). They included clinical staff (nurses and doctors), and a range of other staff who support children and young people with cancer, including play specialists, social workers and teenage support workers. In addition, service managers and research service staff participated, along with patient experience leads and representatives from charities working in this field. A small number of non-NHS staff with experience of devising and leading consultation and engagement activities with children and young people was also included in the study.

The interviews (both telephone and group discussions) were semi-structured. A topic guide was used to guide the interviews, and all information was audio recorded. Two members of the research team attended each group discussion, and NHS England attended as an observer at one of the three groups (London). Fieldwork was conducted between December 2017 and February 2018.

The content was analysed using a thematic analysis approach, and the report follows broadly the flow of questions identified in the topic guide.

### 3. Findings

#### 3.1 The role of patient experience in children's cancer services

There was consensus among respondents across the study that the first duty of the service was to do whatever was required (and whenever this was possible) to treat the cancer and secure the life of the patient. This was to be done in a way that ensured that the quality of life of the patient undergoing treatment and after treatment was as good as possible. It was in this context that respondents identified the importance of understanding and responding to the experience of the patient, no matter what stage of treatment. Respondents pointed out that regardless of the clinical diagnosis and whether a patient was likely to have a treatable cancer or a terminal diagnosis, made no difference to the importance of collecting and responding to patients' needs as identified through patient experience information.

'We think that when a child arrives with a diagnosis of cancer, the priority is to treat the cancer. That's the focus. During and after treatment we need to ensure that the life is one that is worth living. We have to try to make the side effects produced by the treatments as small as possible so their lives can be as enjoyed as best as possible. The only way we can understand that is if we collect the experience of people going through that and use that information to understand what variation there is in people's experience and get their thoughts to improve that experience.' Paediatric Oncologist, Leeds

#### 3.2 Views on the purposes of patient experience

Respondents were asked what they understood patient experience to be, and how it was used and should be used. There were three broad views, and while there was a tendency towards each view being expressed by different types of respondent, there was overlap.

##### Summary of views about the purpose of patient experience by respondent type

Immediate and 'real time' information used to inform everyday interactions: to inform staff of the needs of patients and their families, and to enable a rapid response to address these needs	Frontline staff (Play Therapists, Clinical Nurse Specialists, Teenage Youth Workers)
A tool for service improvement: to inform the design and development of services to reflect the expressed needs of patients and their families	Service Managers, Senior Clinicians
An objective and independent method to hold services to account: to provide a means of ensuring quality assurance of services. This was of benefit to both staff and service users. The importance of the patient voice as a means of ensuring independence and objectivity featured more powerfully in this element	Patient Experience Leads, Senior Clinicians and Senior Managers, Policy Makers, Charities

### 3.2.1 Immediate and 'real time' information used to inform everyday interactions

The first view, expressed mainly by frontline staff, (play specialists, social workers, teenage/youth workers and clinical nurse specialists) was that patient experience information related to the views and experiences of patients expressed in the moment, as a result of observations, interactions and deliberate enquiry via a range of methods of enquiry, and was used to ensure that individual members of staff could respond appropriately to these needs 'in the moment'.

'The reason it's important is to do with the quality of life of children and young people with cancer, their parents and siblings.' Teenage Youth Worker, Leeds

*'Hearing and responding to patient experience is what we do every day'*

Frontline staff reported that the vast majority of patient experience feedback was collected and acted on, through the close interaction of staff and patients and their families. These respondents reflected on the fact that almost all of their day to day activity involved gathering and acting upon information about patient experience, and ensuring that concerns were addressed in a timely fashion. The intensity of the relationship between service providers and patients and their families was described as unlike that in other areas of healthcare, and one that extended beyond the confines of the health service to other domains, including the home, school, work (for older young people) and social relations.

'Complaints and comments cards are available but hardly ever get used in our service. Because people have a key worker, who is a nurse who works closely with the child, goes to the school and so on, provides lots of support and practical support at that – if there are complaints or challenges, they tend to get discussed with the keyworker, rather than through written feedback. We're unlikely to get a single written complaint in a year.' Lead Nurse Paediatric Oncology, Bristol

'And similarly, positives tend to come back in the form of cards, gifts and so on. The relationship we have with the patients and families is much closer than a school teacher has with a child and much closer than a doctor has with an adult. It's a constant evolving family type feel, rather than a client/mechanic feel to the relationship.' Lead Nurse Paediatric Oncology

Given this understanding of the purpose of patient experience information, there was a view that it was simple to collect and to act on.

'Most of the feedback we get is really simple stuff, like 'I hate it when I'm left on my own, when my mum goes in the kitchen to get breakfast, because I'm not allowed in the kitchen, and she has to leave me.' Play Specialist, London

### 3.2.2 A tool for service improvement

The second view, expressed mainly by service managers and senior clinicians, was that patient experience information was more of an object of enquiry and a planning aid that enabled service managers and policy makers to better design services for children and young people with cancer, in order to make them more responsive to expressed needs. In this version, patient experience information included both the immediate information as in the first view, but focused more on periodic and deliberate moments of enquiry in the form of surveys and focus groups with the patient group. Both of these views assumed that the staff within the services would undertake and assess the information collected.

There was a very clear statement from all groups and individuals that patient experience information was both essential to the planning and delivery of services, that it 'drives' the service, and that it was vital that there were means to elicit the information.

‘I think patient experience is probably the most powerful thing. More than staff. If you have the patient experience information behind you, that’s what makes people want to change things.’  
Teenage Cancer Nurse Specialist, Birmingham

‘(As professionals) we should learn from and be driven by the experience of patients.’ Service Manager, Leeds

#### Understanding what’s good, what needs improving and what’s not known

Overall, professionals were clear and consistent across all interviews (individual and groups) about their needs of patient experience information. This amounted to information to help service planners and providers understand how to devise, develop and improve their offer, based on the views and experiences of the service users. In other words, they wanted to know what their services were doing well, what they were not doing well (and could improve), and importantly, what they did not yet know about. However, in reflecting on what information was needed, some respondents noted that a single method for obtaining patient experience information was not sufficient.

‘What did we do right, what could be done better and what do I not know about. But you see this is where questionnaires are limited because they can only ask questions that we already know about. The more important issue is to be able to ask about areas that we don’t know about that we need to improve.’

Q. How is that found out?

‘Through intermittent groups. I don’t think a questionnaire is ever going to be the whole answer.’  
Paediatric Oncologist, Leeds

#### 3.2.3 An objective and independent method to hold services to account

The third view, expressed mainly by senior clinicians, policy makers not working within individual services and charity representatives, was that patient experience information was a means of obtaining an independent, objective and measurable form of assessment provided by patients and families of the experience of care, that could be used to evaluate the performance of services, hold services to account and be used to make comparisons between services. These respondents felt it important that there was a national, systematic and consistent approach to the collection and use of patient experience information.

While all respondents acknowledged the importance of the first two approaches, there was a concern from proponents of the third view that the focus of NHS England’s recommendations should be more explicitly on the national requirements. For this group, it was the need to develop a tool that was fit for purpose in terms of measuring patient experience at the national level that was the goal.

‘For younger patients there is no national feedback. We don’t have any way of measuring patient experience nationally for children. Local centres do their own thing and its variable what they do and how they do it. But you can’t make any comparisons as a result of services doing their own thing. I think that’s a really big disadvantage.’ Consultant Haematologist, London

An important aspect of the patient experience research process, volunteered by several respondents, was the need for a form of validation of the service provided by the patients and their families, and that it was necessary for those who worked in the services to have a sense that their work was of an agreed quality and standard.

‘I think it’s something we use to rate our service, to measure ourselves against specified outcomes – that they’ve got access to information, that there’s someone they can go to for support or about their journey to us.’ Nurse Liaison, Leeds

The response from all groups was that there was a need for both qualitative and quantitative forms of patient experience information gathering, because it was through the ‘active inquiry’ in the more planned and considered periodic moments, that services could obtain a type and quality of patient experience information that was not revealed during everyday interactions.

‘There is an argument for doing something periodic, because it’s different to everyday interactions. If you’re sitting and chatting with someone, you might not act on it or share it or make a change. It’s about the capture and using of patient experience information to reflect and make a change.’ Service Manager, Leeds

Some respondents suggested that while the close and intense relationship between healthcare professionals and service users was to be hoped for, in practice, not every child and young person with cancer experienced this type of relationship.

‘On the question about the single point of contact, that is really important and really good for getting immediate feedback that can be acted on. But that relationship is not always like that. Sometimes a patient might have a diagnosis, be in surgery very quick and then be out and back at home, and the support drops off, while they are poorly for a long time. At that point they don’t really have a relationship with the service. That ongoing relationship isn’t always the case for every young person.’ Charity Family Support Worker

#### [‘A unique opportunity to get an objective perspective’](#)

Several respondents reported that despite significant changes over the past few years, there was still a cultural norm among many healthcare professionals that was not patient friendly. In this context, the role of patient experience information was seen as vital, as it offered ‘a unique opportunity to get an objective perspective’ from those who use services, to drive improvements.

‘If we think about the way we communicate, of course, any health professional will say they communicate with children and young people to the best of their ability. But when we ask in the National Young People’s inpatient survey, 43% told us, ‘You didn’t engage in the most effective way.’ Experience of Care Lead, NHS

There was recognition that despite the best of intentions, health care professionals could not make an independent assessment of how patients and families experience services.

‘Although we are all very caring and committed people, we don’t always know what is best for patients. And therefore, I think having patient feedback is crucial.’ Consultant Haematologist, London

Analysis of the experience of older children and young people, who had completed the NCPES (those aged 16+), indicated that for teenagers and young people, there were significant concerns about the quality of the patient experience.

‘We’ve pooled the raw data from NCPES surveys to date and analysed it for TYAs (Teenagers and Young Adults). They report poor experience of care in pretty much all domains.’ Consultant Haematologist, London

These respondents were acutely aware that the current position was one where there was no means of collecting patient experience information at a national level, among children and young people with cancer, and this was felt to be a significant failing and gap to be addressed.

‘I think things like group discussions are all fine, but they have limitations. Groups tend to be self-selecting. People come along because they have something to say, which isn’t always a good thing. They have their uses, but in terms of collecting unbiased data, that’s difficult.’ Consultant Haematologist, London

### 3.3 Patient experience, engagement, involvement and consultation

There was confusion among respondents over the use of language to describe patient experience. A variety of terms including ‘patient experience’, ‘patient engagement’, ‘patient involvement’ and ‘patient consultation’ were used interchangeably. It was sometimes difficult for respondents to identify distinct points of difference between these concepts. Many respondents felt that they were all concerned with what they understood patient experience to be about, namely identifying insights from patients and families that could be used to improve the experience of the so called ‘cancer journey’, both within physical settings of hospitals and clinics, but also in relation to home life, social life, education and for the older age group, work.

Respondents with greater professional experience of patient experience as a subject of inquiry argued that while there was a strong relationship between experience and engagement, there were differences, and that good engagement was a pre-requisite to obtaining patient experience, but not a substitute for it.

‘I see the differences between them. You need both. You can’t have one without the other. But experience is very much concerned with the relational aspects of care: how we communicate what matters most. This then enables us to pick up the environmental aspects of care, nutritional support, family centred measures. If you can promote and facilitate the patient voice and advocacy that enables us to find out about the experience of care.’ Experience of Care Lead, NHS

When asked how patient experience research was conducted and how insights were gathered, respondents frequently described activities that would not be recognised as research methods in a traditional sense, but rather as ‘engagement’ activities. Groups and events that were set up for a specific purpose were frequently referenced as means of obtaining patient experience information. These included peer and sibling support groups and other informal gatherings of patients and their families.

### 3.4 Children’s cancer services: more patient experience focused than other areas

Respondents discussed the fact that the level of interest in and use of, patient experience in this area of healthcare was probably far superior to that in other areas. This was attributed to the unique focus on children and young people, the fact that the nature of the medical conditions was life threatening and because of the investment of resources and involvement of charities, that have a special interest in ensuring the NHS meets the needs of the whole person.

‘I suspect it’s to do with the strong links between the TCT (Teenage Cancer Trust) and Macmillan.’ Nurse Matron, London

‘The amount of patient experience information we use is so different from everywhere else I’ve worked. In those other places we didn’t even ask the patients what they wanted or how they felt. It was just an add on. Whereas at (hospital) I truly believe that we do listen to the patients and make it part of their standards and care package... We are very patient experience led; all of the values are

patient focussed. Patient experience is really highly valued. To the point where I am asking the charity (Macmillan) for funding for a new post and they are very keen because it is patient experience led.’ Play Specialist, London

### 3.5 Inclusion and representativeness

Professionals were very attuned to the risk of failing to respond to the needs of patients, and of the risk of overlooking the needs of the more vulnerable and less vocal groups, and of the importance of ensuring that research methods were as inclusive as possible.

‘One of the things that worries me about patient engagement is the different way we engage different age groups. It’s looking at the different ways we engage them. We will often get the ones who want to be engaged. The ones who don’t engage may have very valid views that are different from the ones who do engage. How do we engage the ones who don’t want to engage?’ Service Manager, Leeds

Some respondents felt that the methods used for collecting patient experience information overcame the concern about excluding groups of respondents to some extent, by being accessible to all, and by not relying on English language (spoken or written) to communicate concerns.

‘Our postcards don’t have to be written; you can draw pictures and use the iPad. We obviously have interpreters as well. But a lot of patients can just draw pictures of what they want – it doesn’t have to be the written or spoken word. And the post cards are always on display for anyone to fill in. You don’t have to ask. And they are used.’ Play Specialist, London

Others felt that the issue of representation was best dealt with through ensuring a more systematic approach to sampling and inclusion of diverse groups of respondents, through a survey methodology.

‘I agree there is a risk of missing out those who are most vulnerable, which is why the more formalised and standardised support to complete a survey would be good. The patient experience is also about parents of the young ones who cannot speak.’ Nurse Matron, London

However, it was clear that surveys are as fallible as other methods in terms of excluding certain groups.

‘We know this is a challenge. Take responses to the CQC survey. White families are more likely to respond than BAME patients and when we drill down into experiences, we’re more likely to find poorer experiences of care among the minority groups, and among children with Long Term Conditions and disabilities.’ Experience of Care Lead, NHS

Other considerations about inclusion were identified by respondents who questioned whether some children and young people who had experienced brain cancer for instance, would be able to participate in ‘standard’ approaches to research. These respondents commented on both the physical and the psychological impacts of cancer, and the consequent need to ensure options were available to enable potential respondents to participate.

‘Some might not be able to write anything. Often language is affected. And they may have severe depression, low self-esteem and fatigue. A survey or an interview might not work, but having options according to their needs is really important.’ Charity Family Support Worker.

While there was agreement that patient experience was important for all groups of patients, some respondents identified a special concern for patients with a terminal diagnosis, and questioned



whether the same tools or research methods were appropriate for this group as for patients with a more 'chronic' condition (the vast majority of cancer cases in children and young people).

'For those with an incurable diagnosis, it becomes as important as it can be to ensure that their life is as good as it can be, and to focus on the balance between the toxicity of the side effects, because the ultimate aim will not be to cure that person for ever but to make their life longer.' Paediatric Oncologist, Leeds

### 3.6 Obtaining feedback across the 'cancer journey'

An important observation was the need to ensure that young people and their families were able to provide feedback on their experiences of the totality of their treatment and care, and not just on those issues that were felt to be important to the treatment services. Several respondents pointed out that the patient experience should cover both the experience of care received as an in-patient, but also the care received while at home and provided by community based services.

'We definitely need more of a look at the whole journey, not just the in-patient part. Some of our children can't have bloods done at home because there's no community nursing. Some communities don't have 24 hour palliative care services available. It's about looking at the whole package and what happens when they finish treatment.' Clinical Nurse Specialist, Birmingham

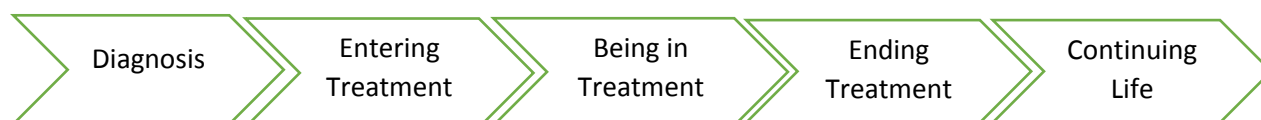
Other respondents commented that feedback should be 'holistic', 'reflect the whole person' and take account of the 'entire journey' from diagnosis through treatment and beyond. Many of the most challenging aspects of people's lives were described as occurring after the health service had completed its work, and when the young person and their family faced the consequences of what were frequently life changing events. In this context, respondents were concerned that the health service should be even more integrated with schools and colleges and workplaces and that feedback from young people and their families should reflect this.

'I have thoughts about the ongoing journey. Schools are a real constant in the child's life. They know the child really well and the relationship between the child, school, the health service is really important. Perhaps schools are a good way of giving feedback. Teachers would be well placed as a safe place and trusted adult to give feedback to. We have a number of children who have really struggled to re-integrate with school after treatment. Nearly every person I work with has concerns about schools and health care.' Charity Family Support Worker

The 'snapshot' nature of a periodic survey was felt unable to reflect adequately the changes that children and young people and their families experienced over time and at key moments on the journey.

'It's such an ad hoc issue, and when do you collect it? At diagnosis or on treatment or end of treatment? And it's going to give different results.' Data Manager, London

The key stages on the 'journey' where it was felt important to obtain feedback were identified as follows:



In considering how feedback might be collected to reflect these various stages, some respondents spoke of the importance of using a mix of methods, some of which would be based on routine data



collected by clinicians and others, while some of the information may require specially designed patient experience research.

‘I know that might not be possible (to collect information across the journey). It doesn’t have to be a survey necessarily. But it could be captured by services.’ Charity Family Support Worker

In some instances, there was evidence that this work is already underway, at least in part.

‘We do gather data across the journey. It’s partly done through routine data; we look at how many trips were made to the GP before diagnosis for example, and partly asking them in person.’ Social Worker, London

### 3.7 Ethical principles that should inform patient experience research

Respondents were asked whether there were (or should be) principles or values that underpinned the collection and use of patient experience research among this patient group.

There was consensus on some the key principles, namely that staff should be clear about why they would ask questions, about what would be done with the information, and that the service should communicate to the patients and their families what had been done (or not) as a result of having received this information.

Some respondents argued that if children and young people and their families were better informed about why the information was being collected, and the purposes to which it would be put were explained, there may be a better level of response to patient experience research.

While most respondents felt these values and principles to be self-evidently necessary as preconditions, they were not always implemented.

‘First thing, sounds really obvious, why are we asking these questions, what will we do with the information. What’s different from the questions being asked by the regions? I know that we have discussed this for a while. Can we all use one set of questions that is applicable for everyone? It’s quite hard to know the answer, about what you are going to use the information for.’ Paediatric Oncologist, Leeds

#### **Questions that should be considered before patient experience information is collected**

- Why are we asking these questions?
- What will be done with the information?
- How will information be communicated to patients and families to demonstrate what the service has done as a result?
- Is there a need to always inform participants about why the information is being collected and how it will be used?
- What information is needed by the Centre (NHS England) that is different from what is collected at the local level?

For some respondents, this question about ethics of conducting research led to a discussion over whether there was an imperative to always disclose the fact that information provided by children and young people and their families, may be used as patient experience data to inform service planning. Given the diverse range of methods identified by respondents to obtain information, many

of which relied on using groups and activities established for a separate purpose, this posed a dilemma that was not easily resolved.

‘I suppose it depends on how the information is going to be used. I do wonder if you might hear different things in groups that are more relaxed. But in terms of getting specific responses, I think the participants need to be informed about what the information is going to be used for.’ Charity Family Support Worker

### 3.8 Using patient experience information to change practice

An important aspect of patient experience research concerned the utility of the information, but also the means to enact what was learnt. Respondents were asked how they ensure the information is used by those in a position to ensure appropriate responses are enacted.

Several respondents made the point that, for a variety of reasons, not all suggestions or concerns identified by patient experience research was acted on. However, respondents were keen to ensure that even when no action was taken, there was clear and transparent communication about this fact and the reasons for it.

In most instances, the mechanisms for acting on patient experience information were ad hoc and local to the service. Team members who identified concerns or views of patients typically reported them to relevant colleagues at team meetings or to the service manager.

In responding to the concerns, and reporting back to patients and families, there were a range of methods used to communicate the facts that the information had been received, and how the service was responding. The most commonly reported method was simply to write the information on a board on the ward, in the form of, ‘You said. We did’.

‘The Patient Experience Lead would take the information and liaise with all the various departments – and it would go up on the board to say what you said and what we did. Even if we can’t respond, we’ll say why we can’t, or if we fail we say what we did and why it failed. It’s about being open and honest.’ Play Specialist, London

‘It’s similar with CLIC Sargent in our team, it is an ad hoc way that we respond, we had feedback from parents about the lack of physical activity available, so we developed a relationship with Fitness First and we hear about how parents are spending a lot of money on food, so we now have food vouchers.’ Social Worker, London

Patient experience information was also used as part of the reporting process at meetings of the Trust board, although it appeared to be the case that most of this related to the whole Trust, rather than specialist units including cancer services for children and young people.

### 3.9 Other drivers: financial incentives and management processes

At one of the three groups of professional respondents, it was reported that there was an additional pressure and requirement to collect and record certain types of patient experience information, because of financial incentives in the NHS. While financial incentives for patient experience information was not a major feature of the discussion group, it did beg the question whether this was something that should be encouraged, and whether financial incentives were appropriate for improving patient experience.

‘With anything we record, we ask, ‘What are we recording?’ and ‘Why are we recording it?’ and, ‘What are we going to get out of it?’ So, we’ve started to record some of the CNS (Clinical Nurse Specialist) contacts, but that’s only if they’re for admissions avoidance and we can claim that money

back from the CCGs (Clinical Commissioning Groups). So, if they had a contact that stopped that patient coming into hospital, then we can claim that back as 'activity', and I think it's something like £24 per contact they have. You might call 6 patients in one day and only prevent one of them coming in. That's the only one we'll record. It's not that it's not happening, just that we're not recording it.' Service Manager, Birmingham

'The reason we're recording these contacts now is because there's a financial incentive to recording them, to make a business case. We have to have outcomes for our work. We record patient experience cards – the cards 'thank you' for positive and negative feedback, and that is reported on the board.' Play Specialist, Birmingham

#### Incident reporting and Learning from excellence

The Birmingham group also discussed the role of the IR1 form (incident reporting) and IR2 form (learning from excellence) as means of promoting good patient experience.

'We have IR1 and IR2 forms to reinforce positive behaviours. There's a great enthusiasm for this on Twitter and in the real world. It's about staff recognition really, when a member of staff recognises that someone has had a positive experience on the patient, they report it and it promotes positive behaviours.' Patient Experience Lead, Birmingham

### 3.10 Methods used to obtain patient experience information

Respondents were asked to describe the various methods used to elicit patient experience information from children and young people with cancer, and their families. We describe below the range of methods and approaches identified in this study.

#### 3.10.1 What does not work: the written word and formal research events

Respondents also volunteered information on methods that they felt were not valuable for obtaining feedback from children and teenagers, notably anything that involved writing.

'The written word is unlikely to engage children and young people, regardless of whether it's online, social media or paper.' Youth Work Coordinator, Leeds

As discussed elsewhere, some (but not many) of the methods identified as valuable will be recognisable as qualitative research methods, while others perhaps will be better understood as 'engagement' activities.

What is remarkable are the range of approaches and techniques, as well as the creativity and sensitivity of those working with this patient group, to develop and use effective methods to elicit information about needs and concerns.

#### 3.10.2 The importance of context for enabling disclosure of experience

An important finding was that the specific method was of much less importance than the intention and to gain an understanding of the views and concerns of the patient group and their families.

#### Time, place and manner

Several respondents commented on the importance of the attitude and disposition of staff, and on the need for a relaxed context and environment for eliciting information relating to patient experience.

'I would argue that if you're in a relaxed environment, experiences will come out without you needing to ask in an overt manner. If you are creating that receptive environment. It's not just about

‘tell me your feedback’ but listening to their experiences, and taking it away and thinking about how to improve our offer.’ Patient Experience Lead, Birmingham

‘It really doesn’t matter what the tool is, it’s a vehicle to give the child a voice to their experience. The art – be it music, painting, literature - are all ways, that not many people use to allow children to express themselves.’ Head of NHS Innovation

The importance of timing, as well as ensuring a relaxed and unthreatening disposition and environment, was also crucial to the quality of interaction.

‘The difference between what they tell you when you’re in uniform and not is incredible. It’s all about time and place.’ Clinical Nurse Specialist, Birmingham

An example of how timing of asking questions relating to patient experience was provided. This concerned the neonatal department of the hospital, but the same principle applied to children with cancer.

‘Neonates realised that the critical period was 40 days after admission when families turned from being overwhelmingly grateful for saving the life of their child to having and expressing concerns. So, now at 10 days the service manager distributes cards saying her door is always open, to pre-empt concerns and address them early – it starts that relationship off.’

### 3.10.3 Qualitative approaches

The range of qualitative approaches identified from interviews with professionals was extensive.

#### Third party representatives and advocates, including healthcare workers and parents

Community representatives and other third party advocates were identified important sources of information about patients’ experience. These people were especially valuable in situations where these individuals could provide insights that were not available through more direct methods of communication with the patient. This included people with little or no language, including young children and recent migrants to the UK.

‘There are some great models of patient experience. For example, a conversation with the Community Engagement Lead worker of a particular community. It’s about using connections and working with allied health professional colleagues like Speech and Language Therapists and Occupational Therapists. Take ‘Talking mats’, these enable us to hear their experiences. It’s down to us, to find creative ways to want to listen.’ Experience Care Lead, NHS

#### Observation techniques

Several respondents mentioned the importance of observation of especially young and pre/non-verbal children, as a means of assessing their experience and ensuring they were not in discomfort. Related to this was the recognition of the importance of age appropriate methods of eliciting information.

For very young children (0-5 years), the views of parents and carers were the main means of eliciting information. Some respondents mentioned the importance of specialists who work with babies and toddlers.

‘I have a colleague who is skilled at patient experience among young children. It’s very observational based, using psychologists to pick up on body language, noises they make.’ Play Specialist, London

#### Interactive activities for very young children: figures, puppets, playdough and baking clubs

For younger children, respondents stressed that the focus must be on the activity and the interaction between the child/children and adults. The patient experience information was then gathered while the children were occupied on the task in hand.

Examples of activities mentioned by respondents included baking groups, where a group of children engage in the activity of baking, and playing with playdough. The latter was referred to in the context of a one to one activity between the Play Specialist and a child whose sibling had recently died.

‘At homes with a young bereaved sibling, I might use playdough to talk about the child that’s died and talking while we play. It’s about talking while playing, one to one. You could do it in a small group but usually it would be one to one. The method is secondary. It’s about finding the right vehicle to enable the child to articulate what they’re feeling.’ Play Specialist, Leeds

#### Story-telling and story-making

For younger children, a story telling charity was used in Nottingham. This involved story-telling and story-creating and encouraged children to describe their experiences of illness.

‘First Story. It’s an organisation that goes to schools to improve literacy. I worked with First Story at Nottingham Hospital with children and young people with Long Term Conditions. By writing about it, this was the first time they’d ever reflected on their condition and their experience.’ NHS Improvement

#### Art and other therapies: crafts, construction, music, clowns, entertainers and pet therapy

Several respondents described using art therapy and music therapy and entertainers and pet therapy as means of engaging children (including very young children) to express their feelings, needs and concerns. As discussed elsewhere, respondents felt it more important that there was attention paid to encouraging self-expression, rather than focusing excessively on the particular method by which it was done.

‘A lot of my work involves supporting children through experience based activities – craft, cutting and sticking, making and construction, Lego, jewellery – it involves finding out what the children are interested in. We also provide youth sessions every week, discussion life skills, anything and everything.’ Play therapist, Birmingham

‘I think there are areas that use art. Tiles – there’s part of the (hospital) where children paint a tile. It doesn’t matter what the tool is, it’s a vehicle to give the child a voice to their experience. The art – be it music, painting, literature - are all ways that not many people use this, to allow children to express themselves. I think it’s not culturally normal in the health service, because of the problems of time and so on.’ Head, NHS Improvement

#### Group based social activities: meals out, days out, short breaks

Support groups including peer groups of siblings and patients were identified as an important source of patient experience information. The crucial learning was that the setting should be relaxed, the environment should ideally be away from the hospital and the purpose of the group (from the point of view of the young people) should not be to elicit views and experiences, but to have an enjoyable, social event.

‘The best way we get feedback from young people is through ‘Chomp n Chat’, where on the first Thursday of every month we go into town and we go to a restaurant to get some food. We have 20 young people and that’s the best way we get any feedback. We just sit and chat in an informal way.

It's just something we set up ourselves. It's actually a support group, but if you tell teenagers it's a support group they won't come.' Teenage Youth Worker, Leeds

'We just take them out. We pay for everything and all they have to do is attend. And we get the ones who otherwise wouldn't come or be able to afford to attend coming. The amount of things we get out of them at that! We recently had a refurb of the ward, and (when asked for feedback in a more 'normal' manner) no one had come back with their ideas of what they thought they wanted on the ward or themes or anything. We took out the plans at the restaurant and they all just gave their views on that. They wouldn't have done that if I'd only emailed it out.' Teenage Youth Worker, Leeds

A similar food-based group operated in London under the title of 'Pizza Club' and in Birmingham a range of similar activities were reported.

'We take teenagers out for meals, holidays, go karting. Funding is provided by TCT for outside activities. We take them to charity funded holidays.' Clinical Nurse Specialist, Birmingham

#### Games with prompts and triggers to discussion

Several respondents described using board games as a means of stimulating a group discussion on patient experience. One in particular, 'Whose Shoes?' was mentioned as a valuable tool for engaging patients. This game involves a board game with pieces that are moved around the board according to the throw of the dice. There are four sets of squares that participants may land on, that require the picking up of a card. On each card is written a statement or a quotation, based on the experience of four types of person: a patient, a parent, a member of staff, and a service planner. The intention of the game is to prompt discussion about participants' feelings, whether they agree or disagree or identify with the statement or quote on the card. It was reported that this game worked very well for teenage patients.

'We played a game called 'Whose Shoes' – it's a board game. They loved it... You might pick up a card that says, 'My mum cries whenever I go to an outpatient's appointment'. So that then works as a trigger. It's just quotes that are used to initiate and prompt discussion.' Service manager, Leeds

#### Video Booth, Big Brother Diary Room and animations

In Leeds, respondents described a Video Booth that operates across the children's hospital. This is a resource that children and young people and their families can use to familiarise themselves with what life on the ward is like. It includes films of patients' experiences and of staff who work on the wards. These are available online from the Leeds Children's Hospital website, <http://www.lchtv.com/patient-stories>. It also offers existing patients the opportunity to create their own content. There were some variations on this idea, with the use of the 'Big Brother Diary Room' operating in a similar way.

#### Post cards and Comment cards

In London, respondents reported the use of post cards as a quick and easy mechanism for patients and families to inform staff of their needs. They were described as being accessible to anyone, regardless of ability to write (as the 'sender' could draw a picture of their needs or concerns, either on paper or on an iPad/tablet) and efficient, in that staff could read and respond immediately. Staff would ask the person who wrote the card if they would like their concern to be written up on a board on the ward, and then a response would also be provided to demonstrate what action had been taken.

'Our postcards don't have to be written; you can draw pictures and use the iPad. We obviously have interpreters as well. But a lot of patients can just draw pictures of what they want – it doesn't have

to be the written or spoken word. And the post cards are always on display for anyone to fill in. You don't have to ask. And they are used.' Play Specialist, London

#### Coffee mornings and strategic planning meetings

Several professional respondents described how they make use of informal coffee mornings to elicit information from parents about their views of services and of the care provided to their children. In some instances, these informal gatherings had been used as 'strategic planning meetings' in the minds of service developers at least, who viewed them as a vital component of their service, because they were used to both obtain information from parents and as a vehicle to disseminate information to the 'parent community' and to advocate for change.

#### Social Media

The question of social media and its potential for addressing patient experience elicited a wide range of responses, from the very enthusiastic to the very doubtful. It was evident that there had been either no or very little training of staff or guidance in the use and management of social media for collecting patient experience information. As a result, the experiences of using social media in this context were characterised by a lack of planning, coordination and management, with both disappointing and at times negative consequences.

#### Enthusiasts

Enthusiasts for social media argued applications including Facebook and Twitter enable patients and families to engage with services in a new and exciting way. They felt that social media provide a simple, no cost and easily accessible means of reporting experiences of care at a time and in a manner that was comfortable to them, and in a way that enables health service providers to respond in a timely fashion. The fact that social media have become so commonplace, and that people have access to a range of apps via their mobile phones and other hand-held devices, was seen as a highly democratising development. Everyone agreed that social media will become more culturally 'normal' for most people, and especially for younger people, and that it makes little sense for the NHS not to engage with these media.

At the same time however, the most enthusiastic respondents acknowledged that at present, staff in the NHS lacked knowledge and skills about how to use social media for collecting and acting on patient experience information.

'My challenge is this. What do health professionals know about social media and the opportunities available to us? We're not taught about this stuff. There's a responsibility on us as health professionals to find out and use the most appropriate forms of social media.' Experience Care Lead, NHS

The 'enthusiastic' point of view was expressed most cogently by a small minority of respondents, none of whom worked currently as frontline staff. However, even respondents who were more doubtful about the potential of social media, agreed that regardless of what they identified as the problems (described below), they were very aware that social media were now a fact of life for many people (including themselves) and that rather than avoid engagement, there was a need for health services to identify solutions to the concerns they had encountered, and that informed their more negative attitudes.

#### Reasons for doubt: questions about effectiveness for engaging children and young people

When asked what experiences they had of using social media for collecting information on patient experience, very few professional respondents working in treatment services volunteered information. Indeed, when it was raised as a question, some reported that posting questions and



seeking feedback had not been found to be an effective method for obtaining information from children and young people.

‘I recently put up a Facebook page for teenagers and said, “What do you think about some changes we’re planning”? I’ll be very lucky if anyone gets back to me. They just don’t want to do it. The best way for that will be through Chomp n Chat.’ Youth Work Coordinator, Leeds

Respondents concluded that there was something about the age group that made eliciting feedback challenging, particularly from teenagers, and also that any method that relies on writing, rather than talking, is unlikely to be effective.

‘I think there is a challenge of the age group. Would a 15 year old be interested enough?’

#### Online discussion groups

However, in the same way that support groups in the ‘real world’ were identified as important sources of insight and feedback, some respondents mentioned that online support groups were valuable for obtaining feedback about specific forms of treatment and about individual services. In practice, most of the groups discussed were used by parents, rather than children and young people.

‘We have a Facebook group of about 700 members mainly parents. It’s really valuable for parents on experiences of a treatment or a service. It’s mainly an emotional and peer support group for parents but we also use it for obtaining feedback on specific issues.’ Charity Family Support Worker

One example was provided of a website with a ‘Live Chat’ function. The respondent reported that this service was well liked and well used, and could be used to obtain feedback. However, again this was found to be mainly used by parents.

#### Concerns about safeguarding online

There were concerns about the safeguarding of children online, and the worry that online discussion groups required moderation, which could not be guaranteed by service providers.

‘If we open a Facebook group that is open to children, how do we monitor that outside office hours to ensure that children are kept safe? That’s been a barrier to us operating that kind of thing. We have also found it difficult to find out what young people might engage with and how they would want to give feedback.’ Charity Family Support Worker

#### Negative experiences of using social media for obtaining feedback

One group of respondents described how a negative experience, where there had been two fatalities on the children’s ward, had led to recriminations and anger being expressed online by the families of the deceased children. Unsurprisingly, some of this content had been very emotional and accusatory, and had upset both staff and other families. Ultimately, the service had decided to close the Facebook account.

‘We used to have a Facebook account. We stopped it because it brought up a lot of issues. We had a few deaths and families were understandably unhappy. They were posting things onto that group page that other families found distressing about care, so that’s why it became unhelpful.’ Clinical Nurse Specialist, (Hospital)

#### The need for rules relating to governance and management of social media

‘I don’t think we’ve had a meaningful conversation about what does social media really mean for patient experience among children and young people.’ Experience of Care Lead, NHS



As a result of that experience, staff at (hospital) felt more informed about the risks of using social media, but also about the importance of the need for clear protocols relating to governance and resourcing, that would ensure that social media are used constructively. They felt that having appropriate rules relating to the posting of comments was important, as was the resourcing of a 'moderator' to ensure that the content was not harmful to the interests of the group.

'As a Trust we have a massive social media presence on Facebook and Twitter. It's very active. The CEO is very active on Twitter. At speciality level it's more difficult. The Trust has a whole comms team dedicated to social media. Unless we're going to have that in our speciality, it just becomes a bit difficult. You're adding workload to people. Who would manage it, where would they get their advice, what are the governance issues, what if someone posts something unhelpful and how do you manage that? It's not impossible – I just think it would require someone to be accountable for that and there'd need to be clear guidelines.' Service Manager, (Hospital)

Those respondents who had experienced the negative effects of the impact of social media were sanguine about the future. They acknowledged that the 'genie was out of the bottle' and that engagement with social media was necessary. They simply felt overwhelmed given the current circumstances, to resource and manage this additional area of activity.

'Now the kids have got their own 'journey' Facebook pages. These things are happening all the time. But they're completely unpoliced by anyone.... In the right situation it could work. I think families would be receptive to it. But you'd need ground rules... A lot of charities have them but they have very clear boundaries and they have one person who takes responsibility for it. You need everything in place and you need the time to do it. There's no point if you can't respond to it...' Birmingham Group discussion

There was a challenge to this cautious approach to the use of social media for exploring patient experience. This view was that healthcare professionals are not well equipped to know how to exploit social media to its best advantage, and that while there does need to be an assessment of risk, this should not be reason for failing to explore the possibilities that these new media offer.

'There's a responsibility on us as health professionals to find out and use the most appropriate forms of social media... There is more that we can be doing. I don't think we've really had a meaningful conversation about what does social media really mean for patient experience among children and young people.' Experience of Care Lead, NHS

#### 3.10.4 Other sources of information

[Independents organisations: PALS, Healthwatch and Care Opinion](#)

One respondent (from a cancer charity) reported that families she worked with had found the PALS service valuable. Another respondent reported that she felt more use should be made of independent patient experience services such as Care Opinion. There was no reference to Healthwatch, and in general, these external sources of patient experience information appeared to play a very marginal role in the discussion about patient experience in this area.

[Dedicated patient experience app](#)

At Birmingham, there had existed a specially designed app that had been announced as an innovation in the field of patient experience. However, staff reported that in practice it had not been widely used and that it was to be discontinued.

'We're not going to continue with that. We're just launching a new website and replicating the app's functionality, so that you can leave anonymous feedback.' Patient Experience Lead, Birmingham

### Routine data

Across all interviews there was little reporting of the use of routine data for patient experience among children and young people with cancer. The following were mentioned as containing some patient experience measures, but they were generally considered to be very limited and were only mentioned when pressed.

Oncology data sets: include contact with CNS, cancer waiting times, time to be treated

Mortality data: reviewed to identify failings in all aspects of patient management

### 3.10.5 Survey based patient experience information

Perhaps surprisingly, given the extensive use of qualitative methods to obtain patient experience information, the interviews with professionals revealed a strong desire for some form of quantification of patient experience information. Currently, this was most obtained via ad hoc surveys of patients and their families.

There was an acknowledgement that surveys are an inherently problematic method for collecting reliable information on patient experience, and yet all respondents had experience of working in services where surveys of patients and families were a central element of the patient experience research methodology.

‘There’s something quick and easy and simple about a survey. It can be done on a phone or a tablet. Yes, there will be gaps both in understanding and the choice of questions. But it’s the ease and simplicity.’ Charity Family Support Worker

As has been pointed out elsewhere, a fundamental concern with surveys was the fact that they are able to collect information only on already identified parameters.

‘The most basic concern about surveys was that they can only ask questions about concerns that have already been identified, and so may miss important information simply by not asking the right questions.’ Paediatric Oncologist, Leeds

#### 3.10.5.1 Friends and Family Test (FFT) feedback tool

Respondents were asked their views of the FFT. None of the respondents volunteered information on this feedback tool as a method they used to collect patient experience information. The vast majority of views regarding the FFT were negative. The FFT feedback tool was described as being overly simplistic, poorly worded, and the single closed question was felt to be inappropriate to a cancer treatment service for children and young people. The survey was felt to have been designed for a single acute hospital episode, rather than for a chronic and frequent treatment schedule that was more common for many children and young people with cancer.

‘FFT is awful because it is over simplistic. It’s based on an acute care single visit model of care. When you have people coming in and out of the ward several times a week, they think, ‘Why am I being asked to fill in these questions again and again?’ It doesn’t sit with a multiple visit, chronic disease type experience, and it doesn’t reflect anything truly meaningful and that is very much one that is just seen as a tick box exercise. But it doesn’t give us anything to work on. It’s utterly pointless. Hardly any free text sections are completed and because it’s connected to a sense of pointlessness it doesn’t get used. It’s just another thing we’re directed to do.’ Paediatric Oncologist, Leeds

‘FFT? We don’t find it of value because of the wording. Most people interpret the question as, ‘Would you recommend this service to family and friends’, and they say, ‘No – I would hope they don’t get cancer!’ Matron, London

‘Also, it is unrealistic. First it was said it should be voluntary, but then the targets were set so high that we were being asked to virtually stand by the door to ensure it was filled in. It is totally wrong. I don’t know what other trusts think but at (hospital) we don’t think that the data from FFT is informative.’ Service Manager, London

#### 3.10.5.2 Children and Young People’s Inpatient and Day Case survey

There was a general lack of awareness of the Children and Young People’s Inpatient and Day Case survey. As a result, there were few comments on this study.

‘I’m not aware of that and I haven’t heard from families or young people talking about that.’ Charity Family Support Worker

#### 3.10.5.3 Locally produced surveys

Respondents reported that all the PTCs operated some form of locally produced patient experience survey. However, while these were felt to be of more value to the service than any alternative survey, there were many points of dissatisfaction with this method.

Concerns related to the difficulty for respondents who had experience of being treated in both a PTC and Shared Care service, to identify the specific setting under investigation. This was a particular concern identified in those areas where patients are more likely to receive the bulk of their care from the Shared Care service, and only occasionally attend at the regional PTC, as in the South West.

Some respondents felt that the questions asked of patients and their families failed to produce meaningful information. Most commonly, respondents spoke of data that was ‘too high level’, and ‘too general’ to have value for them. Additionally, it was felt by some that questions and responses failed to discriminate and identify the ‘shades of grey’ in the experience. Instead, the surveys tended to produce overwhelmingly positive responses, especially where staff were involved.

However, some positive changes had been achieved as a result of patient experience surveys. In London, a decision to integrate the communication systems of the PTCs and Shared Care services was prompted by feedback to a patient experience survey that the information flow between NHS services was inadequate.

‘Our patient experience survey is bi-annual and shared back to all London services – PTCs and Shared Care services. In (hospital 1) and (hospital 2) we meet at senior clinician/service managers to discuss what was found, and we ask what to do. For example, the survey identified problems with communication between services. This led to changes in how email is used and as a result we all moved to an nhs.net account. This all came about as a result of the patient experience survey.’ Nurse Matron, London

Elsewhere, there were reports of changes that had been precipitated by a survey finding.

‘For younger children, it’s mainly been around the questionnaire and discussions with parents rather than the children directly. And here similarly these have led to changes in service provision.’ Paediatric Oncologist, Leeds

We asked whether they’d met the CNS, whether the care was appropriate for their age, what they thought about the activities on the ward, what they’d like to have, whether they were told of their diagnosis and whether they were happy with the way information was provided. There was a tick list about what support they received from the CNS and why, e.g. signposting, fertility.

Response was very low – we got about 23 responses from around 200 on the list. Most were patients who had just had treatment. That’s an issue for response.

#### Features of the surveys used by services

- Tend to be 'home-made' surveys with non-validated questions and with little input or support from expert survey methodologists
- Designed by staff, with little involvement from patients or parents
- Conducted ad hoc, usually at around one survey per year to one survey every three years
- Collected information that reflected what services felt were important metrics, often based on NHS performance targets
- The information produced was generally not felt to be very helpful with assisting the development and improvement of services
- The data were frequently described as producing findings that were 'too high level' to be meaningful
- Many questions elicited overwhelmingly positive responses (particularly about staff). However, much of this information was of little or no value for developing or improving services.
- Some respondents felt that the reasons for the positive responses reflected the 'halo effect' about the treatment service, leading to a lack of discrimination about specific questions
- There was a lack of human resource to analyse and report on the data. This task frequently fell to service managers and clinical staff, who lacked adequate skills in data analysis and reporting
- The administration of the surveys was acknowledged to be 'sub-optimal' and the response rates were often low

#### 3.10.5.4 The National Cancer Patient Experience Survey (NCPES)

Respondents were asked their views on the current NCPES for adults, and whether they felt there would be merit in extending the age limit to children and younger people. The current adult survey is from 16 years.

There was an overwhelming desire among professionals that this survey should be extended to children and young people. However, there was a recognition that any survey of a younger age group should be considered in detail, and that simply extending the age range of the existing adult survey to a younger group was unlikely to be viable, despite the benefits this would offer for making direct comparisons.

Instead, there was an acceptance that there would need to be adaptations to the content and to the methods of administration of the survey. Respondents were concerned that any survey of children and young people should be made accessible and relevant to their needs and interests. In order to do this, further work would be required to explore question areas and methods of data collection that will engage children and young people.

'I support the idea of doing a national cancer patient experience survey - below 16 they are still people - but doing one that includes information and questions that are more relevant to a younger age group, I think that's a very good idea. But it would need further development to identify what areas of data should be included to get better information.'

An important factor in wanting to see the NCPES extended was the desire for standardised information to be collected and reported on, across all cancer services for children and young people.

‘There needs to be some standardisation of what we collect in terms of patient experience for children and cancer. I’m keen to see how this work will progress. We have been waiting for this. We really need something national. As a person who is interested in improving the lives of children and young people with cancer, it would be good.’ Nurse Matron, London

‘There should be a questionnaire based experience based survey that is the same across the country that includes questions that are important to children and parents and families, and also to the NHS. But that this is not the ‘truth’ of the whole experience – that it should be supplemented with engagement activities that are conducted. And the survey questions should not be set in stone – the questions need to change and develop.’ Paediatric Oncologist, Leeds

‘Why re-work something that’s already working?’

‘It should definitely be adapted and used for children and young people nationally.’

### 3.10.5 Challenges for any new national survey

#### Small numbers, low response rates and ethical concerns

Several respondents mentioned what they identified as important challenges for a national survey of patient experience among children and young people with cancer. These included the small numbers of children and young people with cancer, the low response rate to surveys of this nature in general, and the associated concern of representativeness. In addition, respondents with experience of NHS surveys warned that because of very low numbers, there would be a risk of identifying individual respondents to the survey if/when data were reported by individual treatment service.

‘The challenge for a national survey is that the response rate is low, making it difficult to advocate for changes. That’s partly due to the rarity of cancer in the age group but also completion rate and administrative methods. There’s a particular problem with people who have moved address etc. especially for older teens.’

However, when discussing the problem of small numbers and low response rates, some professional respondents countered that the size of the patient population should not be seen as a reason for not researching their experience.

‘I am sure to NHS England the issue of small numbers on a survey is true. But to the 1500 families per year who have a child with cancer, they don’t consider themselves to be a small number or unimportant. The noise I tend to hear around cancer and patient experience is ‘they don’t care about us’ or ‘they only care about us when it’s about cute children’ that they use on poster campaigns. Yes – it’s small but you either say as NHS England we are only conducting it among adults, or you say we’re conducting it among adults and young people or you say we can’t run it at national level but we would advise every centre to run a survey and collate results. It might be better if it comes from your local centre than NHS England because the majority of people have a very positive relationship with their local treatment centre.’ Paediatric Oncologist, Leeds

All respondents felt that it was important that the content of the survey be amended, to reflect the needs and concerns of the younger age groups. And that more than one version would be required, as the needs of children under 12 were very different to older teenagers.

‘(The NCPES) is not young person friendly. It would have to be developed. What’s it for? What questions are on it and where did they come from? What areas are we missing for children and young people, and then working with this group and parents, produce something that is doable and achievable. And then whether it comes to respondents by NHS England or by the local centre. I think

you might get a surprisingly good response rate if it's been designed and led by them, and promoted by them.'

Comparisons – is that a goal?

'I think the primary purpose would not be to compare or to rank. It would be to find out the experience in order to improve it. When you get down to ranking with small numbers it gets mathematically dodgy, but the more experiential stuff would still be positive. If each centre sent out the same survey, it would still be pool able, but it might be that it gets a better response coming from the hospital than the centre.'

'It might be that the CYP and parents say – it's fine, or that the parents can answer on behalf of their children, or they might say, it's missing important areas- nowhere does it talk about play or the care of siblings – and we know that the care of siblings is really important as is the issue of play and the ability to go to school.'

#### Views of survey specialists

An important observation was that few of the respondents working as care providers had expertise in survey methodology, and as a result, few had experience of the challenges regarding sampling, the implications of small numbers and low response rates, nor of reporting restrictions that may lead to identification of respondents.

On the other hand, survey specialists interviewed for the study were forthright about the challenges of conducting a reliable and meaningful survey among this patient group.

Respondents who designed and administer the Children and Young People's Inpatient and Day Case survey discussed what they identified as significant challenges, based on their experience of managing a range of surveys on behalf of the NHS. These included the following:

- A small universe of children with cancer (1,600 cases per year)
- Problems relating to sampling. Information on children and young people is held by the local Trust. To overcome known response biases (BAME) there is a need to over-sample certain groups. Currently, information is not collected on socio-economic variables, because this is not held by the Trusts.
- Method of administration of any survey. Currently the Children and Young People's Inpatient and Day Case survey exists only as a postal survey, and involves the child's parent's address. In 2014 of 18,000 responses, less than 1% was completed online (online responses were not available for the 2016 survey). There are significant data protection concerns with sampling and seeking responses from children via email and mobile phone numbers. While CQC is exploring this for the future, currently there are no plans to include online sampling and responding. [The experience of Birmingham Children's Hospital suggests that a sampling frame that used mobile telephone numbers of children and young people (to send a text link to an online survey) would be viable. Professionals who participated in the group discussion indicated that text numbers were recorded by the service, and that very few children and young people refused to provide this information.]
- Point at which the survey is conducted. The Children and Young People's Inpatient and Day Case survey is timed to be sent to respondents at approximately 18 weeks after treatment. For children and young people with cancer, this may be a problematic judgement, given that for many children there are several rounds of treatment.

- Response rate. The response rate for the 2016 Children and Young People's Inpatient and Day Care survey was 26%. It was slightly lower among the 0-7 age group (completed by parents/carers).
- Restrictions on reporting at Trust level. Reporting of data where there are fewer than 30 responses to a given question is restricted, to avoid breaching identification of respondents. There was a concern that if any national survey was conducted, it was unlikely that many questions would be reported at Trust level as a result.

'Say there are 1,600 cases per year, and you get lucky and get 500 responses. We are not allowed to report at Trust level if there are fewer than 30 cases, in case of identifying the respondent. And in any case, the statistical validity of such small numbers is very doubtful.' Survey Researcher, CQC

### 3.11 Reporting and communicating responses from patient experience information

Respondents were asked how information on patient experience is communicated to patients and their families. For 'real time' and immediate feedback, the main method was direct communication in the form of talking with patients and families. Beyond this, a few other methods were identified, all of which aimed to demonstrate qualities of openness and transparency, the fact that the service valued and welcomed the views of service users, and that it was keen to demonstrate that it was a responsive service. Several respondents insisted that even where information was not acted upon, the reasons for inaction were communicated.

#### 3.11.1 'You said. We did'

The most common method of displaying patient experience information, and the services' response, was via a 'You said. We did' board, most commonly displayed at the entrance to the relevant department.

#### 3.11.2 Tops and Pants

Another widely reported method of communicating how services respond to patient experience information was via the use of a simple 'washing line' of comments. Positive comments (Tops) and negative comments (Pants) are displayed on cardboard shapes which are then hung out on a washing line. This is strung out at the entrance to the department or ward. In some services, there is further colour coding, with the use of traffic light colours to indicate positive, neutral and negative. Alternative versions included a tree with different coloured leaves, with comments written on the leaves.

#### 3.11.3 Graffiti walls

Graffiti walls were reported as having been used in one off sessions, often after a day or half day event with families. However, they can be adapted for use within services on a more regular basis.

### 3.12 NHS England's role and reputation

Respondents mentioned spontaneously a number of ways in which NHS England's involvement in the collection and use of patient experience information would be beneficial. These included the following: training, supporting, acting as a central repository for information and providing guidance: allowing services to play an active role in the branding and promotion of any national data collection method, not forcing meaningless and unhelpful comparisons on services as a result of the data collected.

#### The reputation of NHS England among some services

Some respondents had a view that the reputation of NHS England among children's cancer treatment services was negative. There was a sense that NHS England was seen as a centralised



body that issued 'commands and demands' to over-stretched services that struggled to respond. As a result, respondents felt it important that if a national survey of patient experience was to be successful, and to have the full support of local services, NHS England's involvement must be seen to be supportive and facilitative.

In keeping with this thinking, respondents identified the following roles for NHS England: collation, analysis and reporting of patient experience information, but not necessarily branding and direct administration of surveys or any other method.

#### A 'bottom up' approach to data collection

Several respondents felt that in order to best engage with patients and families, the branding and promotional material associated with any data collection method, should figure the local service as this was the point of contact that service users had greatest emotional connection with. They felt that any NHS England branded communication would be more likely to be dismissed by patients and their families.

Respondents described the network of children's cancer services in the UK as a 'family', with lots of formal and informal networks, very close relationships between centres, and between individual members of staff. Several professional networks were identified, including the CCLG (Children's Cancer and Leukaemia Group) network among others. As a result of this close network, it was felt that consensus on developing an agreed method for collecting and using patient experience information would be relatively straightforward.

In this model, the data collection tool(s) would be prepared by NHS England in collaboration with professionals, patients and families, but administered by the local services. The completed questionnaires (or other forms of data collection methods) would be passed to NHS England for collation, analysis and reporting. The services would then be provided with reports produced by NHS England of the national picture and of their local services, with guidance about where to focus actions to develop and improve.

NHS England would also play a central role in providing ongoing training and support about how best to collect and use patient experience information, including the use of social media and other qualitative methods.



## Appendix 1. Survey based methods for capturing patient experience information

Survey name	Respondent profile	Strengths	Weaknesses
Friends and Family Test (FFT)	Patients and families	An existing method with national NHS support. Some (though limited) use is made of the open/free text box	Designed for acute, single episode hospital visits, not chronic conditions with multiple and frequent visits. Single quantifiable question considered irrelevant by staff, patients and families. Poor response rate. Age and condition specific data is not nationally reported but could be collected at local level.
Children and Young People's Inpatient and Day Case Survey	Children and young people	An existing method with national NHS support commissioned by the CQC. Higher response rate than FFT	Levels of awareness were poor among professionals. Questions not designed for children and young people with cancer. Cancer specific results not available
Locally produced surveys of children and young people with cancer and families	Children and young people with cancer and families	Surveys are more relevant to the needs of the service. Provide some evidence of assurance and some information that is used to develop services	Lack expert input to the design, administration and reporting. Staff required to spend time analysing and interpreting findings. Lack standardisation and validation. Lack of attention to response rates and implications

## Appendix 2. Qualitative methods for capturing patient experience information

Approach	Respondent profile	Strengths	Weaknesses/comments
<b>Advocates</b> Using the views of third parties (parents/carers, health professionals, allied health professionals) to voice interests of children and young people unable to speak for themselves	Infants, very unwell children and young people	For some children, there is no alternative to having to rely on third parties. In most cases, those advocating for children will do so in the best interests of the child as they see them	Some children may not have effective advocates. Sometimes the advocate may not be able to articulate what is in the child's best interests
<b>Observation techniques</b> (body language and other non-verbal communication)	Babies and toddlers (pre-verbal)	Enables insights that would otherwise be unavailable among a frequently overlooked group	Requires professionals with training in observation of development of young children
<b>Interactive play and tasks.</b> Examples include play with figures, puppets, playdough, baking clubs, story-telling/making, art based activities: drawing, painting, tile design, music, clowns, entertainers, pet therapy	Young children (toddlers onwards)	Simple and easy to implement. Limited or no cost. Can be conducted one to one or in a small group. Allows the child to express their experiences	Some activities may require specialist input
<b>Group based social activities.</b> Examples include outings to restaurants ('Chomp and Chat', 'Pizza Club'), support groups.	Older children and teenagers (age 6/7 onwards)	Simple and easy to organise. Helps with group bonding, inclusive activities. Valuable for eliciting views and concerns in a social and non-pressured environment	Comment: requires staff to understand that eliciting information is a by-product of the activity. Requires staff to be attentive and to, have a mechanism for, recording and reporting
<b>Coffee mornings and other 'drop in' events</b>	Parents and carers	Simple and effective in engaging parents/carers. An opportunity to learn and discuss views and concerns	
<b>Video based techniques.</b> Examples include Video Booth, Big Brother Diary and animations	All groups of children and young people (age 5/6 onwards)	Enables respondents to recount and share experiences directly May include answering 'prompts' about	Costs of purchase and use of equipment. Requires staff to assist (editing and uploading content)

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		experiences. Of value to the individual and to others, who may watch the films online	
<b>Post cards and Comment cards</b>	Children and young people (age 5/6 onwards) and families	Quick, simple and accessible. Low/no cost. Can be on paper or on tablet/computer. Respondent can use words or pictures. Enables staff to give speedy response	Requires patient/family member to take the initiative. A passive form of enquiry. Risk of excluding some groups (e.g. those who do not feel able to complain)
<b>Social media and apps</b>	Older children and teenagers, and families	Very accessible and no cost. Exciting means of gathering honest, detailed and time-sensitive feedback. Offers opportunity to respond quickly and sensitively	In practice, few professionals reported much use of social media for collecting patient experience. Those that did reported negative experiences and lack of skills and resources to use the method effectively
<b>Written complaints to the NHS Trust, independent feedback forums and agencies (e.g. PALS, Healthwatch, Care Opinion)</b>	Anyone	Independent and capable of addressing more serious concerns about patient experience	Professionals did not identify these methods as significant to the everyday business of services. Only for serious concerns about breaches of care and treatment

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### Appendix 3. Methods for displaying responses to patient experience feedback

Method	Features	Comments
<b>Tops 'n' Pants washing line</b>	Colours and shapes of comments/concerns denote positives and negatives	Simple to create and visually impactful. Demonstrates willingness to respond to criticism as well as positive feedback
<b>'You said. We did'</b>	Comments from patients and families displayed on board with response from the service	Simple and easy to implement. Demonstrate responsiveness and transparency (even if action is not achievable)
<b>'Graffiti wall'</b>	Created by service users. Displays views and comments.	Visually impactful.

## **Annex 3 – Report of research with children and young people with cancer to explore views on whether and how they would prefer to provide patient experience information about their care and treatment**

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## Summary

- The study found overwhelming support for the collection and use of patient experience information to improve the care and treatment of children and young people with cancer.
- Respondents were keen that the voices of young people should be heard and used to inform both the delivery of care and treatment to individuals questioned AND that this information should be used to improve the design, planning and delivery of services for others.
- Based on this small study, age appropriate research methods, including adjustments to research instruments (e.g. use of simplified language and the use of symbols rather than words or numbers for scoring/rating for example), would be required to ensure younger children are able to contribute meaningfully. Similarly, the range of question areas may need to be restricted for younger children to immediate (non-abstract) aspects of care and treatment such as the time frame for questions would need to be focused on the 'here and now' rather than days and weeks in the past.
- Again, based solely on this study, recruitment of young people with experience of cancer may be more challenging than imagined. This fact should be considered in the design of patient experience research. The use of telephone interviews was found to be the most effective method for this study, following several abortive and disappointing efforts at recruiting groups both in person and online. Small financial incentives (£5-£10 per person) may be effective in encouraging completion of a survey and larger sums (£20-£25 per person) for participation in qualitative research.
- Older respondents (from 13 onwards) demonstrated the ability to participate fully in patient experience research. Many of the research themes and questions used on the adult National Cancer Patient Experience Survey (CPES) would be appropriate for children over this age.
- Respondents felt that a mixed method approach to collecting patient experience information would be preferable. All suggestions for how this should be done involved both qualitative (group discussion or one-to-one interviews) and survey research.
- All except one of the teenage respondents reported that their personal preference would be to be interviewed either face to face or in a group discussion, as this would enable more information to be collected, and to hear others' experiences that may trigger thoughts and memories that would be of benefit. The one person who did not agree with this reported that she would not have been able to contribute to a discussion group or interview while on treatment because she had felt too ill to participate. Surprisingly, no respondents volunteered a telephone interview as a preferred method, but this approach should be considered.
- Several respondents said that it would be important that any qualitative interviewing of this type should be conducted by an independent person, not connected with the hospital or NHS. There was a fear that anyone connected with the NHS would not be impartial, and young people may feel intimidated or reluctant to be completely honest about their experiences. Some respondents reported the potential for possible repercussions of saying something negative to those providing care.

- There were several suggestions about WHEN would be best to collect information from respondents. All agreed that qualitative research should be undertaken some time after the start of treatment, so that responses could report on both the experience of diagnosis and treatment. However, one suggested it should be done periodically (once every few months) during treatment, another suggested 'about half way through' treatment, so that there would be an opportunity for the hospital to make adjustments in response to the patient experience information provided. Others suggested it should be collected towards or at the end of treatment.
- All respondents agreed that a survey was an important additional research method that should be used, and all felt that this should include open ended (free text) question(s) to enable respondents to elaborate responses to closed questions. All felt that the survey approach was the most democratic of methods, giving all patients the opportunity to respond, in contrast to qualitative research which would only involve some patients.
- There was agreement among all respondents aged 13 and over that the following themes/question areas, (many of which are used on the adult NCPES) should be asked of children and young people:
  - ✓ whether they felt they were treated with respect
  - ✓ views on the quality of communication with medical and other staff
  - ✓ views on the friendliness of staff
  - ✓ whether they felt fully informed about the care and treatment, including side effects of medications
  - ✓ whether they were fully involved in decision making
  - ✓ whether the environment was clean and hygienic

In addition, the following were identified by respondents as additional themes to include on a child and young person's survey (in no particular order of importance):

- ✓ whether young people felt they were treated as an autonomous and independent person, or whether medical staff spoke about them (with parents etc or other healthcare professionals) rather than to them
  - ✓ whether young people were able to see family and friends whenever they wanted
  - ✓ whether there were other children/young people of a similar age on the ward/unit (and opportunities for socialising and making friends)
  - ✓ whether there were adequate facilities to alleviate the boredom/tedium of being on treatment, including electronic gaming/devices and Wi-Fi etc as well as DVDs/books and traditional games
  - ✓ views on the school hospital service and on the support provided by the hospital with education more broadly (including working with respondents' schools to address uninformed 'teasing' and bullying related to cancer)
  - ✓ views on the quality of food provided
  - ✓ whether there was sufficient privacy (including noise)
  - ✓ whether they were able to regulate the temperature of their room/environment
- There was a range of responses to the question about how respondents would like to receive and complete a survey. Based on the findings from this study, a method that enables respondents to reply by either postal questionnaire or online would be required. In addition,

there was a reported preference for online invitations to be sent via email rather than text or a social media application.

- In addition to asking about preferences regarding how patient experience research should be conducted with children and young people with cancer, the study asked about respondents' own experiences. While most respondents reported that their experience of the NHS had been generally positive, several reported elements that were not positive and that could have been improved. These included for one respondent being permitted to be treated at a hospital of her/her parents' choice, being fully informed about side effects of treatments, the quality of food, the school hospital service and matters concerning privacy and equality opportunities for social relationships with children of a similar age, and environmental/comfort factors including control of temperature in hospital, the quality of pillows/bedding materials.
- An important finding was that for several respondents, the presumption that young people would want to have control in relation to the decision making about their treatment and care, was in fact, not a significant concern. These respondents explained that the reality of the cancer was such that they were happy to entrust the decision making to their parents and the medical staff, and that they were, in any case, simply not well enough to engage with these matters. Similarly, some respondents reported that their recollection of time spent 'on treatment' was very hazy, as they had chosen to seek medication that had enabled them to sleep through much of the treatment, because the alternative would have been a very painful and unpleasant prospect.



## 1. Aims and objectives

The broad aim of interviews with children and young people with cancer was to explore their views of how best to capture patient experience information from people like them. More specifically, the interviews sought to answer questions about 'when' during the so-called cancer journey it would be best to collect this information as well as 'how' this should be done. Finally, the interviews with older children sought to address the 'what' question, namely the areas of questions that it would be appropriate to ask about.

Additionally, the interviews with older respondents asked about individual experiences of care and treatment. These are also reported as they provide context to the reasons for the young people's responses.

## 2. Methods

The original research plan involved three discussion groups with children and young people and their parents to be held in the same locations as the professional groups (Leeds, Birmingham and London).

Key informants who had participated in the professional group discussions, kindly agreed to assist with the recruitment of children and young people by inviting current and former patients to attend a group discussion. The three groups were segmented by age (Leeds: under 11s, Birmingham: 12-15 and London: 15 and over).

For the London group, CLIC Sargent agreed to assist with recruitment by sending invitations to its database of children and young people with cancer. As much notice as possible was given, (between 4-6 weeks) and the groups were scheduled for a time of day, and day of week, that would be convenient to children at school (groups in Leeds and Birmingham were arranged for a day during half term week and the London group was arranged for a Saturday).

Interviews with children and young people were conducted following those with professionals and after the completion of the literature review. Both of these elements were used to inform the design of the study with children and young people.

### **Adjustment to research plan**

The first and most important observation in relation to the research approach was the difficulty experienced in recruiting children and young people to participate in the study.

In both Leeds and Birmingham only 3 children attended at each location. This appeared to be the result of general low levels of response to the invitations, and also to several last minute 'no shows' on the day. In both locations staff working at the children and young people's cancer treatment service, including staff whose posts were funded by the Teenage Cancer Trust, assisted by sending invitations to hundreds of eligible children and young people and their parents who had used the service in the recent past.

In London, despite the sending of invitations to thousands of families registered on the CLIC Sargent database and its Facebook page, and invitations to individuals known to key staff at UCLH (University College London Hospital), not a single young person confirmed that they would attend, and the proposed group had to be cancelled.

Following this cancellation and in consultation with CLIC Sargent and staff at UCLH, it was proposed to invite young people to an online focus group. Ten days' notice was given and again invitations

were sent via CLIC Sargent's extensive database of contacts and UCLH's own database. Unfortunately, once again the invitation led to no young people responding.

Following these abortive efforts to hold a group discussion with respondents in London and online, key informants in Leeds and Birmingham were re-contacted. With the agreement of NHS England, the group discussion method was abandoned in favour a series of telephone interviews. Invitations were sent via text message to young people known to a key link worker at Birmingham Children's Hospital, and this resulted in eight individuals expressing interest in taking part in an interview of whom seven were interviewed. The remaining one did not respond to the follow up invitation.

An incentive of £25 was offered to participants. All group interviews and telephone interviews with children and young people were conducted by Adam Crosier between January and March 2018.

### 3. Findings

There were important lessons from the study about the strengths and limitations of conducting research with (especially young) children with cancer.

#### 3.1 Interviews with under 11s

In developing the research session for the younger age group, we reflected on findings from the literature review, and the observations from interviews with professionals about which practices were likely to be effective in engaging this age group. Both sources had identified the importance of activity-based play, as a means of engaging younger children with the subject of patient experience.

We designed what we hoped would be a non-threatening and interactive event to engage the children in the subject of the research. An approach based on a 'customer journey map' had been developed in which children would be invited to think about the elements that make up a familiar journey (a family holiday for example), and to apply this knowledge to their own 'cancer journey'. The goal was to encourage the children to recognise that a journey consists of distinct stages and to consider both responses to the individual elements of the journey, the transitions and the overall experience. This would help to indicate *WHEN* on the journey/cancer pathway it would be appropriate to collect information about their experience, as well as *HOW* this should be done.

The intention was that children would be asked to attach different coloured 'post-it' notes describing their experiences at different stages of the journey, to a chart on the wall depicting the overall journey, with an indication of whether the emotional experience of each element was 'good', 'average' or 'bad', and to make the experience fun and visual. In practice however, this goal was not entirely achieved. As stated above, only three children attended (with their parents) and two of the three children were receiving treatment for their cancer at the time of the discussion. Both were connected to intravenous drips, and one had her leg immobilised, making movement impossible. The fact that they were on treatment and no doubt not feeling well physically, may well have contributed to them feeling unable to fully engage with the research session.

Moreover, at this group, each child was accompanied by a parent and in one case an additional family member. There were also several professionals from the cancer treatment service in attendance, both from a point of view of safeguarding and professional curiosity. In retrospect, it is likely that this substantial number of adults was a barrier to the children feeling comfortable to participate.

More effort should perhaps have been made to request parents to allow the children to answer for themselves and to limit the number of professionals in the room. In practice, questions were frequently answered by parents if (as happened) children were not immediately forthcoming with responses. However, this level of 'speaking on behalf of' their children was an important observation. It appeared completely normal for the parents to respond to questions that were addressed to their children about any aspect of the care and treatment, including the children's emotional responses and feelings about these concerns. Neither the children nor the parents appeared to find anything unusual about this.

In an attempt to address this situation where parents were speaking on behalf of their children, the second half of the session was restructured so that parents were separated physically from the children. As a result, there was more response from the children to questions about how they would like to provide feedback on their treatment and care.

## **Limitations of the research approach with young children**

However, another important observation was that the children in this group appeared to be both shy and compliant and consequently were 'eager to please' and apparently very responsive to any suggestion about how patient experience information may be collected from children and young people. This may have been the result of the unnaturalness of the research setting and the children's wish to be helpful. It may also have reflected the age of the children involved, and it may also have reflected the individual personalities of the children in the group.

Whatever the reasons, a consequence of this compliance was that it was very difficult to assess which research method(s) to explore views about their experiences were genuinely preferred, as the children tended to agree with any proposal put to them. It was difficult to draw meaningful conclusions from this one group.

## **Focus on immediate, 'here and now' issues rather than abstract thought**

There were however, some important findings that were relevant to the study. These included the observation that children of this age group were capable of a) knowing that they did not like certain aspects of care and treatment and b) knowing that they were able to make their voices heard.

Examples were given of when this occurred. In one case, a child had a fear of needles, another found swallowing tablets very uncomfortable and the third had a strong dislike of the plaster that connected the intravenous port to his body. In all three cases, the respondents reported that the staff had been very patient and sensitive in addressing their concerns, and all three were happy with the quality of care provided. The important aspect of these examples was that they were all somatic concerns that impacted the respondents in an immediate way, either through physical pain or anxiety. This form of 'patient experience' was clearly understood and children reported that they were able to describe it and to seek to have it addressed.

On the other hand, it was clear that some of the patient experience 'domains' that were identified as important to some older children and young adults, including questions of control and autonomy for instance, were not grasped by this age group. Abstract thought was very limited.

Another observation was that children's ability to reflect on their care and treatment at this age was limited to the present and the very recent past.

Perhaps the clearest and most representative response that illustrates the level of the group to engage with questions about patient experience, was that when asked who they would like to talk to about their care and treatment, the answer given by all three was 'mummy and daddy'.

Having said this, when presented with options about how to complete a survey (that did not involve their parents), all three agreed that they would prefer to use a hand held electronic device (an iPad or tablet for example) to do this. They also agreed that they would prefer to see symbols (smiley or sad faces for examples) rather than words to indicate levels of agreement/ disagreement with statements.

### 3.2 Interviews with teenagers

The interviews with teenagers were much more successful and yielded very rich information.

The group discussion at Birmingham Children's Hospital involved three young people aged M13, F15 and M17. The responses from this group have been combined with the responses from the telephone interviews for the sake of simplicity. There were seven telephone interviews with teenagers (M16, M16, F15, F13, F14, F15, M14). The group interview and telephone interviews focused on the same issues.

Each telephone interview lasted between 30-45 minutes and all were conducted in March 2018.

To guide the telephone interviews, background information and a series of questions were sent by email prior to the interview to the young people who had agreed to participate, so that they had time to prepare and consider their responses. However, only two of the telephone respondents had read the information in advance of the interview. This may have been due to the email being diverted to 'junk' or simply due to oversight. However, this observation is mentioned as a consideration when deciding how to send information to young people online.

The interviews were rich in detail about the young people's experiences of care and treatment. Some detail of the experiences of the respondents is included in this report, to provide context and colour, and because in many cases the experiences informed directly the views about the research questions.

Overall, the respondents were very thoughtful and considered in their responses. All appeared to value the opportunity to contribute their thoughts and experiences and were keen to know that their views may help NHS England to improve the quality of care and treatment for others.

#### Views on the importance of collecting and using patient experience information

All the teenage respondents interviewed by telephone were very keen that the views and wishes of young people like themselves should be sought and acted upon both 'in the moment', in relation to care and treatment affecting patients, and more generally, to improve the quality of service provision.

'I think it's really important that you can influence things that affect your care, because some things affect you but not others. I think it's important to take into consideration what each person wants. I feel that maybe if I'd been younger I would have preferred my parents to talk to me (about the diagnosis), rather than some doctor I didn't know.' Female 15, High Wycombe

'I think it's important to ask about all the places where people are seen. Personally, I've had good experiences everywhere, but I know some people haven't and I think it's important to ask about all the places where we are seen.' Female 13, Wolverhampton

'At the end of the day it's your body, your life and once you reach a certain age you should be able to make decisions for yourself.' Male 16, Wolverhampton

'They always asked me if I had any questions or needed anything. I wouldn't have been happy if they hadn't taken account of my feelings.' Female 15, Shrewsbury

Overall, respondents felt that it was important for the local services to collect information about the experiences of patients they treated through a series of regular qualitative approaches (group discussions and/or individual interviews with children and young people with cancer), and that these should be supplemented with a survey that was sent to all patients (over a certain age). There was

agreement that this survey should be uniform across the country and that it should be used to assess services and to improve the quality of care provided.

There was a desire to know that the information provided would be used to address both individual and local service level concerns, and to improve the quality of cancer services for children and young people overall.

For a minority however, (those interviewed in the group setting) the presumption that children and young people with cancer would be especially concerned to ensure that they were fully involved in all aspects of their treatment and care, was not so clear cut. Of the three respondents, two appeared not to have questioned this notion prior to being asked, and when they were, responded that they had been too ill to even consider the notion of wanting control over decision making. Instead, they reported that they had been very willing to entrust all matters to do with their medical condition to their parents and the medical staff.

‘To be honest, I was so out of it, physically and things, really sick all the time, that I wasn’t thinking like that... I just went with what they (parents/medical staff) decided...’ Male 17

#### Views on HOW to provide feedback

While all respondents reported that they would favour a mixed method approach (qualitative and survey based), one respondent – the person who had the longest period of in-patient treatment – reported that she would have preferred to complete a survey rather than be interviewed in person. Her reasons for suggesting a survey reflected her personal experience, stating that it would have been impossible for her to contribute to a face to face or group interview during much of her treatment, because she had felt too poorly.

‘I feel that a group would be good for support rather than to give information. If I was invited to one now, I wouldn’t mind going to it. But when I was ill I wouldn’t have done it. I would prefer a survey. I was on a clinical trial and for that they did send a survey every couple of months. And I think that for me, when I was in hospital, for a lot of the time I was just too ill to engage with a group discussion or anything like that. The advantage of a survey is that you can look at it when you want and fill it in when you feel you can. And it should have open questions as well so that you can write in your feelings about questions.’ Female 15. High Wycombe

#### Views on WHEN to conduct the data collection

All respondents (other than the one person already described) reported that the **survey** would best be administered AFTER the completion of treatment while responses to the appropriate point to collect qualitative data were more varied.

All acknowledged that it would be important to conduct the **qualitative** data collection at a point in time after the initial diagnosis and commencement of treatment, in order to obtain a view that reflected the different stages of the journey.

The responses reflected in part the length of stay in hospital and the overall duration of their treatment. The respondent who had the longest period of continuous treatment said that she felt it would be best to be asked periodically (every few months) for her reflections on her experiences.

‘My experience has been very long (from August 2015 to January 2018) so I think it should be done at regular intervals. I think patients would be happy with that, every few of months or so. If I’d been asked say 3 months into it, I’d have been able to comment on the diagnosis part and the early part

of the treatment. But then a few months later, things were different, and it would be best if I'd been asked again at that point.' Female 15. High Wycombe

One respondent reported her view that the collection of information via group discussion or one to one interviews should be undertaken some time after the diagnosis and commencement of treatment, but within a time period that meant that the respondent would be able to judge whether things had improved as a result of the information provided.

'I think the group discussion would be a good idea – both at the end but also half way through. Because then they could talk about what has happened already, but they could also discuss what was coming up. If you had had a bad experience, you're putting through some ideas that could make it better. If you only do it at the end of your treatment, you're not going to know if these things could have been done to make it better.' Female 13. Solihull

Another respondent felt that it would be preferable to conduct the research exercise towards the end of the treatment period and pointed out that re-visiting the experience could be painful and upsetting.

'To get something meaningful it has to be done some time into the treatment. You can't do it early on and expect a full overview. So maybe towards the end of your treatment. Once it's done you want to put it behind you, because it's not pleasant really.' Male 16. Wolverhampton

#### Views on how best to administer a survey

Perhaps surprisingly given the ages of those involved, two respondents felt that a traditional paper and pen survey, sent by post to their home, would be preferable. The first favoured this method because he lived in a very rural setting in Wales where there was only intermittent access to the internet and no WIFI at home, while the second reported that, 'contrary to what people think about people my age (13 years) we don't all have access to email or social media.'

The remaining respondents all felt that an online survey would be the easiest to administer (for NHS England), the cheapest (which was identified as a factor) and the simplest to complete.

These respondents felt that an online invitation should be sent by email rather than text as they claimed to ignore 'random' texts and email lent an air of authority. Again, based on the experience of this study, the use of email should be carefully considered. Only two of the eight telephone respondents had received and opened the email sent to them in advance of this study.

'I guess it's most convenient to do it online really. And then you just send it off to them. I definitely think most people nowadays have a tablet or a phone or a computer. I think it should be sent by email. Because knowing myself, I reckon I would ignore random texts, and email is a bit more official.' Female 15. Shrewsbury

#### Views on how to promote and incentivise completion and return of the survey

Respondents recommended that in order to encourage response and completion of the survey, the invitation should include clear information about the value and purpose of the survey. Wording should include the information that answers would be used to help the NHS to improve care for other young people with cancer. Asked about the potential impact of a financial incentive, all respondents reported that a small financial incentive (£5-10) would help to ensure completion and return of the questionnaire.

'For the survey, online would be easiest. By email. A reward would motivate people to do it. I think about £10.' Female 15. Shrewsbury

'I would feel motivated to complete and return it. You could say how much it is going to benefit people to come and how important it is for you guys to send it back. I think some people will be motivated by an incentive of a voucher. I'm not sure how much money would be enough! Maybe £5 or £10. I think that would make a difference to some people.' Female 13. Solihull

'If it's a survey that's sent to you, some people might think, 'what benefit is it to me to do this' especially if they've had a negative experience from the NHS, so yeah, I think a small incentive would help. Even like £5 would work for a survey because it's a small amount of your time. I think a voucher for Amazon or Argos. You can redeem codes.' Male 16. Wolverhampton

'I think a voucher would work. I'd do it for a fiver. If the child is younger the money isn't going to make a difference. For someone my age, money is much more important. Maybe from the time they go to secondary school around 11. I think it would make a big difference. An Amazon voucher or Argos would be a lot better than a Tesco's voucher for instance.' Male 16. Welshpool

#### Age appropriateness of a survey method

Teenagers felt that such a questionnaire would be suitable for respondents from roughly secondary school age, and that a modified, simpler version would be appropriate for children aged 7/8-11. For children under this age, they suggested questions should be asked in the form of interviews and group discussions. And finally, for very young children, they agreed that parents should respond on the child's behalf.

#### Views on WHAT questions should be asked on a survey

Respondents were invited to suggest question areas that should be included on a survey of children and young people with cancer.

The following were used as 'prompts' and respondents were asked whether they felt that these would be appropriate questions for young people of their age. In all cases, each of the question areas was considered appropriate.

- Whether you felt you were treated with respect
- Views on the quality of communication with medical and other staff
- Views on the friendliness of staff
- Whether you felt fully informed about your care and treatment, including side effects of medications
- Whether you felt you were fully involved in decision making
- Whether the environment was clean and hygienic

Respondents were then asked to add their own suggested question areas that they felt should be included in a survey of patient experience.

- Whether young people felt they were treated as an autonomous and independent person, or whether medical staff spoke about them (with parents etc or other healthcare professionals) rather than to them
- Whether young people were able to see family and friends whenever they wanted
- Whether there were other children/young people of a similar age (and opportunities for socialising and making friends)
- Whether there were adequate facilities to alleviate the boredom/tedium of being on treatment, including electronic gaming/devices and WIFI etc as well as DVDs/books and traditional games



- Views on the school hospital service and on the support provided by the hospital with education more broadly (including working with respondents' schools to address uninformed 'teasing' and bullying related to cancer)
- Views on the quality of food provided
- Whether there was sufficient privacy (including noise)
- Whether they were able to regulate the temperature of their room/environment

All these issues were mentioned by at least two respondents, with questions about being treated as an independent agent, as well as those about food, privacy, noise, and facilities to alleviate boredom, being most frequently mentioned.

'These [those read out] are the questions I'd want to answer. Distractions to alleviate boredom, that's a good question. In my experience there was a room for kids on the ward. I found that good. Socially and privacy – that's important. There was only one person near my age and she finished two months into my treatment, so there was no one I was friends with really after that. The other children were like 9 years old. And ask about hospital school and whether this was any good.'

Female 15. High Wycombe

'I'd say you should you use the same questions [as those read out] but for teenagers include the questions you asked me – like was I able to make my voice heard, was I treated as an independent person and was I able to make decisions for myself. Those sort of questions are important for teenagers because some teenagers don't get an input on their treatment. Also include questions about whether there were enough games and things to help with the boredom. And privacy – that's an important question.' Female 13. Wolverhampton

### Experiences of treatment and care

Overall, the young people interviewed for this study reported a generally positive (and in many cases a very positive) experience of care and treatment provided by the NHS. This was particularly noticeable in response to whether they felt their voice had been listened to by medical staff, and whether they had been enabled to make their views known.

### Positive experiences – being informed about diagnosis and treatment

An area that appeared to be well managed in general was the experience of how the diagnosis and treatment plan was communicated and discussed with the young people. None of the respondents reported felt excluded from this process. All felt that the manner in which doctors had spoken with them (and with their parents at the same time) had been unproblematic. None felt that that medical staff had spoken about them but not to them, nor that they were made to feel that their views were not important.

'When they were deciding the treatment, I felt I was fully involved. I was always asked before they were doing anything. They always had me and my parents there and they talked to us all, explaining it all to me and them.' Male. 16. Welshpool

'I've always been told that they would never do anything without talking to me first. They said I'm old enough to make my own decisions and I have been heard at all times. They have always talked to me and my mum and dad at the same time. I've never felt excluded.' Female. 13. Wolverhampton

'Everything I asked, I got an answer to. I was definitely listened to. And that was true the whole way through. With the surgeon, I wanted to see the CT scans and she was fine about it. At every shift change the nurse would come in and introduce themselves and say, 'just push the buzzer if you wanted anything'. The diagnosis was as positive as it can be. First and foremost, they were talking to

me. My mum was there too. But it was at the point where I could make my own decisions, so they were talking to me.’ Male 16. Welshpool

‘They listened to me most of the time and my voice was heard. There weren’t any times when I was treated in ways that were bad. I was diagnosed at (hospital) and the doctor explained things quite well. I felt that they were speaking to me. They always asked me if I had any questions or needed anything. My oncologist would always ask me if I had any questions.’ Female. 15. Shrewsbury

### Negative experiences

While the general picture of communication about diagnosis and treatment was positive, there were isolated instances of disappointment where respondents felt they had either not been fully informed about the possible side effects of medications, or where they felt that medical staff had not engaged with them respectfully.

One person (Female 15. High Wycombe) reported a series of negative experiences, the most significant of which was not being permitted to be treated at a hospital of her (and her parents’) choice (hospital 1), resulting in a more difficult journey that she was required to attend (hospital 2), as well as poor quality of food, and not feeling that she was fully informed about the possible side effects of medications.

‘We asked to stay at (hospital 1) because it was more convenient, but they just refused and said, ‘no, because it’s closer to you, you have to go there’ (to hospital 2). But it was difficult for us to get there and it’s along country roads and things. They just really refused. I would have liked them to have listened to me and let me stay at (hospital 1), not (hospital 2). But they said ‘no’. It took a day or two extra to get what I needed as a result.’ Female 15. High Wycombe

‘I don’t think I was informed of all the side effects of my treatment and I wasn’t prepared. A couple of months prior, they said that they’d arrange a meeting with my consultant. But that never happened, and we never received a date. You know, now when I go as an outpatient I see comments cards, but at the time when I was inpatient, I never really did any of that – I wasn’t really well enough to do anything like that. I don’t remember anyone saying, ‘if things aren’t good, here’s how you can let us know.’ Female 15. High Wycombe

Other respondents reported their experiences of care and treatment more positively, but did discuss moments of care that they felt had been concerning.

‘In (hospital) they would come in every morning and look at you and they go into a group without talking to you. That was a bit weird... They explained a lot. But they didn’t explain what would happen when I came off steroids and the way my skin went tight. The big things they did – like feeling sick and hair loss – but maybe they didn’t know about how the steroids would affect me, but that wasn’t explained.’ Male. 16. Welshpool

Female 15 High Wycombe also felt that it was disappointing that the quality of provision for teenagers like herself that was available at (hospital 3), was not available at the hospitals where she was treated.

‘In (hospital 3) the TCT unit was from 13 plus and in (hospital 4) it’s 16+ and there weren’t many services for my age group. There was stuff for younger kids, but nothing for 13-14 year olds. In (hospital 3) they had an adolescent ward that has all the teenagers in one ward, and it was well equipped but there was something like that in (hospital 4) but only for people over 16. And at (hospital 3) there was someone from TCT who provided information and showed support and she

was really nice providing support, and checking up. And then coming back to (hospital 4) there was nothing like that. There's nothing like that in (hospital 4) for under 16s. It's all the same stuff just for 16 and over. We were asking about it, but they just said, 'no sorry'. At (hospital 2) it was the same – only for 16+. The nurses were very nice but nowhere is as good as TCT at (hospital 3).' Female 15. High Wycombe

#### Views on the importance of being able to have control of decision making

Without exception, all telephone respondents felt that it was very important that they were given an opportunity to express their views and opinions on their experiences as a patient. For all respondents it was very important that their needs and views were sought and addressed both throughout their course of in-patient treatment and beyond.

'It was really important to me that I was involved fully in the decisions about treatment. I was made very aware of everything that was going on. At the end of the day it's your body, your life and once you reach a certain age you should be able to make decisions for yourself.' Male. 16. Wolverhampton

This view contrasted with the three respondents interviewed at Birmingham Children's Hospital, for whom the question of control and autonomy appeared to be less important. They all reported that they had been content to give over responsibility for their care and treatment to their parents and the medical staff, and that the business of coping with the cancer itself had been such a challenge that they did not have the motivation to be very concerned with whether they had been fully informed about all aspects of their care and treatment.

#### Experiences of when respondents' needs were listened to and addressed

Respondents were very appreciative of the care taken by staff to get to know them and to make them feel as comfortable as possible.

'My support nurse at (hospital) was the reason I went there. She was brilliant and just understood me.' Male 16. Wolverhampton

'I filled in the cards on the ward at (hospital) quite a few times. If you had a good experience. There's a box for any room for improvement. You write what ward you're on. I wrote how helpful and cheerful the staff were and how nice they were and how much they do to cheer you up. You can write about a particular member of staff and put their name down and the message gets passed on and then the hospital praises them I think.' Female 13. Wolverhampton

'They did listen. I was in a lot of pain and they changed that. And each time there was a problem with pain, they changed it. They always asked if I wanted anything before they left the room. None of the nurses were in a rush. In some hospitals you get the feeling that they're too busy to listen. But the Macmillan nurses weren't like that. There was always someone coming up and saying, 'if you need someone there's always someone to speak to.' Female 14. Coventry

'In (hospital 1) the pillows would scratch my head and the charity would bring a new pillow within a couple of hours... In (hospital 2) (staff member) was always helping to distract you – to take you away from the treatment.' Male. 16. Welshpool

#### Areas for improvement: food, school hospital and support at school, privacy/sociability

Several respondents mentioned without prompting the quality of food in hospital as a major concern.

'The only problem (at hospital 1) was the food. That was also the case in (hospital 2). But there, my mum could buy better food outside and bring it to me.' Male. 16. Welshpool

Where respondents had longer periods as an in-patient, the issue of food was clearly more of a concern.

'In (hospital 1) the food was dire. It was micro-waved and really hard, but I didn't know what to say. It's not like they're going to change it overnight. In (hospital 2) the food was very good.' Female 15. High Wycombe

Two respondents also volunteered information about the impact of their cancer on their sense of self confidence. One suggested that it would have been helpful if the hospital could have done more to tackle misunderstanding and ignorance about cancer and treatment for cancer at his school.

'My friends were really good with me and treated me like a normal person, but not everybody knew about my cancer. I imagine that it's worse in a bigger school. The hospital could send someone out to talk at the school to explain what's going on. Because everyone asked me, and it's not something I really want to talk about. If they could explain what I could and couldn't do, that would have helped big time.' Male 16. Welshpool

The school hospital service was also commented on by other respondents, some of whom reported that it was not well connected to the local school in the town, and that as a result, work was set that was inappropriate for the age group.

'They had someone come in but she could only do work that was for the year below me. It was because they're not working with the local secondary school in (hospital).' Female 14. Solihull

'The school service was ok but they only came on the last day I was there.' Female 15. Shrewsbury

Several respondents commented on the fact that they had felt either isolated in a room away from other people, or conversely that there had been insufficient privacy.

'The social aspects: that was not so good. Because in (hospital) all the cancer patients are put in a side room, so you don't see people.' Female 14. Solihull

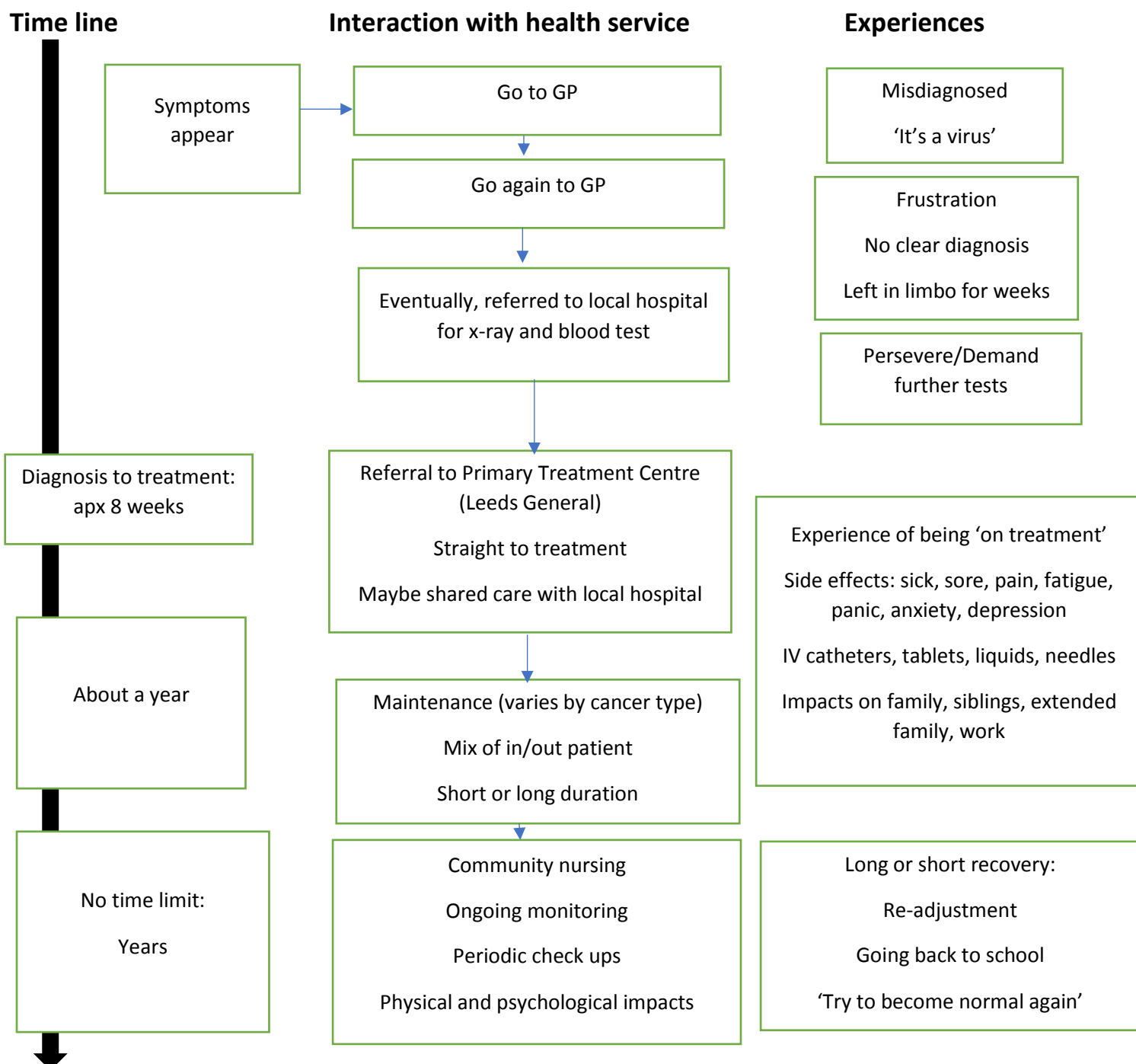
## Appendix 1 Parents of children with cancer

The study did not explore in depth the views of parents, about how they would prefer to provide feedback about their experience of cancer treatment services.

However, during the group discussion held at Leeds General Hospital, parents were asked to contribute their understanding of the elements of the cancer journey their children were experiencing, and also to provide their views in graphic form, about how they would like to provide feedback at key stages of the journey.

The following charts are a representation from that discussion.

### A 'composite' patient journey for parents/children with cancer interviewed at Leeds General Hospital



## How parents would like to provide feedback

HOW	STAGE OF JOURNEY	WHO	WHEN
Online feedback Visible and transparent	Diagnosis GP/Walk in/A+E Dept	A nominated Feedback Manager and mediator	24x7
Verbal Immediate feedback to Ward Manager (for urgent issues)  Written Feedback form, particularly for positive experiences	Surgery/treatment Principal Treatment Centre or Local Hospital	Ward Manager	24x7 and immediate
Both written and verbal	In/Out Patient treatment	An app online and an online survey for children	Survey: periodically (every few months)