



# Being Participatory Through Interviews

# 6

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## 6.1 Introduction

This chapter takes as its starting point the following ‘top tip’ from The NSPCC website:

‘Children are experts when it comes to their own lives, but you can help them express themselves’ [1].

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We, as researchers, need to be aware of the many different ways available to us to help children and young people to express themselves. One such approach is the research interview, a place where researchers hold conversations with children and young people: these have in the past been avoided. The long-held belief that children and young people did not have the social competence to recall credible accounts of their experiences has been replaced with a more contemporary view that prioritises children's rights in a broad framework of child-centred research [2, 3]. As a result, there are now vast amounts of literature detailing different ways to carry out interviews; see, for example, O'Reilly and Dogra [4] and emerging literature on undertaking interviews in the home [5], as well as interviewing children and young people about sensitive topics [6]. Solutions to what were once described as the challenges of using interviews, such as language, literacy, age and cognitive development, have been identified, and interviews are now described as a highly versatile research 'tool'. The researcher of today is presented with many different ways to use interviews, thereby realising the benefits the method has for collecting data directly from children and young people [7]. We can now be confident that interviews can:

- Generate insights into participants' lives which would otherwise remain hidden to healthcare professionals and researchers
- Give access to individuals' understanding of the contexts they are in, to their opinions, aspirations, attitudes and feelings
- Generate complex insights into others' perceptions of social phenomenon and why they make certain choices and act in the way they do [8]

One main reason for this increased confidence in the role of interviews, within the 'toolkit' of methods used by researchers working with children and young people, is the ability to make these 'conversations' nonthreatening, more participatory and individualised to the interviewee ([4], pp. 95–108). By being participatory, we mean a research style, an orientation to inquiry, that enables us to work with our research participants in the 'knowledge-production process' ([9], p. 2). Participatory research is designed and executed in collaboration with the target population—it is research with the population, not just on it: this shift in methodological thinking in research methods has been charted elsewhere (see, e.g. [2, 3, 10–12]). What we offer here are more of the practical issues associated with using the research interview in a participatory way with different child populations, techniques and strategies we have learnt through 'use in the field'. Our focus is on practice, with each example illustrating the basic principles of openness, good communication and the appropriateness of the method to the study population.

Our intention is not to reproduce the many different theoretical perspectives on the use of interviews with children and young people; the reader can refer to the growing body of texts that do that (see, e.g. [4, 8, 13, 14]). We first present a research study, to present an exemplar for how participatory group interviews have been used with a child cancer population. We then give examples of techniques, again from our own research studies, in which interviews have been used in a variety of ways: reflecting on how interviews were actually used and how the method was adapted for the population. We hope by taking this very practical approach we offer what is

often missing in research articles: the real data about the method and how it was applied in that particular study. We present in this chapter group interviews, focus groups, peer-to-peer interviews, interviews with children and young people who have a learning disability as well as a more traditional approach to interviewing adolescents: providing examples where flexible techniques have helped to enable active engagement with diverse research cohorts. Underpinning the following sections are Shier's [15] five levels of participation: (1) children and young people are listened to; (2) children and young people are supported in expressing their views; (3) children and young people's views are taken into account; (4) children and young people are involved in decision-making processes; and (5) children and young people share power and responsibility for decision-making.

## 6.2 Example from a Research Study

### 6.2.1 Children and Young People's Experiences of Cancer Care: A Qualitative Research Study Using Participatory Methods [16]

In this study, a range of approaches to data collection were used, including play and puppets with children aged 4–5 years, draw and write with those aged 6–12 years and an activities day with young people aged 13–15: it is the activities day referred to here, more specifically the focus group, that was part of the overall day (see Table 6.1). Using these different approaches to interview, we sought:

1. To explore the perception of children and young people with cancer regarding their care and support needs
2. To map the needs of children and young people with cancer from their perspective
3. To gain an understanding of their views of current cancer care services, including positive experiences and issues that have been less positive
4. To offer developmental work on fostering avenues of communication with children and young people with cancer

**Table 6.1** Plan of the activities day

Listening to children and young people with cancer project	
12:00 p.m.	Introductions
12:20 p.m.	Split into pairs to interview each other about your experiences of hospital
1:00 p.m.	'What is important for you?'
	We will talk about the interviews and write down on post-it notes the points that came up. These post-its will be stuck onto the wall to show what you think are the most and least important aspects of what we have talked about
1:30 p.m.	Lunch
2.15 p.m.	Focus group
	We will talk together as a group about the things that came up in the morning sessions
3.15 p.m.	Drinks
3.30 p.m.	'Choice of hospital' exercise and your thoughts about the day
4 p.m.	End

### **6.2.1.1 Target Population/Who Participated/Recruitment**

Participants were recruited from three hospitals, two for the study with adolescents. At each of these hospitals, the researcher identified suitable participants with assistance from clinical staff. The researcher or clinical staff approached potential participants when they attended as an inpatient or outpatient. Posters were also displayed in each of the hospitals. Young people who expressed an interest in taking part were given time to consider their decision. Confirmation of participation was ascertained via telephone contact if the young person was at home or at a face-to-face visit if in hospital, and background information was recorded. If the young person declined to take part, they were asked if this information could be recorded to monitor whether a representative sample of young people was included in the study.

Two activities days were originally planned; one for young people aged 13–15 years and one for those 16–19 years. The study was conceived this way to take into consideration the potential for a wide variation in emotional and social maturity of individuals. However, it was difficult to find a date when the older group could attend: individual interviews were carried out instead and with anyone from the younger age group who were unable to attend the activities day or felt more comfortable talking on a one-to-one basis. The participants selected the interview venue; five were interviewed at home and two when they were in hospital. It was left up to the young people to decide whether they wanted a parent to be present during the interview. Four young people gave their views at the activities day.

### **6.2.1.2 Research Methods/Tools Used and Rationale for Their Use**

The ‘activities day’ was facilitated by two researchers and comprised a focus group alongside other methods including peer interviews and written tasks. It took place at a weekend in a private room of a pizza restaurant. The day lasted 4 hours with the focus group taking place after lunch, allowing participants to get to know each other beforehand, which facilitated open discussion. Having a variety of group and individual activities, selected to suit young people’s tastes and skills, worked well. At the end of the day, a ‘secret box’ was provided where participants could write down and post anything else they had wanted to say but felt unable to share in the group [17]. We sought to encourage both individual and shared perspectives through our approach to data collection.

It has been suggested that focus groups can work well with children aged 6 and above as by this age children usually have the social and language skills to engage in group discussion [18]. Participants are usually invited to attend a focus group because of common experiences related to the topic of interest (in this case young people who had cancer), and they are encouraged to share their ideas, attitudes and perceptions in a relaxed atmosphere. Focus groups allow participants to ‘feed off’ each other as they respond to each other’s comments and support or disagree with each other; thus they can provide richer data than an individual interview: used not to reach consensus but to better understand different needs and opinions. Groups with children and young people can be fun to undertake, and the presence of peers can produce a more natural environment and reduce some of the ‘power’ issues involved where there is an adult researcher interviewing a child on a one-to-one

basis. We thought that all of these characteristics would enable young people to recount their story better and that we could maximise this ‘group feel’ to help them share what was important. Although there are similarities, a focus group involving children or young people demands a slightly different approach than a focus group with adults [19]. This includes modifying the number of participants, format and length of the groups: all of these issues are discussed later under the heading ‘techniques’. For all of these broad reasons, using a focus group was an obvious choice.

At the outset we wanted it to be more than what might be traditionally thought of as a focus group. We wanted to use activities that would allow space and time for young people to think on their own, and we also wanted to draw upon their experience from the outset, hence the inclusion of the peer-peer interviews. We provided a ‘starter’ list of questions and encouraged young people to ask other questions they thought important. Each participant selected one key headline to share with the group. These were then shared and discussed as a group, allowing participants to provide more detail if they wished about the story behind the headline. The focus group questions emerged out of these two exercises: the interview schedule was generated from participants’ contributions. Although this approach to developing the focus group questions required the researchers to be very organised, and confident in the approach taken, the benefit of ‘going deeper’ and engaging in dynamic conversations shaped by young people’s accounts was our reward.

### **6.2.1.3 Ethical Issues**

Signed parental consent was obtained for participants under 16 years old prior to data collection. Participants over 16 signed their own consent forms and participants under 16 signed an assent form. Before each interview/focus group began, the researcher outlined the study again, what it involved, reaffirmed that it was their choice to take part or not and explained that they could stop taking part at any time. The protocol was subject to ethical scrutiny at the NHS Trusts where data were collected and approved by relevant Local Research Ethics Committees. To ensure confidentiality, the young people’s names were replaced by pseudonyms. All the young people were given a voucher for participating; they were not informed of this until after they had participated in order to avoid coercion.

### **6.2.1.4 Findings**

Data analysis was based on an inductive thematic analysis approach, initially analysed within the defined age groups associated with each data collection method and then brought together into key themes through a process of iterative integration [20]: these findings are reported in Gibson et al. [16]. Five themes, with subthemes, were identified from this data set:

1. ‘Life in hospital’, food, environment, activities, privacy and keeping different ages separate
2. ‘Making the hard times better’, parents, friends, nurses and keeping things as normal as possible

3. 'Reading the signs, watch, think and then act'; relationships with nurses, doctors and other staff; being left alone; being able to ask questions; and being listened to
4. 'It's my body—talk to me, not my parents', information, offer choice and ask, don't presume and be prepared
5. 'Treatment—getting on with it', know own body, how treatment makes me feel, getting on with it, waiting and specialist vs. nonspecialist care

### **6.2.1.5 What You Would Do Differently in the Next Project**

Checking out the venue thoroughly is really important. There were two issues with the venue for the activities day that were not apparent on first booking: the first was that although it was a private room, other people in the restaurant had to walk through our room in order to access the toilets with changing facilities. Secondly, the room was open plan, which meant noise from the kitchen downstairs travelled making it difficult to record discussions.

### **6.2.1.6 Impact on Participants**

The participants commented afterwards that they had enjoyed talking with other young people with similar experiences to themselves. Two participants kept in touch with the others following the activities day. Some of those aged 16–19 commented that meeting other young people with cancer was something they looked forward to and had influenced their decision to take part in the project, so they were disappointed when we were unable to schedule a group for them. Perhaps paired or peer interviews might be a solution where a larger group is not possible. The researcher contacted the young people/family by telephone in the week following the activities day, to check that the day had not raised anything distressing for them. Overall, the participants' feedback indicated that taking part had been a positive experience for them. One parent commented that she thought her son had been quieter than usual during the evening following the group, she thought that it had made him reflect more on his cancer and situation, but she did not feel this was a cause for concern.

### **6.2.1.7 Dissemination Techniques**

A summary leaflet (two sides of A4) was written to feedback the findings of the study to participants. This was posted to the children and young people at home. Three versions of this leaflet were written to reflect the findings from the different age groups of children and young people participating in the study and to tailor the information to reflect their understanding/reading ability. Young people were also sent a copy of the full report from the project. We received feedback from young people on our summary leaflet prior to finalising.

### **6.2.1.8 Conclusion**

Planning a focus group with young people is intensive in terms of the organisation beforehand, but as the above findings demonstrate, focus groups can provide rich data. The participants appeared comfortable to discuss their experiences and views with each other; this was aided by them having the shared experience of cancer and

having time to get to know one another first prior to the focus group. Using a variety of different techniques in addition to the focus group enabled the participants to express their views in different ways and privately if they wished. The participants, as well as the researchers, reflected that overall the activities day was an enjoyable experience.

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## 6.3 Technique Section

Here we reflect on the use of the interview with different populations, in different ways, to show its versatility: a technique that can be part of a ‘toolkit’ of methods. We offer our top ten tips for the use of interviews with these different populations. We start with focus groups, reflecting on the study we presented in detail earlier in this chapter, making explicit techniques that will help in the running of successful groups.

### 6.3.1 Focus Groups with Children and Young People

In a study seeking children and young people’s views and experiences of cancer care, one of the data collection methods we used was a focus group [16]. Our intention at the outset was to use an approach that would facilitate both group and individual contributions.

Composition of the group is crucial. To increase involvement, level of engagement and quality of responses, limit the numbers to four–six participants when working with younger children and up to eight if working with older children [18]. Even when participant numbers are small, rich data can still be yielded. Over-recruiting by a few participants is often a good idea in case of cancellations. Holding groups with children of similar age (2–3-year difference) helps to prevent children’s responses from being overly influenced by older peers and enables the facilitator to pitch the discussion at a level that is accessible and interesting for all participants. Another important consideration is the gender mix in the group, and depending on the topic of discussion, it may be appropriate to have single-sex focus groups.

Preparation is key. Focus groups are often perceived as saving time when compared with individual interviews; however they require considerable preparation. The venue and timing must be carefully planned. Holding the group at an ‘interesting’ location may encourage attendance. The venue should be easy for participants to get to and not start too early in the day; this may particularly put young people off attending. Recognising the other commitments that children and young people have is important, so timing the group out of school hours, perhaps at a weekend, may increase attendance. An ‘ideal’ time for all participants to attend is always a challenge, as indicated in this study where we were unable to schedule a group that fitted around young people’s weekend jobs, college work and sporting activities. Offering to reimburse travel expenses for participants and an accompanying adult (or friend in the case of young people) is important. The duration of stand-alone focus groups

with younger children (e.g. those under 6 years) should not be more than 45 min to 1 hour, while this may be extended to 90 min for young people [21].

Setting the tone, getting the environment right helps everyone. Children and young people are more likely to be engaged in focus groups that foster a relaxed environment where they feel comfortable enough to express their thoughts and feelings. It is important to put participants at ease as soon as they arrive through informal introductions to other participants and the venue. Participants should also be allowed to leave the focus group before it ends if they so wish, and given that young children may be involved, it is important that parents are aware of this and can be contacted if necessary. Once everyone has introduced themselves, ice-breakers are a good way to put children and young people at ease and build trust with each other as well as with the facilitators. Ice-breakers serve a number of functions: they help participants to feel relaxed and comfortable before starting data collection; they give everyone a chance to practise saying something in the group; they help the participants and facilitators to get to know each other; and they also help to establish an environment in which sharing and listening are valued. For example, participants could pair up with a partner to learn something about each other and take turns introducing their partner to the rest of the group, or a game can be introduced that gets children and young people to talk to each other. Ice-breakers need to be chosen carefully, based on the likely skills, interests and capabilities of the participants, taking account of disabilities or difficulties some children may encounter. Participation of the facilitators in the ice-breaker is a good way to break down the more traditional adult-child relationship often associated with a classroom setting and helps the participants to view the facilitators in a more informal way, hopefully encouraging honest and open responses later. Following the ice-breaker, it can be beneficial to establish ground rules. Ground rules help children understand their role in the group, what is expected from them and what they can expect from the facilitator. Key 'rules' include the importance of enabling individuals to make their points without being interrupted and listening and respecting other people's views. Asking the participants to establish the rules themselves is a good strategy as it helps them to take ownership and shows their opinion is important, as it will be in the discussion that follows. This is also a good time to talk about confidentiality and explain how what they say will be used/shared. It is important to allow participants to ask questions addressing any concerns they might have at the outset. Establishing this two-way communication is essential if participants are to feel part of the process.

The skills of the focus group facilitator are essential. This will influence the quality of the discussion. The facilitator should be experienced in talking and working with children and young people around the same age as those attending the group: an understanding of the distinction between age and competence will help here so that we do not underestimate children's capacities to participate [22]. A focus group is not to be understood as an extended form of an interview. It is therefore not the facilitator's role to ask questions directly to all participants but rather to take care to engage all participants equally and to avoid leaders in a group dominating the conversation. In a group with adults, once the discussion has started, the facilitator would usually hold back as far as possible, to allow the participants to talk freely.



However, groups with young children especially may need more input from the facilitator to keep the conversation moving. A co-facilitator is also necessary to handle any unexpected issues that may arise (such as someone wanting to leave early), take notes and monitor participants' stress/comfort levels. It is essential that participants understand the role of the co-facilitator including why they are observing the group and writing things down.

Types of questions to be asked need to be considered at the outset. The focus group guide should primarily consist of open-ended questions, with direct questions only used as a means to clarify or elicit more detail on a response. Close attention should be paid to the wording of questions to ensure they are developmentally appropriate and that children and young people will understand what they are being asked. Starting with 'easier' questions, such as 'tell us a little bit about your illness', can provide a good lead into the discussion, leaving more difficult or personal questions until later when participants feel more at ease, for example, 'what is the most challenging issue you face with cancer today?' Depending on the age of the participants, a dry 'question-and-answer' format may not work for the entire session; more interactive and creative activities might be necessary to maintain children's concentration and interest. Other ways to ensure individual thoughts are gathered are to add in another method to the focus group, such as free text writing, where children and young people can record their own thoughts [23]: combining these two approaches presents an opportunity to elicit shared understanding and meaning and can offer children ways to express their views in a range of different ways [8]. For example, we asked young people the following question: 'If you moved to a new town you did not know and there were two hospitals you could receive your care from, what would make you decide which one to go to?' Their responses were posted in a post box and looked at after the session, offering an opportunity for a private contribution. With prior permission of participants (and parents), focus group discussions can be recorded by voice or video. The advantage of recording by video is that it allows the researcher to assign the voices of individuals to particular statements. However, a video camera can be intrusive. An alternative is for a co-facilitator to take detailed notes (in addition to a voice recorder) as to who said what, if indeed this level of information is required.

### **6.3.1.1 Top Ten Tips for Undertaking Focus Groups with Children and Young People**

1. *Do* think carefully about when and where to hold the group to make attending as easy as possible with the least disruption to the everyday lives of participants and their families.
2. *Do* prepare for cancellations and non-attendance. Contact families a few days before the group to check whether they can still attend. Over-recruit to the group in case of drop-outs.
3. *Do* consider the composition and dynamics of the group, and have children of a similar age within a group.
4. *Do* consider what the parents will do while their children take part, and provide a room where parents can wait and have refreshments.

5. *Do* start with an ice-breaker to help everyone get to know each other and feel more relaxed.
6. *Do* establish ground rules for the group so that everyone knows what is expected of them.
7. *Do* have a main facilitator who leads the group and a co-facilitator who can provide any additional help that is needed, including taking notes.
8. *Do* consider using interactive and creative activities within the group session rather than just a question-and-answer format, particularly for younger children.
9. *Do* monitor how everyone is participating—encourage everyone to have a say; there will often be a participant who finds it hard to speak up in a group.
10. *Do* offer an additional way for participants to raise points they may not wish to say in front of the group (e.g. a written task).

### 6.3.2 Peer-to-Peer Interviews with Young People

The ‘Essence of Teenage and Young Adult (TYA) Cancer Care’ was a feasibility study carried out to determine how best to answer the question ‘Does specialist care for young people add value?’ The ‘Essence of Care’ study was novel in that we worked alongside five young people with a previous cancer diagnosis as co-researchers, who assisted with study design, data collection, analysis and dissemination [24, 25]. Engaging young people and incorporating their unique expertise into the research process were important, and researchers have largely welcomed this approach with the potential to combat paternalistic attitudes that can influence more traditional research [26]. Although specialist care is advocated for young people with cancer in the National Institute for Clinical Excellence Improving Outcomes Guidance for Children and Young People with Cancer [27], four key points remain unanswered:

1. What is specialist care for young people with cancer?
2. What are the core parts of this service?
3. What outcomes are affected?
4. How much does specialist care cost the National Health Service, young people and their families?

One of the aims of this feasibility work was to determine the impact of cancer on the lives of young people, aged 13–24, of how having a cancer diagnosis impacted on their everyday lives and ability to return to ‘as normal a life as possible’. We wanted to develop a patient survey for young people with patient experience as an outcome measure, which captured their unique life-stage commitments. Following a meta-analysis of the lived patient experience [28], we carried out in-depth interviews with young people working with our young people co-researchers to undertake peer-to-peer interviews [24]. We aimed to add to the limited evidence base by offering greater insight into young people’s experiences of cancer, as well as testing out this approach to data collection.

### 6.3.2.1 Why This Approach Above Any Other?

We wanted to capture what really mattered to young people, to gather a narrative that was a true representation of their cancer experience. Previous patient experience surveys have come under some criticism for their lack of theoretical basis and patient involvement [29], and we aimed to address this by developing a conceptual and theoretical framework on which to base the survey, ensuring young people were involved from the beginning.

We chose to use peer-to-peer interviews where five young people who worked with us as co-researchers interviewed other young people during a 1-day workshop. We recognised early on in our study that young people would be more likely to share more intimate details about their experiences if they were talking with someone who had been through a similar experience and were a similar age. The interviews were approximately 30 minutes long and were digitally recorded. The interview guide had been developed by the research team and our young co-researchers. Our co-researchers were encouraged to explore issues beyond the interview guide, drawing upon their own experience where they thought it might help. The transcripts revealed a wealth of information much of which we felt would not have been disclosed if the interviews had been professional-young person conversations, for example, information about reactivation of sexually transmitted diseases during treatment, the importance of healthcare professionals beyond their treatment team such as the cleaners and a lack of general health information such as the impact of alcohol and recreational drug use during treatment. Young people spoke about the benefits of having young people as co-researchers and vice versa:

‘I have also enjoyed interviewing other TYAs the unique connection between two TYAs who can share a cancer experience can never be underestimated.’—Core Consumer Group Member [30]

Young people valued having a ‘safe haven’, an environment which allowed in-depth transparent and honest discussion around their experiences adding value to the study and the development of the survey.

### 6.3.2.2 What Particular Issues Are Relevant to the Population You Were Working with?

Involving young people as co-researchers is resource intensive; however, for this particular study, the benefits were clear and similar to other researchers, confirmed the benefits of these experiences outweigh any costs [26]. Support systems for young people working as co-researchers need to be established and implemented prior to the study and include a degree of flexibility as the study progresses. These include practical things like booking travel, accommodation and processing expenses, as well as who will be responsible for the training of the young people.

It is important to have an experienced healthcare professional on site during data collection to manage any potential upset which may manifest for either the peer interviewer or interviewee in revisiting what could be potentially difficult and sensitive topics. It is also important to check up with each of the co-researchers and

interviewees following the interview to ensure that upset has not manifested, although, in our experience to date, this has not happened.

For this particular study, we wanted to capture young people's experiences of care. Because young people have a tendency to focus on their diagnostic trajectory, we specifically asked them to focus on the point from diagnosis, which helped manage the time of the interviews, recognising that both the peer interviewer and interview may be susceptible to fatigue.

### **6.3.2.3 Ten Top Tips When Using Peer-to-Peer Interviews**

1. *Do* carry out the interview away from healthcare premises.
2. *Do* allow for flexibility in timing of interview (evening and weekends).
3. *Do* make arrangements in advance of how you will contact participants: if contacting the young person from an 'unknown' number, let them know prior to calling what time you will be calling (many do not answer unknown calls).
4. *Do* think in advance about the degree of participation, creating opportunities for young people to have a genuine influence on the research process; this requires shared confidence between researchers and co-researchers and for researchers to see co-researchers as equal partners.
5. *Do* ensure the young people know what interview they are taking part in and why and that they will be interviewed by a peer.
6. *Do* provide training and support for the young people doing the interviews, provide mentors, provide feedback and facilitate their engagement throughout the study from data collection, analysis, to write up.
7. *Do* let the young people know you will contact them within 24–48 hours of the interview to ensure the interview has not caused any distress for either party in the research conversation. Have a process in place/sign posting if distress has been caused.
8. *Do* provide payment or financial voucher to the interviewers.
9. *Do* stress the importance of confidentiality to all partners in the process.
10. *Do* ask if they would like to receive a copy of the study results. Ensure this is available in an understandable format.

### **6.3.3 Interviewing Children with Learning Disabilities**

Arts-based interviews were used with children and young people with learning disabilities as part of an ethnographic study aimed at understanding the hospital-related needs and experiences of this group of patients, as well as those of their parents [31]. This study was titled *Individualising hospital care for children and young people with learning disabilities: it's the little things that make the difference*.

Interviews were used to elicit participants' feelings about being in hospital and views of what was important to them during this time. Interviews were carried out in the hospital setting during the child's inpatient admission or immediately before/after an outpatient appointment. Four different arts-based activities were used during interviews. The card sorting activity involved children decorating two

**Fig. 6.1** Activity 1: Likes and dislikes activity



boxes, one to represent their likes and the other their dislikes, and placing hospital-based symbol cards into one or both of the boxes (Fig. 6.1). Those who were able to express their views were asked why they had placed the card in the relevant box, which generated further discussion. The symbol activity was a simplified version of the card sorting activity, with children matching hospital-based symbol cards with an emotion card and indicating, if able, why they had made that choice (Fig. 6.2). A third activity involved children decorating a cut-out ‘gingerbread’ figure to make an imaginary person (Fig. 6.3). They were invited to name the person, and this was used as an avenue for discussion. During a fourth activity, the researcher asked children to draw onto a life-size cut-out paper person anything that reminded them of tests/treatments they had experienced during their admission (Fig. 6.4).

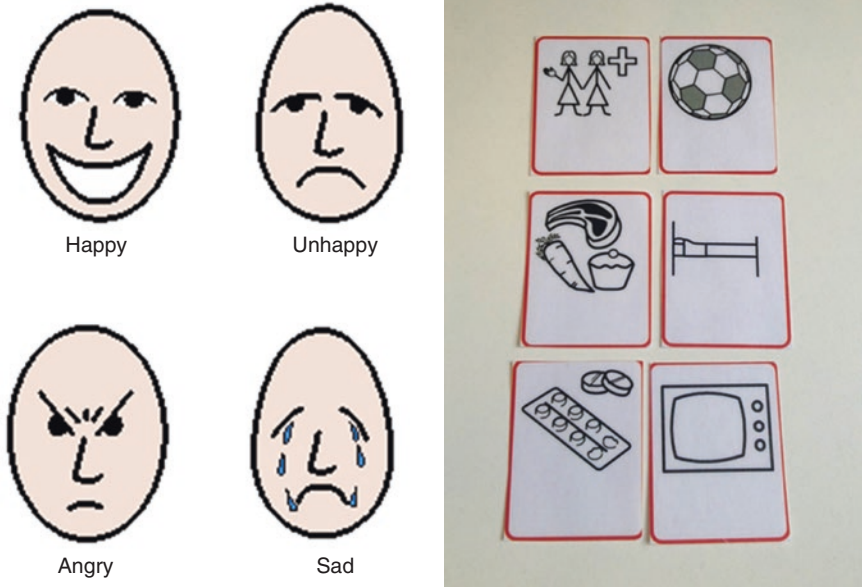
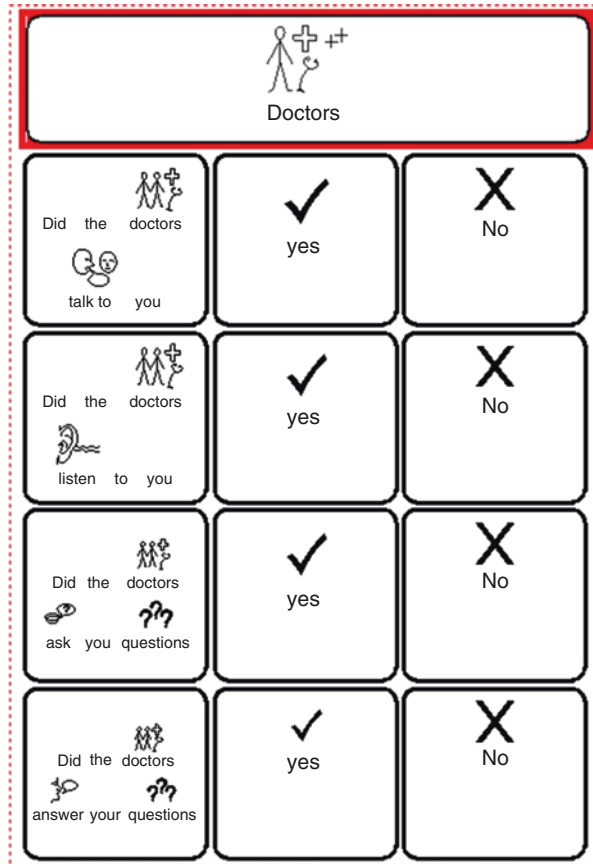


Fig. 6.2 Activity 2: Emotions activity



Fig. 6.3 Activity 3: Person craft

**Fig. 6.4** Activity 4:  
Example of specific  
questions to gather  
experiences



**6.3.3.1 Why This Approach Above Any Other?**

Semi-structured individual interviews were felt to offer the best opportunity to capture how children with learning disabilities feel about being in hospital, what their experience is like and what needs they have during that time. As very little is currently known about this subject, we wanted a data collection method that allowed participants the freedom to raise issues of importance to them and that facilitated exploration of these issues. It was important with this population of participants, however, to have structure to the interviews rather than being completely open-ended in our approach. Interviews were arts-based, providing children with learning disabilities a creative way of expressing their views and experiences rather than relying solely on them communicating verbally. Due to the individualised needs of children and young people with learning disabilities, individual interviews were favoured over focus group interviews.

**6.3.3.2 What Particular Issues Are Relevant to the Population You Were Working with?**

Children with learning disabilities have a reduced intellectual ability which impacts on one or more areas of their learning, such as thinking, attention or

memory [32]. Their reduced ability to understand new or complex information [33] needs to be taken into account when providing information about the study prior to gaining assent. In terms of providing information about the study, the use of symbols/photographs and/or pictures may be useful. We used Communicate in Print Software to produce three versions of the patient information sheet—(1) full symbol version with a symbol for every word, (2) partial symbol version with a symbol for keywords only and (3) words and symbol version with a symbol for each statement. The need for this emerged after consultation with a parent of three young people with learning disabilities whose daughter would not read the partial symbol version because it ‘had symbols missing’ and was not what she was used to, whereas the full symbol version may be too ‘busy’ for some children. We also provided each participant with a talking photograph album comprising pages of symbols/photographs each one with an accompanying audio message explaining the purpose of the interview, how it would be carried out, by whom, where and so on. Combining audio with visual information may be particularly useful for children with accompanying visual impairment and those with limited reading ability. It also means children have repeated access to simple, consistent information about the interview process, which can be particularly useful for those who also have impaired memory.

Interview questions need to be kept short and simple using language and concepts that the individual child is familiar with. We used a ‘scaffolding approach’ to our arts-based interviews, which involved targeting children’s strengths, abilities and interests, breaking down creative activities into short sections, demonstrating and talking through each activity and using visual cues and prompts [34]. The card sorting activity, for example, was built around children’s likes and dislikes and was broken down into participants first thinking about what they like and dislike, decorating each of two boxes to represent their likes and dislikes, selecting symbols that related to their experience of being in hospital, choosing which box to put the symbol into and finally explaining why they had made that choice. At each stage, the researcher became increasingly responsive to the child and able to tailor the next stage of the activity or subsequent activities according to their individual needs. For example, one participant with associated physical impairment found decorating his likes/dislikes boxes challenging and tiring and hence added in a break before moving onto the card sorting.

Children with learning disabilities may have a reduced attention span, which will impact on the timing and length of the interview session. Some children who participated in our study were only able to concentrate long enough for the rapport-building activities, with interviews being scheduled for another time, often spread over two or three short sessions. One child’s attention span was limited to just a few minutes, which precluded her from being interviewed. In this instance, interviews were replaced with observation and interaction.

Communication needs are an important consideration when conducting interviews with children with learning disabilities. They may have limited or no verbal communication skills and use alternative methods of communication such as Makaton or a picture exchange communication system. Where possible, it is



important to use the child's usual method of communication rather than trying to introduce something new. One child who took part in our study also had processing issues, which meant he took up to 15 seconds to formulate and verbalise a response to questions. Having full knowledge of his communication needs prior to interview was vital in ensuring he was given sufficient time to answer the interview questions. The use of symbols, pictures and photographs alongside interview questions were used.

Children with learning disabilities are more likely than other children to have challenging behaviour. It is important when interviewing them to be aware of things that can trigger such behaviours and how best to respond to them should they arise. This is important for minimising the child's distress and also maintaining safety of both child and researcher. Children with learning disabilities can quickly become emotionally attached to the researcher, which can make ending the interviewing particularly challenging. In our study, one child asked for the researcher in the recovery room after her surgery and later became very upset and tearful when the researcher said she had to go home. The use of social stories can help prepare children with learning disabilities for how and when their participation in research will end.

The most important thing when conducting interviews with children with learning disabilities is not to make assumptions but to collate as much information as possible so that the interview can be tailored to each child's individual needs. These are not procedures that can be rushed. If we are to avoid the risk of tokenism, then we need to keep asking ourselves what trust we can place in our methods and check that we have not overly predetermined the views that we have encouraged to be heard [35].

As Nind [36] states, the premise for all studies should be that:

- The difficulties experienced by people with learning difficulties, communication difficulties, autistic spectrum disorders, etc. will be subtly different, but none of these groups are homogeneous, and the impairment does not define the individual and their experience.
- The challenges faced by qualitative researchers doing research with this group, like the challenges faced by the disabled individuals themselves, are as much a product of the interactions between them and the wider context as of any inherent impairment.
- People with learning/communication difficulties have something to say that is worth hearing and experiences that are worth understanding, making it important to commit serious attention to the methodological challenges involved in undertaking research with them.

### **6.3.3.3 Ten Top Tips for Interviewing Children and Young People with a Learning Disability**

1. *Do* prepare well; preparation is key—know your participants, plan everything carefully and work in partnership with parents.
2. *Do* take your time—test out your methods first, build rapport and be patient.
3. *Do* break down the interview process into short sections.

4. *Do* keep tasks simple and concrete.
5. *Do* use simple language and fewer words—less is more!
6. *Do* be flexible—come armed with a toolkit of resources, and be ready to adapt them.
7. *Do* think in advance about the space and environment; they are important.
8. *Do* empower children and young people; do not patronise them.
9. *Do* consider combining interviews with other data sources.
10. *Do* keep expectations realistic—prioritise what you need to come away with.

### 6.3.4 Interviewing Adolescents

A longitudinal qualitative descriptive approach was applied in this study using in-depth interviews as the primary source of data. This study followed adolescents with cancer over their first year following diagnosis and was entitled ‘I’m a survivor, go study that world and you’ll see my name’. The actual research question was ‘What are the thoughts, needs and perceptions of adolescents diagnosed with cancer related to their cancer experiences over time?’

The longitudinal nature of the study was a challenge, particularly keeping track of adolescents. Maybe in future studies, social media, and/or texting or email, would be useful to keep in touch with participants [37]. Preparation was key to getting good data, including having a good interview guide and well-thought-through plan for the interview. This is particularly true when working with adolescents who may have difficulty conceptualising abstract thoughts and opinions and communicating them to others [38]. It is crucial that adolescents are able to understand the meaning of the interview questions and the degree of detail the interviewee is seeking in the response [39].

We share here specific tips related to the successes and pitfalls of interviewing adolescents from our experience of this study, combined with about 10 years of experience in this field (see also [40, 41]). While adolescents and young adults with cancer ‘can be great fun to work with’, they can also present some practical challenges to the researcher because they are in a demanding time of life, both developmentally and situationally [42].

#### 6.3.4.1 Why This Approach Above Any Other?

Open-ended questions are key to gathering good data from an adolescent population. Some adolescents will try to answer even the most open-ended question with as few words as possible so it is important to develop questions that encourage them to feel comfortable and to talk. Whereas some only need to be given space, ask questions that are important to them, for them to be able to contribute fully. The following are some recommendations for a good interview guide:

1. Check each question to ensure it is open-ended (cannot be answered with a ‘yes’ or ‘no’).

2. Start the interview with a general question that is topic specific but can be viewed as an ice-breaker. For instance, with my population, I asked them to tell me about hearing that they had cancer. It invites a story from them and lets them know that you are there to listen.
3. Have less questions but more probes, and use participant's own words as part of the probe 'you mentioned XX, tell me more about that'.
4. If your participant seems uncomfortable or is trying to answer your open-ended questions with 'yes' or 'no', ask another question that is more storytelling focused like 'tell me about what it was like to XX'. This may encourage them to start talking more, and as you listen carefully, their comfort level will increase.
5. Always have a conversational tone. Read your interview guide out loud to yourself and/or practise with an adolescent prior to actually using it with study participants. If you use language that is not adolescent-friendly, you will alienate your participants. While you might be interested in 'self-efficacy' or some other similar concept, now is not the time to use that term! Speak like you are having a conversation with them, not a formal interview. This will help build rapport.

#### **6.3.4.2 What Particular Issues Are Relevant to the Population You Were Working with?**

In addition to a good interview guide, it is vital to have a good plan for the interview itself. Particularly with adolescents and young adults, there is a need to consider their schedule. When is a good time for them to talk? Scheduling interviews to coincide with other appointments and meeting them at a neutral location near their home are all good ways to respect their time and acknowledge that they have a life outside of the illness for which researchers are seeking information. When you are considering the timing of data collection, it might be best to consider the average sleep and wake times of adolescents in order to get the best data from them. The average adolescent is not up at 8 a.m. ready to talk! In the case of adolescents with cancer, it is also important to plan interviews around procedures if they are receiving active treatment. Adolescents who have received sedation do not generally make good interviewees.

Set up a comfortable place to have the interview. Choosing a location that is comfortable is also helpful. Sometimes having a drink or snack available is appropriate. Always sit at a level with participants and not above them, which will help establish a rapport where they will feel comfortable to talk rather than feeling like they are being interrogated. For this study, we planned data collection around appointments that participants had already scheduled with their medical team. Interviews were conducted at the oncology clinic because it was convenient and comfortable for them and did not require an extra trip which was very important for this population of participants who had already missed a lot of other activities for cancer treatment. Rapport was built with the first interview, with participants seeming to look forward to subsequent interviews when they could talk about what had happened in the intervening months. Having

decided perhaps that the interviewer was someone who would listen to them, they appeared eager to share information, both positive and negative about their lives since the last interview.

The challenges in this study centred around attrition. One participant decided he did not want to talk about his experiences beyond the first interview as he was simply ‘done talking’, while another participant passed away during the study. Other participants were lost to follow up because without multiple ways to contact them, it was hard to reach them if they did not answer their phone. As well as thinking through how to interview adolescents, it is important to think about alternative methods of contacting them during their busy lives, since keeping them in the study is key to having the opportunity to interview them!

### **6.3.4.3 Ten Top Tips for Interviewing Adolescents**

1. *Do* set up a comfortable environment for the interview.
2. *Do* plan the interview for a time that is convenient for the adolescent.
3. *Do* plan your interview guide so that the questions are meaningful and open-ended.
4. *Do* establish rapport before starting the interview.
5. *Do* start with a question that invites the adolescent to talk.
6. *Do* approach your questions with a conversational tone.
7. *Do* probe for more information so that you get rich description of what each adolescent’s experience is.
8. *Do* deviate from the interview guide (with open-ended questions) if your participant starts telling you important information that you had not thought to ask about.
9. *Do* be flexible—nothing in research ever goes 100% as planned! (Appointments run late, participants do not show up, people get sick, etc.)
10. *Do* show appreciation for your participants. They are the only ones who know the answers to the questions you are asking!

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## **6.4 Advantages and Challenges of Using Interviews as a Research Method**

### **6.4.1 Advantages**

- The research interview is flexible, the basic tenets of which can be revised to suit a range of populations with differing levels of skills and abilities.
- Interviews offer opportunity to ‘get beneath the surface’.
- Although the ways of using new technologies to undertake interviews are increasing, being face-to-face with a child or young person provides the best opportunity to reduce the power dynamic that probably exists, the researcher can read non-verbal cues, and there is more opportunity to probe and explore responses.
- Interviews, used correctly, might also appear less like a test, less reliant on literacy and handwriting/computer skills that other techniques may require.

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### 6.4.2 Challenges

- It is not always possible to predict all challenges; researchers must always be prepared, able to think of their feet and draw upon solid theoretical and practical knowledge of working with children and young people.
- Recruitment usually takes longer than expected—plenty of time should be factored into study timelines and for rearranging appointments for data collection if it is no longer convenient for the participant.
- Environment is important, and it is not always easy to find the right space at the right time. Consideration of space, access for those in wheelchairs, not too medicalised and not too ‘child-like’, with privacy and not too noisy are all difficult specifications to match, so preparation in advance is key.
- Interviews require a particular type of investment from children and young people in terms of what they give of themselves—how and when to end research relationships require consideration at the outset.

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### 6.5 Key Advice

1. Consider the many different interview techniques available; consider the benefits and limitations of each, in the context of the population you are working with, and the research question being addressed; and then make your final choice (see, e.g. [43]).
2. Preparation is always key to all interview techniques, good, thoughtful planning, where time has been allowed to consider the essential steps to assure success: be prepared also to be flexible; thinking on your feet will still be required for the unexpected.
3. Confidence is essential; this comes with knowledge, as well as a described skill set: training, education, practice and feedback from our peers and our research participants are the core features of assuring personal belief in being able to have a research conversation with children and young people.
4. Patient and public involvement at all stages of research is essential. In this context, consulting children and young people about interview techniques, what might work and what would be more appealing could assist with recruitment, quality of data and dissemination.

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### 6.6 Conclusion

This chapter has provided a platform for researchers to share their knowledge and skills about the use of the research interview. Those being interviewed are at the centre of these descriptions. Researchers illustrate how they ensure they get the most out of these research conversations, through diligent planning, considering a range of eventualities, understanding the methodological issues and applying expertise to the research questions and study design. The focus has been on the practical considerations, but implicit is expertise, developed through practice, adapted and refined over time, with researchers being creative where needed. Reinforced here is

the need for researchers to have a ‘method toolbox’, used with skill to ensure a relationship is built from the outset, one which the research conversation will benefit from. Being flexible, thoughtful and knowledgeable about the populations we work with is clearly essential. But we also need to be brave, to embrace the notion of ‘serious fun’ and to make the interview process as enjoyable as we can. Throughout this chapter, the emphasis has been on ‘giving children and young people a voice’; having made that happen, we, the researchers, need to explain to our participants how and why, having heard their views, we are making (or not making) a particular response [36].

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## 6.7 Useful Resources

1. <http://www.azcourts.gov/casa/Training/Training-Courses/Interviewing-Children>. (On online training course when interviewing children.)
2. <http://www.mefirst.org.uk/resource/interviewing-and-communicating-with-adolescents-headss-technique/>. (The focus here is on adolescents, but there is also a section about children.)
3. <http://blogs.lse.ac.uk/gko/tools/guides/participatory-research/>. (An international project with some useful tips.)
4. <http://www.youngcarer.com/resources/ptp/participation-pack>. (Lots of very helpful resources are here about children and young people’s participation.)

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