

This is the peer reviewed version of the following article: Vindrola-Padros C, Martins A, Coyne I, Bryan G, Gibson F. From informed consent to dissemination: Using participatory visual methods with young people with long-term conditions at different stages of research. *Global Public Health* 2016 DOI: 10.1080/17441692.2016.1165718.

From informed consent to dissemination: Using participatory visual methods with young people with long-term conditions at different stages of research

C. Vindrola-Padros¹, A. Martins², I. Coyne³, G. Bryan², and F. Gibson^{2,4}

¹ Department of Applied Health Research, University College London, London, UK

² Department of Children's Nursing, London South Bank University, London, UK

³ School of Nursing & Midwifery, Trinity College Dublin, Ireland

⁴ Great Ormond Street Hospital NHS Foundation Trust, London, UK

From informed consent to dissemination: Using participatory visual methods with young people with long-term conditions at different stages of research

Abstract

Research with young people suffering from a long-term illness has more recently incorporated the use of visual methods to foster engagement of research participants from a wide age range, capture the longitudinal and complex factors involved in young people's experiences of care, and allow young people to express their views in multiple ways. Despite its contributions, these methods are not always easy to implement and there is a possibility they might not generate the results or engagement initially anticipated by researchers. We hope to expand on the emerging discussion on the use of participatory visual methods by presenting the practical issues we have faced while using this methodology during different stages of research: informed assent/consent, data collection, and the dissemination of findings. We propose a combination of techniques to make sure the research design is flexible enough to allow research participants to shape the research process according to their needs and interests.

Keywords

Participatory research, visual methods, young people, long-term illness

Introduction

Research with young people increasingly involves the use of one or multiple types of visual methods. Visual methods, and in particular those involving creative or arts-based approaches, have gained popularity in the field of research with young people because they make participating in research an enjoyable experience, facilitate communication by allowing the young person to express their ideas in non-verbal ways, and allow the researcher to gain new insight into the everyday lives of young people (Carter and Ford, 2013; Johnson et al., 2012; Pfister et al., 2014). Furthermore, researchers commonly argue that visual methods are participatory as they alter age, status, and research-based hierarchies and allow the young person to shape the research process (Close, 2007; Drew et al., 2010). Research designs using visual methods with young people are inherently flexible as they involve a wide range of approaches for young people to choose from and use open-ended instructions or guidelines where participants have the opportunity to create their own outputs (Weller, 2012). Flexible designs suit a range of development-related capacities; an important issue to consider when study samples span a broad age group (Drew et al., 2010).

We hope to expand on the emerging discussion on the use of participatory visual methods by presenting the practical issues we have faced while using this methodology during different stages of research: informed assent/consent, data collection, and the dissemination of findings. Each stage, method, and research setting created particular, often unanticipated, challenges that led our team to make decisions around the degree of participation, the impact of our research, and the factors we should take into consideration while designing future studies. We share here the lessons we have learned and strategies we have used along the way in order to make a contribution to the further development of participatory visual methods both in young and older populations.

Young people with long-term illness

Visual methods have been rapidly incorporated into health research with young people, particularly in research exploring experiences of long-term illness (Sartain et al., 2000). These

methods have been used successfully in the exploration of young people's perceptions of health and disease and how their feelings and ideas change throughout medical treatment (Rollins, 2005). As Sartain et al. (2000) have argued, young people living with long-term conditions have continuous contact with health care services and their daily lives unfold in close connection with their disease. There is a particular longitudinal quality to their experiences that is difficult to grasp in research (as most research only captures a snapshot of the child's life), but visual methods have proven effective in documenting the biographical changes and disruptions faced by young people with chronic conditions as well as the wide diversity of individual illness experiences (Sartain et al., 2000).

Participatory visual methods in practice

Despite the many advantages, these methods are not always easy to implement and there is a possibility they might not generate the results or engagement initially anticipated by researchers. Some methods can be time consuming, require prior training, and create a burden for participants (Drew et al., 2010; Pain, 2012). Not all methods are suitable for all groups of young people or for all research contexts (Coyne et al, 2009, Carter and Ford, 2013; Johnson et al., 2012). Some young participants might actually prefer verbal communication and feel visual methods are not the best way to convey their experience to the researcher. Furthermore, the inclusion of visual methods in the research design does not automatically make it 'participatory' as young people's voices might be relegated to the voice of the researcher or other adults or they might not have avenues or the 'tools' for shaping the research process (Barker and Smith, 2012; Lomax, 2012).

Most of the evidence we currently have on the use of visual methods focuses on data collection, while other phases of research are often overlooked (Weller, 2012). The details of methods used to analyse visual data are often missing from publications (Pfister et al., 2014) and few studies have incorporated visual methods during the informed assent/consent process or when disseminating the findings of a study (Ford et al., 2007; Lambert and Glacken, 2011; Weller, 2012). The use of visual methods during these phases is important because as Dockett et al. have argued, 'the format of the information provided can influence children's understandings of the research itself and what is involved in participation' (2013, p. 805). The use of visual

methods in multiple phases of studies represents an attempt to create more active ways of fully involving young participants in research (Brannen, 2002; Weller, 2012).

The following sections of the article present examples where the authors have used participatory visual methods in three stages of research: informed assent/consent, data collection, and the dissemination of findings. In each example, the authors describe the study, present the rationale for including visual methods in the research design, identify the methods' contributions and limitations, and discuss the lessons they learned from use of these methods in practice. All three examples are based on research with young people. We define young people as a study population including children, teenagers, and young adults: aged 4-24.

Informed assent/consent in the 'Talking with children study'

The 'Talking with children study' was an ethnographic study with families of children newly diagnosed with leukaemia. Data collection took place on the oncology units of a children's hospital in the United Kingdom between May 2011 and May 2012. The aim of this study was to explore children's knowledge of their disease to inform good practice in communication within childhood cancer. Families of children newly diagnosed with leukaemia aged between 4 and 11 years old were invited to take part. Seven children (average age 7.4 years old) and their families were recruited to take part in the study. Three of the children were female. A child-centred approach to negotiating informed assent and consent was taken (Dell Clark, 2010). This approach respected a child's capacity to be involved in informed decision making while simultaneously recognising the parents' responsibility as protective gatekeepers (Lambert and Glacken, 2011). Prior to gaining ethical approval, comments were received on the participatory visual methods from a parent and two children aged between four and 11, members of our study advisory group.

Description of participatory visual methods

Informed consent and assent was negotiated in four stages. A member of ward staff first approached the family to ask if they would be willing to speak to the researcher. If the answer was yes, the researcher then met the family and explained the study to the parents and gave them the parent information sheet, which detailed the purpose, possible benefits and disadvantages of the family taking part in the research, privacy, confidentiality and child protection issues, and the

contact information for the research team and local research office. In the third stage, 24 hours later, the researcher returned to ask for permission to speak with the child about the study. If permission was granted, the researcher then introduced themselves and briefly explained the study. The child was then shown two types of patient information sheets: one in a comic book style aimed at children between four and seven years old (Figure 1) and one with more text aimed at eight to 11 year olds (Figure 2), and asked to select the one they preferred. No reference was made to an age range on the documents to avoid any potential for influencing children's choice. Both documents used child-friendly words and images and included photographs of members of the research team. The younger child's comic book also utilised 'footprints' to move the reader through the comic and indicate which box they should look at next.

[Figures 1 and 2 near here]

The researcher and the child read through the chosen information sheet together. After answering any questions, the child was asked to choose between two assent activities to explore the purpose of the research and what their participation would involve: a storyboard with symbols replacing missing words aimed at younger children (Figure 3), and a word search aimed at older children (Figure 4), in which key words such as 'observe' and 'participate' were scrambled. Each time the word was found in the word search or replaced in the storyboard the child was asked to explain what the word meant in their own context and then again in a research context. These methods were used to determine whether the child understood the key issues of what being involved in the study would require them to do, including that participation was voluntary, that they could withdraw at any time and the possible risks and benefits of taking part.

[Figures 3 and 4 near here]

The child was then asked if they would like to take part in the study. Older children who gave assent were subsequently asked to complete and sign the assent form (Figure 5), which was countersigned by a parent and the researcher. For practical reasons, younger children who gave assent but were yet to start, or who had just started school did not complete this form and instead circled the smiley faces on the storyboard activity to indicate assent. Parents were asked to provide parental consent for themselves and their child to take part only when the child had provided assent. During this process the researcher was mindful of obvious and subtle signs of

child, or parental, refusal such as a child's body language (Lambert and Glacken, 2011). The child's assent to participate in the study was not viewed as a one-off event and was constantly re-negotiated verbally. In order to enhance the children's ability to take a break or withdraw from the research (Lambert and Glacken, 2011), children who joined the study were taught a sign (a thumbs down signal) to demonstrate that they would like the researcher to leave. A picture of this signal was also included in the children's information sheets. The signal was practiced in three hypothetical situations (a mock interview question, during play and during interactions with clinicians) to coach the child to be confident in using the sign (Kumpunen et al., 2012). [Figure 5 near here]

Lessons learned

The research team have a long history of using visual methods in the assent/consent process (Kumpunen et al., 2012). Visual methods convey information about the study to families in a clear and accessible format. The visual nature of the information sheets was engaging and helped the researcher to quickly build rapport and establish a dialogue with children.

The use of visual methods in informed assent/consent is not however without its challenges. Recruitment took place on a busy ward, where space was at a premium. This meant that recruitment had to take place at the bedside. The assent process took some time and was subject to constant interruption from members of the clinical team. There were two different information sheets to choose from, and one older boy recruited into the study was scornful of the 'babyish' nature of the younger child's information sheet. However, other children of similar age did not voice this opinion. In fact, the younger children's information sheet proved to be the more popular of the two.

Although careful consideration was given to all the images included in the documents and comments were received on the assent documents from children in our advisory group, issues were identified with the storyboard assent activity during recruitment. This document used a symbol of an eye to represent the missing word 'observe', which some of the children misidentified as the symbol for the television show Big Brother despite an apparent lack of similarity between the images from the researcher's perspective. Likewise, the picture representing the missing word 'mother' also included a cake and was consequently frequently misidentified as 'birthday cake'. So although review of information sheets in advance by

children was helpful, the individual nature of understanding ‘what we see’ means that explanation might still be required.

We relied on Microsoft Word Clipart for the pictures for the information sheets and assent activities used in this study. In future, we would consider purchasing pictures from a stock photograph and diagram resource to obtain a greater range of images. Although the majority of children selected the younger child’s information sheet, this was viewed as too ‘babyish’ by one child. The use of two different styles of information sheet in future studies to respond to individual preferences is therefore warranted. The inclusion of visual methods in children’s information sheets is a worthwhile, albeit time consuming, process that requires further evaluation by children.

Data collection in the ‘Mapping study’

The Mapping Teenage and Young Adult Cancer Services in England study sought to provide an overview of the way care is organized across the main centers where young people (13 to 24 years of age) with cancer receive care. The researcher spent from one to three days in 11 centers and interviewed 34 staff members, 21 young people, and 15 family members, carried out observations on the units, and used photography and drawing techniques (adapted from the Mosaic approach (Clark and Moss, 2011) with young people to create maps of their care.

The Mosaic approach integrates visual and verbal techniques such as photographs, tours, maps, conversations with the researcher, and observations (Clark and Moss, 2011). It was selected as the main approach for this study because it relies on the combination of multiple methods; it focuses on the lived experience of the research participants and their interaction with the daily environment; and it is participatory and reflexive (viewing participants as co-constructors of knowledge) (Clark and Moss, 2011).

Description of participatory visual methods

Our initial idea in the Mapping study was to bring together a group of young people (who were on the ward at the time when the researcher was carrying out observations) to develop a map of their care. We originally envisioned young people using the cameras we provided to move around the ward individually or in groups and photograph areas they considered important

parts of their care. They would then come together and discuss which photographs they thought should be a part of their map. They would draw the map together on a large piece of paper and paste the photographs in the relevant areas. This process would be documented by the researcher, and the map would be used as an elicitation device, to enable young people to talk about their experiences of care.

In practice, however, we encountered unanticipated situations that led us to change our original plans. The researcher was only able to visit the wards for a few days due to time constraints for study completion (produced by delays in the local Research and Development [R&D] approval process). This meant that sometimes there were only a few young people available on the ward and the group activity could not be arranged. When we could find larger groups of young people on the ward, they often did not want to participate in a group activity and preferred to create the map on their own. This was an issue frequently discussed with the youth coordinators on the wards who indicated that integrating young people of this age into group activities was challenging and many preferred the privacy of their own rooms.

Many of the young people on the wards were in delicate health condition, often dealing with side-effects of treatment such as fatigue and nausea, and did not feel well enough to get out of bed. Regardless of this, some young people still wanted to take part in the study, so we adapted the methodology to allow them to carry out the activity from their bed. For instance, one young person asked her mother to take pictures of specific areas of the ward while another participant only included pictures of areas she could capture lying down. A case that surprised us was that of a young woman who had been very ill all week and had refused to get out of bed. When asked if she wanted to participate in the photography and drawing activity, however, she immediately agreed and asked the researcher to walk with her around the ward to make sure she did not fall while she took the photographs.

Another situation we encountered was the high number of young people who said they preferred to talk about their experiences instead of taking photographs and drawing the map. Some participants indicated that they were not good with that 'stuff' and preferred to have a conversation with the researcher in their rooms.

Lessons learned

The Mapping study allowed us to see that participatory visual methods need to be adapted to suit the needs of the participants and the research context. Many times we assume that young people will prefer these types of method over interviews or focus groups because they are fun and creative, but as the Mapping study showed, these preferences will depend on the mood, personality, and health condition of the young person. When working with ill participants our research design needs to be flexible enough to adapt to the way they are feeling on the day of the interview. By offering research participants different alternatives for taking part in our studies, we are empowering them to shape the research process according to their needs and encouraging them to engage with the methods they feel most comfortable with at that particular time. The more choices we include, the more participatory our design will be.

Dissemination of findings from the ‘Children’s participation in decision-making study’

This study used a qualitative approach to explore parents, doctors, nurses and allied healthcare professionals’ perspectives on triadic decision-making in a children’s hospital in Ireland. Interviews and participatory methods (photo voice, sorting cards, stick a star quiz, and diamond ranking exercises) were used to elicit the views and experiences of participation in decision-making from 23 children and young people (aged 8-16 years with chronic and acute illnesses). These participatory ‘tools’ complemented the information gathered through the interviews and enhanced the quality of interactions and data obtained. On completion of the study, the team was anxious to find a means of disseminating the research findings beyond academic formats. Research reports and short summaries are typically tailored for a more adult audience. To reach an audience such as children and young people in hospital, it was important to utilize both visual and verbal techniques and to involve children and young people in the co-development of an information-leaflet on decision-making.

Description of participatory visual methods

The aim was to distil the key findings from the study into an information leaflet that would be accessible to children aged approximately 7-16 years old (Figure 6). The leaflet had to be visually appealing and the information had to be concise but informative. Thus, visual methods were used with focus group discussions to enable dialogue about aspects of decision-making and to co-produce the leaflet. We set up a co-design group consisting of children with

long-term conditions (7-14 years) and a group of healthy children (11-13 years) and used images (of children) and sorting cards (key statements on decision-making). Our participatory approach was guided by four key principles: consultation and cooperation with relevant stakeholders, experimentation with alternative designs, contextualisation (testing with users and providers), and iterative development (modification in response to evaluation) (Waller et al., 2006). This was an iterative process as we (researchers, children, and graphic design person) experimented with different wording and designs in three participatory workshops.

[Figure 6 near here]

The diamond ranking exercise (O’Kane, 2000) was used to elicit children’s views about what was important to include in the leaflet about decision-making in hospital. The data were summarised in key statements placed on cards and children worked within the focus group (or individually) to rank them according to order of importance in a diamond shape so that the most and least important statements were placed from the tip to the base of the diamond. At the end of the diamond ranking process children were asked to provide feedback and offer a rationale for their choice of placement of the most/least points. Although this exercise helped to reduce the findings to a key list of most important points, the wording had to be re-worked several times to meet with children’s approval. For example when the draft content was reviewed in the third focus group, the wording underwent significant revision as children thought the information needed to be phrased simply and the content needed to convey information as empowering rather than negatively.

This exercise complemented the information gathered through the photo voice exercise where different photos of children in hospital settings were shown. The children disliked the images selected by the graphic design person and instead chose images of happy children of different ages and ethnic origin. They asked for children’s quotes to be placed in a ‘voice bubble’ beside the image to make the content more visually appealing. The content and format were tested and modified in response to evaluations by children primarily and latterly by other stakeholders (parent, children’s nurse, children’s lecturer, member of the Children in Hospital Ireland (CHI)).

Lessons learned

The participatory workshops worked well and the children found the process stimulating and easy to do. Since the group of healthy children had never been hospitalized, before they could contribute, the researcher had to provide fuller explanations using pictorial representation of decisions to explain the different types of decisions that children might be involved in hospital settings. Using pictures helped children to understand and discuss decisions and then to select the key points for inclusion in the leaflet. The visual methods helped make the focus groups enjoyable and enabled children of different ages with varied literacy skills to participate. Involving children in each step of the co-design process greatly assisted in the refinement and phrasing of content, layout, colour, formatting and style. The sorting of the pictures and data (on cards) by the children led to a personal investment in those tasks and facilitated the discussion. Although the rationale for the diamond ranking exercise was explained, some children had some initial difficulty sorting the cards as they felt that all the data were important.

Improving our use of participatory visual methods

The three studies described here have pointed to common issues faced while using participatory visual methods with young people receiving long-term medical treatment. The experiences described here point to the fact that guaranteeing the participation of young people in research is not a simple and linear process. While reflecting on the use of participatory methods with children, Kefyalew has argued, ‘participatory techniques were only effective when false expectations were not raised, when resources were properly used and stereotypical views (of both methodologies and children) were set aside’ (1996, p. 210). To these thoughts we would add the following strategies to assist researchers in promoting the active engagement of research participants:

1. Individualization of approaches
2. Contextualization of approaches
3. Taking the time required to design and apply participatory visual methods

Active engagement is facilitated by the long-term presence of the researcher in research settings, and fostering of relationships with research participants. This immersion in the research context can help researchers consider different approaches for engaging young people. Flexible research designs include a wide range of methods young people can choose from to take part in

the study depending on their individual preferences or how they feel on the day. Flexible designs allow for the need to make changes in the research instruments based on feedback from participants or problems encountered while piloting the method (as mentioned before in the example of the interpretation of images in the child information sheets). The aim of flexible research designs providing ample methodological choices is to give children the opportunity to participate on their own terms (James et al., 1998).

O’Kane has indicated that the effective use of participatory methods with children relies on ‘creating a space which enables children to speak up and be heard’ (2000, p. 126). The creation of this space entails reflecting on the conditions under which the method will be used, so that proper measures can be taken to ensure active engagement when the method is applied. In the case of the studies presented here, this process could have entailed recognizing the fact that most young people were hospitalized and ill, thus maybe not feeling energetic enough to carry out demanding tasks and not having plenty of room at their bedside for using large visual materials. For instance, in the Mapping study, we tried to adapt the Mosaic approach, which was originally developed in a school setting with well children (Clark and Moss, 2011), to the work we wanted to carry out in a hospital setting with inpatients. We now realize that we should have carried out further work to make sure our research method was suitable for the setting and characteristics of our research participants. Having said that, it was a method that seemed to energise at least one participant, reinforcing the complexity of accommodating the ‘individual’ in any research design.

Lack of privacy is another issue encountered in clinical settings and should be factored into the considerations made by the researchers during the research design. By thinking carefully about the context where the research will be carried out and the characteristics of the young people who will be asked to take part, researchers can anticipate some of the common problems we discussed in the previous sections. Similarly, greater use of and evaluation of such methods, will ensure they are embedded into many clinical studies, resulting in increased patience of clinical staff/reduction in interruptions through recognition of the value and difference such techniques might add, particularly to the assent/consent process.

In our experience, the design and implementation of visual methods requires a great deal of time and effort (see also O’Kane, 2000; Pretty et al., 1995). When visual material is used to

elicit children's participation, as in the Talking with Children study, attention needs to be paid to the details of the images, format, colour, font, etc. The researchers also need to be open to making iterative reformulations of the research methods to suit the needs and preferences of the children involved. Nieuwenhuys (1996) has spoken in favour of establishing a 'continuous dialogue' with children throughout the research process to ensure research methods are effective. This on-going dialogue might be difficult to arrange and certainly increases the researchers' workload, but in the end it gives research participants the direct opportunity to shape the research process. This capacity to shape the research provides researchers with several advantages such as: to ensure that participants' consent to participate is informed and voluntary, deliver study findings that better reflect the views and experiences of those involved in the study, and provide mechanisms for disseminating research findings that will guarantee they are assimilated to a greater extent by the groups involved in the research (hopefully producing greater impact).

Conclusions

Participatory visual methods are excellent 'tools' for engaging young people in health research, but participation needs to be envisioned from initial stages of research design and throughout subsequent stages of a study. The use of visual methods in itself does not guarantee a participatory research process; participation in the form of active engagement has to be fostered by the researcher to allow young people to fully express their views and mould the study according to their preferences and interests. To do this successfully, the researcher will need to be competent and confident in the use of such methods, be sensitive and responsive to the needs of the research participants, and be prepared to be flexible in all situations.

In our experience, active engagement is achieved through the long-term presence of the researcher in the research setting, through flexible research designs, and the consideration of the particular conditions where, when, and with whom the study is carried out. We hope the examples presented here have illustrated how visual methods can be useful 'tools' for obtaining informed consent/assent, collecting data, and dissemination of findings, and have pointed to ways in which we can continue to improve our use of these methods in health care settings with populations across the age range.

We hope future studies can continue to explore the advantages and disadvantages of using participatory visual methods in different settings and at different stages of research. We certainly need more evidence on the use of participatory visual methods to obtain informed consent and disseminate study findings. An important avenue of future study concerns the role the research site, population, and study aims play in the shaping of both the research methods and the process of participation of research participants, thus leading to more context-sensitive research approaches. We must continue to be brave in our endeavours, to continue to refine our approaches based on reflections of use in practice, as well as feedback from young people. We must continue to share what works well and less well, and in what context, so that as a research community we build evidence that is available to others.

Acknowledgements

The Children's Participation in Decision-making study was supported by the Health Research Board under Grant HO1318 (RP 2008/172). The work of Dr Gemma Bryan was supported by the Olivia Hodson Cancer Fund. The work of Dr Cecilia Vindrola-Padros was supported by London South Bank University.

Disclosure of conflicts of interest

The authors declare no conflicts of interest.

References

Barker, J., & Smith, F. (2012). What's in focus? A critical discussion of photography, children and young people. *International Journal of Social Research Methodology*, 15(2), 91-103.

Brannen, J. (2002). The use of video in research dissemination: Children as experts on their own family lives. *International Journal of Social Research Methodology*, 5(2), 173-180.

Carter, B., & Ford, K. (2013). Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Research in Nursing and Health*, 36, 95-107.

Clark, A., & Moss, P. (2011). *Listening to young children: The mosaic approach* (2nd ed.). London: National Children's Bureau.

Clark, A. (2010). Young children as protagonists and the role of participatory, visual methods in engaging multiple perspectives. *American Journal of Community Psychology*, 46, 115-123.

Close, H. (2007). The use of photography as a qualitative research tool. *Nurse Research*, 15(1), 27-36.

Coyne, I., Hayes, E., & Gallagher, P. (2009). Research with hospitalized children: Ethical, methodological and organizational challenges. *Childhood*, 16(3), 413-429.

Dell Clark, C. (2010). *In a younger voice: doing child-centered qualitative research*. Berkshire, UK: Open University Press.

Drew, S. E., Duncan, R. E., & Sawyer, S. M. (2010). Visual storytelling: A beneficial but challenging method for health research with young people. *Qualitative Health Research*, 20(12), 1677-1688.

Dockett, S., Perry, B., & Kearney, E. (2013). Promoting children's informed assent in research participation. *International Journal of Qualitative Studies in Education*, 26(7), 802-828.

Ford, K., Sankey, J., & Crisp, J. (2007). Development of children's assent documents using a child-centred approach. *Journal of Child Health Care*, 11(1), 19-28.

James, A., Jenks, C., & Prout, A. (1998). *Theorizing childhood*. Cambridge: Polity.

Johnson, G. A., Pfister, A. E., & Vindrola-Padros, C. (2012). Drawings, photos, and performances: Using visual methods with children. *Visual Anthropology Review*, 28(2), 164-178.

Kefyalew, F. (1996). The reality of child participation in research: Experience from a capacity-building programme. *Childhood*, 3, 203-213.

Kumpunen, S. Shipway, L. Taylor, R. M. Aldiss, S., & Gibson, F. (2012). Practical approaches to seeking assent from children. *Nurse Researcher*, 19(2), 23-27.

Lambert, V. & Glacken, M. (2011). Engaging with children in research: theoretical and practical implications of negotiating informed consent / assent. *Nursing Ethics*, 18(6), 781-801.

Lomax, H. (2012). Contested voices? Methodological tensions in creative visual research with children, *International Journal of Social Research Methodology*, 15(2), 105-117.

Nieuwenhuys, O. (1996). Action research with street children: A role for street educators. *PLA Notes* 25, 52-55.

O'Kane, C. (2000). The development of participatory techniques: facilitating children's views about decisions which affect them. In Christensen, P. and James, A. (eds), *Research with children: Perspectives and practices* (pp. 125-155). London: Falmer Press.

- Pain, H. (2012). A literature review to evaluate the choice and use of visual methods. *International Journal of Qualitative Methods*, 11(4), 303-319.
- Pfister, A., Vindrola-Padros, C., & Johnson, G. (2014). Together, we can show you: Using participant-generated visual data in collaborative research. *Collaborative Anthropologies*, in press.
- Pretty, J.N., Guijt, I., Thompson, J., & Scoones, I. (1995). *Participatory learning and action: A trainers guide*. London: IIED Participatory Methodology Series.
- Rollins, J. A. (2005). Tell me about it: Drawing as a communication tool for children with cancer. *Journal of Pediatric Oncology Nursing*, 22(4), 203-221.
- Sartain, S. A., Clarke, C. L., & Heyman, R. (2000). Hearing the voices of children with chronic illness. *Journal of Advanced Nursing*, 32(4), 913-921.
- Waller, A., Franklin, V., Pagliari, C., & Greene, S. (2006). Participatory design of a text message scheduling system to support young people with diabetes. *Health Informatics Journal*, 12(4), 304-318.
- Weller, S. (2012). Evolving creativity in qualitative longitudinal research with children and teenagers. *International Journal of Social Research Methodology*, 15(2), 119-133.

Figure 1. Information sheet for younger children used in the 'Talking with Children' study

Version 2.0 for 2012 (Information sheet for younger children)

Start here

Follow the feet

Who should I ask if I have a question?
You can ask your parents or carer to talk to Gemma.

Do I have to help?
No you do not. Think about what you want to do. Talk with your mum or dad or a nurse or doctor. If you say yes, you can stop taking part anytime.

Do I get any rewards if I take part?
We will give you a gift certificate to say thank you.

What is a study?
A study is what you do when you want to learn more about something or find out something new.

What is the Talking with Children study about?
We would like to know more about how you learn about your disease.

Who will take part?
We will be talking to other children the same age as you and some who are older than you.

Why have you asked me?
We want to talk with about 20 children who are between 4-12 years old. You fit in here, so that's why Gemma came to talk with you.

What will I have to do?
If you say yes, Gemma will come talk with you a few times, or play or draw with you and ask you questions. Your mum or dad will be with you. She may just watch your family talking with doctors and nurses.

How long will the project take?
Gemma will be around for almost a year. You can talk with Gemma whenever you feel like it.

Will I have to make extra visits to the hospital?
No, Gemma will only ask you questions while you are already at [redacted].

What are the good things about this study?
We hope to find out what boys and girls want to know about their disease. This may help children in the future get the information they want.


Are there any bad things about this study?
We don't think so, but you may feel sad or angry when you talk about your disease. Your mum and dad will be there with you. We can take breaks if you're tired.

Who will know what I tell Gemma?
Only us (Gemma and Faith) and two parents of children who are like you who are working with us. If you agree, we will tell your GP that you are taking part, but they will not know what you told us.

Let's explore how information is shared when at the hospital... in the 'Talking with Children' study


End here

Figure 2. First page of the information sheet for the ‘Talking with Children’ study aimed at older children

 **Q: What is a study?**
A: A study is what you do when you want to learn more about something or find out some thing new.

Q: What is the Talking with Children study about?
A: We would like to learn more about three things:

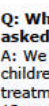
1. What you talk about with the doctors, nurses, play specialists, and other people at the hospital
2. What they tell you about your illness
3. What you know about your illness and what you would like to know more about




Q: Who will be in the study?
A: We will be talking to other children the same age as you and some who are younger than you.

Q: Who will be in charge of the study?
A: Gemma and Faith. They are researchers.


Researchers are like explorers or investigators. They search for knowledge and facts.

 **Q: Why have you asked me to help?**
A: We want to talk with about 20 children at [redacted] who are having treatment and are between 4 and 12 years old. You fit in here, so that's why Gemma came to talk with you.

 **Q: What will I have to do if I say yes?**
A: If you agree to take part in our study, Gemma will come to talk to you about 10 times when you are at [redacted]. Your mum or dad will be with you, if you want them to be.


Gemma will also sometimes watch when you and your family members talk with the people who work at the hospital.


If Gemma is around and you would like to say something in private with your family, you can. Just tell your parents or Gemma





Q: How long will the project last?
A: Gemma will be on your unit for 10 months, you don't have to talk with Gemma every time you see her, just when you feel like it.

Q: Will I have to make extra visits to the hospital?
A: No, Gemma will only speak with you when you are already at [redacted]



 **Q: How will joining help me or other children?**
A: It may not help you directly, but it will help us understand how you learned about your illness. In the future, this may help doctors and nurses give other children like you the very best information in the best way, and at the best times.

 **Q: Can anything bad happen in this study?**
A: We do not think so, but it may make you think a bit about your illness. Sometimes talking about illnesses can make people feel upset, angry, sad, or other emotions. That is okay to talk about too, if you want to.

 **Q: Who will know if I say yes to join the study? Who will see the information I give?**
A: Only our research team. That includes Gemma, Faith, three other researchers, and two parents of children who had a similar illness to yours. If you agree, we will tell your GP that you are taking part, but they will not know what you have told us.











 **Q: Do I get any rewards for participating?**
A: We will offer you a gift certificate at the end of the study to say thank you for all your help.



Figure 3. Storyboard activity used in the 'Talking with Children' study

Let's make a story about the study

When Gemma comes to see me, she will ask me  about how I learned about my disease. We may also sit down and  pictures and talk about them. Sometimes we might just  together. Gemma will only ask me questions when I want, and  or  can be right next to me.

When Mum or Dad and I are talking with the doctors or nurses, Gemma may spend time  how we share information. If I ever want to stop, all I have to do is make this action .

How does taking part in this study make me feel?  

Would I like Gemma to come and spend time with me and ask me questions while I am at the hospital?  




Figure 4. Word search activity used in the ‘Talking with Children’ study



The Talking with Children Study



WORD SEARCH

All of the words written below are hidden in the grid. Can you find them?

P	A	R	T	I	C	I	P	A	T	E	P
F	G	H	R	L	G	E	F	D	P	B	M
R	R	A	L	K	S	B	I	V	N	L	S
P	E	O	M	X	A	F	L	N	X	R	T
T	E	B	N	Z	F	K	H	O	D	E	I
H	V	S	E	I	R	E	T	B	L	D	G
D	I	F	C	G	C	A	Y	E	G	R	Y
A	Q	U	O	S	I	D	L	V	F	O	R
J	L	G	P	M	U	B	P	G	A	C	M
T	N	R	C	T	F	X	R	C	F	E	P
V	O	B	S	E	R	V	E	I	B	R	J
S	C	Z	A	P	E	L	O	N	Y	A	S


We are doing a **STUDY** to understand how information about your illness is shared among children, their parents and health professionals. We would like you to **PARTICIPATE**. If you **AGREE**, we will ask you to speak in an interview, or draw a picture and describe it. Sometimes we may just **OBSERVE** what is happening when you are at the hospital. This could happen many times, or just a few over almost a year. We will use a voice **RECORDER** to record our discussions. It won't be **DIFFICULT** for you, but you can **SAY NO**.

Figure 5. Assent form for older children used in the 'Talking with Children' study


Version 1 August 2011

Patient Assent Form


Title of Project: "Talking with children with cancer about their disease and treatment: a prospective study to improve practice"

1 


I have read the information sheet. ✓ box

2 

I was able to ask questions about the study. ✓ box


3 

All my questions have been answered. ✓ box


4 

I was told what I wanted to know. ✓ box

To be completed by both the child and parent

5 

I know I can stop doing the study anytime and it won't make a difference to how the nurses or anybody else look after me. ✓ box

6 

The Research team may read my notes. ✓ box

I/We agree to take part in the study. _____

To be completed by the investigator _____

.....
Signed by parent/child

.....
Signed by the Investigator

.....
Date

.....
Date

.....
Your name in BLOCK CAPITALS

.....
Your name in BLOCK CAPITALS

Enter the participant number allocated

Figure 6. Information leaflet produced in the ‘Children’s participation in decision-making’ study

There are lots of decisions made in hospital everyday by nurses, doctors, parents and children. You can be part of the decision making about you when you are in hospital. Sometimes you can make decisions by yourself and sometimes you will need help.

There are decisions about your treatment and Usually children prefer their parents and doctor to make the 'big' decisions as they know a lot. But you can take part in the talking around those decisions so that you can let people know how you feel.

Making Decisions

while you are in hospital

Information for children and young people.

WHAT KIND OF DECISIONS CAN YOU MAKE IN HOSPITAL?

Decisions about your everyday care which children call the 'small' decisions but they are very important decisions.

- What you want to eat
- When you want to eat
- What you want to wear
- When to go to the playground.
- When to go to school

Decisions about your treatment.

- Medicines such as tablets or liquids
- If you need medicine for pain
- Having blood tests done.
- Which arm to have your drip in
- If you want cream or spray (which numbs) before having a needle in your arm

Decisions about your treatment which children call the 'big' decisions.

- What kind of operation to have
- When you will have your operation
- What kind of tests (such as X-ray) will be done
- When will the tests happen
- When will you be able to go home

I like to be asked what I think about things well most things before they do it to me. They know what they are doing... like the operation I cannot be involved in deciding that because I don't know anything about it
(Peter age 12)

CHILDREN NEED TO KNOW WHAT'S GOING ON

Most children like to know what is going on. They want adults to explain what is going on. Most children like talking with the adults before the decision is made.

I think it is important if the doctors ask you and explain things to you and it is more important to have a choice, if you can have
(Sophie age 14)