

Children's Participation in Hospital

A short introduction to the theory and practice of involving children in improving the quality of care



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Colophon

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kinderparticipatie](http://www.kindenziekenhuis.nl/kinderparticipatie)

Foreword

In 2010, a project was started with the aim of improving the quality of health care in hospitals based on the experiences of children and young people, under the guidance of Zorgbelang Nederland and the Dutch Child & Hospital Foundation. This marked the first national children's participation project in the Netherlands.

The basic principle of the project was 'we learn best by doing and by reflecting on the actual process and its results'. Eight different participatory methods were applied in ten Dutch hospitals and assessed for their practical value. The lessons learned are described in this practical introduction.

Children's participation is not an isolated matter. Article 12 of the UN Convention on the Rights of the Child states that children are entitled to participate in all decisions affecting them, regardless of their age. Children differ from adults anatomically and physiologically, and they respond emotionally to disease and injury differently than adults do. By taking their emotional and practical needs into account, children feel more comfortable, emotional problems or disorders in the development of the child can be prevented, and the care will be more effective. Child-oriented health care is only possible

when the experiences of children and parents are actually used in order to improve the quality of care. Children's participation results in health care better attuned to their needs.

With this handbook we aim to kick-start children's participation in hospital in such a way that it will become a structural part of the quality cycle of every hospital.

Children's participation results in health care better attuned to their needs.

Hester Rippen
Director, Dutch Child & Hospital Foundation

Peter van der Loo
Zorgbelang the Netherlands



Children's participation is a right.

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PART 1 Introduction to children's participation

Introduction

In order to promote patients' interests, it is essential to have a clear idea of the health care users' needs and experiences. Patient organisations have developed several tools for assessing the quality of health care from a patient's perspective, such as quality marks¹ and quality standards². In addition, patients are often consulted through client panels, focus groups, and individual interviews. Though it is widely recognized that children also have valuable knowledge and experience, they are consulted rarely, if ever.

In the study of Dedding (2009), children with diabetes commented on the large amount of informational material developed by adults: 'this is absolutely not what my life is like' and 'I'm really not such a goody-goody!' Children also recounted that the informational material is not suitable for sharing with their friends, which is a shame because every day these children are bothered with disturbing questions like, 'You're not allowed to eat sugar, right?' or 'You probably ate too much sugar when you were little, didn't you?' With the aid of professionals, these children have developed their own informational material. It is tough, nice, and especially less polite, matching their daily reality: a life in which they take care of their disease, but at the same time one in which the disease plays only a minor role.³

We rarely realise that children can express their own views on illness and health which deserve to be heard, and that adults are not the only ones

who work and care; children do, too. They look after their bodies and their diseases while trying to live as normal a life as possible. Furthermore, children not only take care of themselves, they also care for adults, which is beautifully exemplified in Eric-Emmanuel Schmitt's novel, *Oscar and the Lady in Pink*. Oscar is diagnosed with cancer, and though the adults do not inform him, Oscar knows he is dying. He does not say this out loud, however, because it would only sadden his parents more.⁴

When asked how health care can be improved, children in the Wilhelmina Children's Hospital answered that they would like to see nicer colours on the walls, but also that they want people to listen to them better. Children with Crohn's disease, a chronic bowel disorder, asked for softer toilet paper and softer seats in the waiting room, because waiting is so painful now.⁵ In her book, *Children's Consent to Surgery*, Alderson (1993) shows to what extent even young children wish to be informed and are capable of dealing with complex and sometimes painful information, provided that the individual child is informed with sensitivity, and in a clear and appropriate manner.⁶

One rarely comes across adults who do not want to listen to children. What does emerge time and again is that, in practice, it is difficult to actually hear children, and subsequently to act upon the knowledge gained. Adults often have so many questions, concerns and ideas of their own, competing for priority. Furthermore, children are not as easily drawn out, even when treated very nicely.

But even more important, when thinking about children, we mostly think about what they are not yet capable of, instead of what we might be able to learn from them. Adults assume they know best. Unfortunately, this is not always the case. If we want to know how children experience their disease and what kind of problems they encounter, we have to ask the children themselves.

Listening to children and actually acting upon what they tell us requires not only a cultural shift in the way we think about children, but also knowledge of suitable methods for realising children's participation.

In a pilot study, various methods were tested to investigate the experienced quality of care in the paediatric wards of ten Dutch hospitals. The knowledge and experience gained with these methods are described in detail in this handbook, for other organisations to use.

The aim of this book:

Promoting children's participation in hospitals by:

- describing the basic principles of children's participation;
- demonstrating the significance of children's participation by means of inspiring real-life examples;
- offering guidance on starting participatory projects with children in a responsible manner.

Though this book is about realising children's participation, some examples of projects with parents are also included. The fact that parents cannot act as spokespersons for their children is extensively documented in the international literature.^{7 8} Yet sometimes, for practical reasons, it is impossible to start a project with children, for example because a child is too ill or too young (babies, toddlers),

already has too many appointments, or because it is not feasible to realise the required logistics. It is also possible that the research concerns aspects of health care which parents have more knowledge and experience of than children.

This book is written for:

- Patient organisations and hospitals aiming to improve the quality of health care based on patient experiences.
- Educational institutions which want to contribute to learning to listen to children, and wish to adapt their medical actions accordingly.
- Researchers interested in the views and experiences of children.

Outline of the book:

This handbook consists of three parts. The first part is an introduction to children's participation. The question of 'what is children's participation and what not?' and the arguments in favour of children's participation will be discussed. It also examines which points of attention are important when working with children in a research setting. In part two, seven qualitative research methods are introduced. They were all tested in Dutch hospitals, which revealed the potential and disadvantages of each one, and how much knowledge can be acquired. In addition, the matter of involving parents in research will be discussed briefly. Part three describes the process of data analysis and how the results can be translated into action. This is followed by some frequently asked questions, such as: What can you do when children do not say anything? Can children's participation turn out badly? And how can we set up future projects with children? The book concludes with a summary of the insights gained.

What is children's participation and what is not?

Participation has become a popular concept and is rarely defined. This is problematic as it can have different meanings, varying from consulting to influencing, joint decision-making or taking the initiative. Which of these forms do we search for when discussing children's participation? And is that the same for every project?

Participation can have different meanings, varying from: consulting to influencing, joint decision-making or taking the initiative.

Desirability and feasibility play a crucial role in answering these questions. When dealing with themes which are important to the children themselves and about which they have a lot of knowledge and experience (for example, the use of medication and possible side effects, the interior of the ward, self-management), children's participation will be more desirable than when dealing with subjects more remote from the children (for example, which specialist or examination is necessary). The burden on the child involved should be taken into account, as participation requires time and energy. When it comes to seriously ill children and already overburdened parents, time and energy are often scarce. This does not mean they should be excluded. On the contrary, they are most likely to have wise lessons for health care.

1. Manipulation

Adults use children's voices to convey their own message. Children do what is asked of them without really understanding the matter. *Researchers minimise their own contribution in a report or use children's drawings to make it look like children were actively involved.*

2. Decorative

When children participate but do not understand the essence of the matter and are not involved in the organisation of the event. *Children do the opening act for a new children's ward, but the act was completely directed by adults.*

3. Tokenism

Adults wish to give children a voice, but do not critically observe the degree to which the participation is actually realised. *Children are asked to sit on a committee (e.g. children's board of the hospital), but in reality adults make the decisions.*

4. Assigned but informed

Adults mobilise children for a project, children understand the project, know who is directing the project and why they are involved. Adults respect their opinions. Children who are supplied with knowledge of a disease and spread this knowledge through a theatre performance.

Figure 1: Eight levels of children's participation based on Hart's ladder of participation.

But in these situations we must pay more attention to the way participation is shaped. Consulting children and parents during the preparation of a project can be the key to success: Do you think this project is important? Under which conditions would and could you participate?

Feasibility is also an important factor. All parties (including the children) may find participation desirable, but a project cannot be realised in practice if the preconditions are lacking. For example, when the plans are already designed or when there is no time and money to actually do something with the children's ideas. This is known as *tokenism*. Tokenism arises when professionals want to give children a voice, or feel obligated to do so, but have not properly considered the consequences, which is why we cannot call it actual participation.⁹

Unfortunately, despite the best intentions, this is very common in practice.

Ladders of participation

Various ladders have been developed to illustrate that participation can take place at multiple levels. These ladders can be helpful when deciding in advance which level of participation is desirable and feasible. The goal is not to achieve the highest level of participation, but the level of participation which is desirable and feasible. Hart's ladder of participation (1992; see figure 1) distinguishes between different levels of participation, but also of non-participation. Children can make a valuable contribution at each level.

5. Consulted and informed

The initiatives are designed and run by adults, but children are informed and consulted about the process. Children understand the process, and their opinion is taken seriously. *Children are asked to participate in a quantitative research on a new manner of consulting. They are informed about the objectives, are asked if they want to participate and are informed of the results.*

6. Adult-initiated, shared decisions with children

Adults have developed the original idea, but children are involved in every step of the planning and implementation. Obstructions are discussed openly. *The paediatric ward has received funds to organise a trip; a group of children is invited to make plans for the day together. All cheer for Disneyland Paris, but given the limited budget, a feasible alternative is searched for together. After an activity has been chosen, the organisation and guidance of the day are considered jointly.*

7. Child-initiated and -directed

Children come up with the original idea and decide how it will be executed. This process rarely comes about except in play. It requires attentiveness from the adults to recognise the initiative of children, to let it happen and to not want to control it. *Children who are in a ward together want to help another child who is feeling sad. They decide to change the layout of the ward so the child feels less alone.*

8. Child-initiated, shared decisions with adults

Children come up with the ideas, take the initiative and invite adults to make decisions with them. *Children decide to write a book on their disease, from their perspective. They decide who will contribute to the book, what will be in the book and what the book will look like. An adult accompanies the process wherever the children wants him/her to, organises training and/or executes tasks upon request.*

Hart's model sees shared decision-making as the highest level attainable. The reason behind this is that, in order to really make a difference, children always need the help of adults, for example in the form of specific knowledge or financial resources.¹⁰ The ladder of participation by Shier (2001) also identifies three degrees of commitment that organisations may have at each level of participation. This model can be helpful as a tool for organisations to explore what level of children's participation is desirable, how it can be achieved, and if it is part of the policy or should become part of it.¹¹

Arguments for participation

There are numerous reasons to increase patients' participation within an organisation. The most important arguments for the participation of children do not essentially differ from those for adults. Participation can benefit the patient, health care providers and the health service.

Thinking about children's participation is not without obligations.

1. Children have the capability

Children's willingness^{12 13 14} and capability.^{15 16 17 18 19 20 21} to participate have been demonstrated repeatedly. They have the unique knowledge and experience of their body, disease and life, into which only they themselves can offer an insight.

2. Participation leads to better decisions

Taking into account the children's perception and experience can lead to decisions that meet their wants and needs better. Moreover, their experiential knowledge can be used to improve the quality of health care and service.^{22 23}

3. Participatie draagt bij aan de persoonlijke ontwikkeling van kinderen

It is important that children learn to participate.

When they are not given that possibility, they are deprived of the chance to learn to take responsibility for their own health.^{24 25} Furthermore, participation can add to the development of cognitive and social skills,^{26 27} and it can boost the children's confidence and self-esteem.²⁸

4. Children have the right

Thinking about children's participation is not without obligations. It is stated in the International Convention on the Rights of the Child (1989) that children have the right to information and freedom of expression (Article 13), the right to freedom of thought and expressing this thought (Article 14), and the right to have a say in all matters affecting their well-being (Article 12).²⁹ Article 12 is considered the most explicit encouragement for children's participation. It states that: 'The child who is capable of forming his or her own views, shall have the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'.²⁹

Article 12 does more than just state that children are allowed to express their opinions and that they should be taken seriously. It explicitly obliges adults, in their role of parent or professional, to enable and encourage children to contribute their views on all matters affecting them.

In addition to the international rights of the child, there are also specific national laws which have established the right to children's participation. For example in the Netherlands, in the Dutch Medical Treatment Act (WGBO)³⁰, the principle of informed consent was established: a patient must consent to a treatment. This must be based on detailed information of all the advantages and disadvantages. This act explicitly refers to children: children not only

have the right to age-appropriate information, they must also be able to actively participate in decisions regarding their life, which includes decisions in the area of their illness and health.

Conditions for meaningful participation

Participation can take many different forms. Which one you choose depends on a number of factors. First of all, the extent to which children have knowledge and experience relating to the theme and the extent to which they want and can participate. Second, the available means in terms of budget, time and skills. A participatory course is intensive and complicated and requires a lot of organisation. Third, the extent to which change is desired for the target group. That is, the extent to which one may expect that the results of participation will actually benefit children. Thus, again and again an optimal balance must be sought between excluding children and sharing or even relinquishing control.

We consider participation to be meaningful when:

- 1) it is meaningful for the children themselves, that is, matches their perception, social environment and needs;
- 2) it actually leads to change.

Conditions for meaningful participation

Participation is not a method, but a value. A way of examining how people relate to each other. That value is, in short: all those involved have relevant knowledge, and one aspect of knowledge is not by definition better or more valuable than another. It is important to communicate this value in the attitude you assume in relation to the target group. The important element of participation is to acknowledge experiential knowledge as an indispensable addition to the knowledge of professionals. This allows a complete, or at least more complete, picture to be built up. Facilitating children's participation and allowing for multiple perspectives, which can also conflict, is not easy. This is why we recommend calling in an external party, for example a patient organisation or researcher. This chapter describes which elements may be helpful to promote a good start of children's participation.

1. Creating commitment

Children's participation sounds nice, but it soon raises conflicts when the things children say and wish do not correspond to the ideas of adults and institutional norms. This is why it is important to carefully consider a project's chances beforehand, as well as which obstacles may arise. Do not promise things you cannot realise and carefully communicate both the possibilities and the limits of participation. Participatory research is not aimed solely at collecting the experiences and ideas of children. It is important to place the acquired insights alongside the knowledge, experience and needs of professionals and parents. It is also important to take into account the context in which the data

Participation is not a method, but a value.

were collected, for example the extent of mutual trust, a child who has recently undergone a tough examination, or a parent listening in from a distance. Department chiefs and directors must be involved in the project from the planning stage, or it will have little chance of succeeding. After all, they are the ones who can make sure the results actually lead to change. Experience shows that the commitment to consider seriously the results of the research grows when the results are submitted in an early stage and the directors are somehow involved in the process, by participating or watching.

2. *Inviting the children*

There is a risk with participatory projects that only children who are enthusiastic and show a lot of initiative will be invited. These children are definitely necessary to help carry the project. However, for high-quality research, it is imperative to include a broad range of children, including the shy ones, the children you do not have a connection with at first, and the children you think are uninterested. These children often need a little more time to open up, but they supply just as valuable insights as the group that is immediately enthusiastic.

The children must be given sufficient information so they know what the research is about, what is expected of them, what the aim is, how their privacy will be guaranteed and what will happen with the collected data (such as pictures, drawings, letters) and the results of the study.

It is best to ask the children themselves if they want to participate rather than invite them through their parents. Do, of course, inform their parents. In this way, you explicitly indicate that the child is important and that you take him/her seriously. With a letter you ask children to participate in the research. Openings like 'adults do not know what it is like to be in hospital

as a child, you are an expert in this area' tend to work well in practice.

Add a consent form which both the child and parents have to sign. Ask children to return the completed letter by mail or to hand it to the researcher. In any case you must discuss with the child that:

- Participation is not obligatory: 'You do not have to participate!'
- The child can always decide to stop, without there being any negative consequences: 'You can always stop, at any time.'
- Information will be treated confidentially: 'Parents and practitioners will not hear who said what, and no actual names will be used in the report.'

Generally, this ethical approach receives a lot of attention at the beginning of a participatory project, but then it fades from sight. This is why we argue viewing ethics as a process. This means that the above approach will be regularly repeated in the contact with the children and that the researcher is attentive to unintentional damage as a result of the project, children not being forced to participate, children being well informed about what is expected and whom they can call on if they have questions or concerns.²⁸

Commonly, this ethical approach receives a lot of attention at the beginning of a participatory project, but then it fades from sight.

3. Setting

To support children's participation, it is important to give some thought as to how you, as an adult, can create an atmosphere in which children actually feel encouraged to share their experiences and ideas. Your own ideas about children play a significant part in this. If you do not believe that children can tell you something new and have valuable knowledge, you will project this. Another aspect involves the experiences that children have had before with adults. Children are aware that adults often end up doing what they think is important. You will have to show the children that you are sincerely interested and really want to do something with their ideas. Characteristics of the ideal attitude are: respectful, flexible, transparent, vulnerable, familiar, affirmative and clear.

The setting controls the atmosphere but often also says something about mutual relations. Before you can engage in a conversation, everyone must feel comfortable in the room where the conversation will take place. In hospitals, professionals are at home and children are guests; they conform to the rules of the hospital. When an interview takes place at home, the roles are reversed. However, it is not always possible or desirable to visit children at home. A few tips to create a comfortable working environment are:

TIP 1 Reverse the roles: ask the child to take the seat of the doctor, or the seat of the chief.

TIP 2 For a group session, meet in the basement of the hospital, for example, where the normal rules suddenly do not apply.

TIP 3 Avoid the classic setting in which the interviewer sits across from the interviewee. This setting may soon look like a cross-examination. Choose to sit at an angle of 90 degrees, sit together on a couch, or choose a round table.

TIP 4 Ensure that the children's privacy is guaranteed. Do not choose a room where people can easily look in from the hall. This not only violates confidentiality, it is also distracting.

The atmosphere is determined not only by the researcher's attitude and the location, but also by the time 'available'. Time and attention are notions which are closely related. Make sure the children have enough time to get used to the researcher and to share their experiences. Spend enough time approaching and engaging other key figures, like parents, the board, and the nursing staff, so the research project is widely supported, and the process can run smoothly.

TIP Parents and other guardians are important in the lives of children. They sometimes need extra information or reassurance before agreeing to their child's participation in a project. Show yourself, talk with them beforehand, and afterwards summarise what has been done.

4. Sharing control

Do not attempt to stick stubbornly to your own planning. Participation is by definition unpredictable. Moreover, sharing control with the children produces better results, as the example below from the study of Dedding (2009) illustrates:

At the beginning of the interview, I handed the recording device to Iben. I explained how the device works and told her that she can stop the recording at any time. Of course I was afraid that important information would not be recorded... To my alarm, Iben stopped the recording after only ten minutes. 'So weird,' she said, 'this device records my voice, but it does not see how I feel,' after which she turned the device back on and explained her emotions that accompanied the things she talked about before.

Other ways to share control are to put the questions in a box of cards on the table rather than hold a list in your hands. Children can then view which question has been asked and which has not, and they will answer the questions they think are important in detail. Sharing control allows the children to feel like co-owners and thus co-responsible. This requires a high level of flexibility and daring from the researcher, but experience shows that it is very rewarding.

Sharing control is only useful if you stick to things the child has experienced. After all, these experiences of life are the basis of assigning meaning, knowledge and skills. This means specifically that you look for a connection to the knowledge, skills and interests of the target group you are working with. It not only improves the validity of the study, it also helps you to accept the children as they are.

5. Recording obtained information

When conducting a study, various kinds of information become available and have to be recorded. It is important to distinguish between who said what (children, parents, professionals) and your own interpretations. Put literal statements (quotations) immediately between quotation marks, as a reminder for later.

Experiences of the children

- To the best of your ability, make a record (including quotations) of the stories children share with you orally. If the child consents to it, audio recordings are very helpful.
- Save all information obtained from the research; pictures, drawings, letters, videos, and so on.

Experiences of the researcher and third parties

- Keep a journal during the conduct of the research, describing the course of the project, your subjective experiences, considerations and remarks.
- Record the reactions of third parties (parents, nurses, doctors) concerning the research, whether or not obtained from the direct use of research methods.

By not only focussing on the 'official' results, but making notes from the start of the project, incidental findings will not disappear from sight. By recording the reactions of the other people involved, you can place the children's ideas in a context and make a better assessment of what is necessary for the children's voice to actually have an influence.

PART 2 Methods

What is important when choosing a method is the extent to which it encourages and stimulates children to share their experiences freely. This is why the choice of the method should match the children's experiences and interests. But attention should also be paid to how a method is presented, as a tight format with numerous rules and instructions, or as an aid which can be partly shaped by its users. The latter will often make children feel more encouraged to talk about their feelings and experiences freely. And of course all methods and techniques must be adjusted to the specific target group and local circumstances. In this part of the book, seven methods of children's participation are explained. Each description provides a short overview of the requirements, the target group for which the method is appropriate, its duration and strengths. The indications given for time and age are meant to serve as a guideline, and adjustments can be made depending on the situation. For confidentiality reasons, the names of the children in the cases have been changed.



Photovoice



Online chats



Statement box



Wish wall



Guided tour by children



Diary room



Letter to the chief executive



Methods involving parents



1. Photovoice

Photovoice is a research method in which children get to work as photographers to record and reflect on different aspects of their care or the hospital environment.³¹ The images the children take form the starting point for a dialogue between child and researcher.³²



Requirements

- Camera
- Computer with photography programme
- Instructions for the camera
- Note explaining the project to third parties
- Consent form for the publication of data and the use of photographs
- Device for audio recordings



Target group

- Individuals or groups of 4-6 children at the most
- > 7 years



Duration

- Minimum of 30 minutes for taking the pictures (including time to reflect)
- 15-45 minutes for the photo-elicitation interview



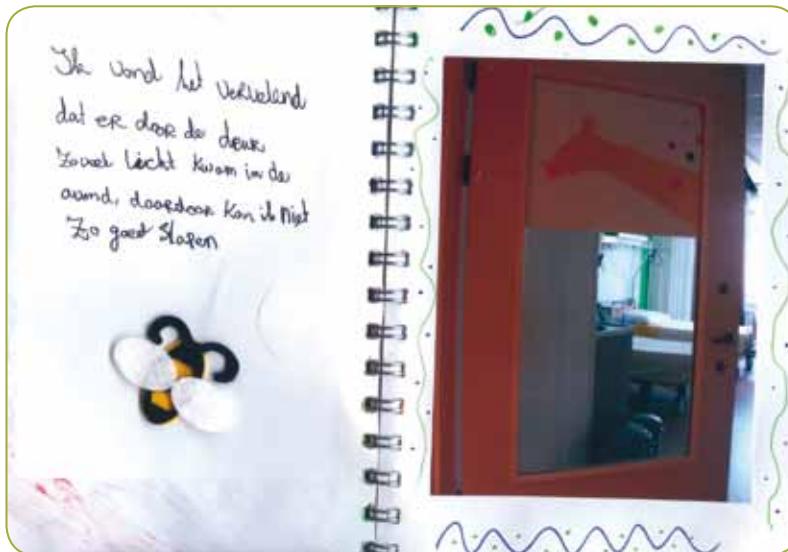
Strength of the method

- Minimal guidance from the researcher; children determine which pictures will be taken and thus what the topic of the conversation will be later on.
- Pictures literally and figuratively provide a look into the experiences of children.
- Working with photographs increases the attention span and intensity of the conversation.
- Photographs reduce possible verbal obstacles.
- The possibility of asking in-depth questions during the photo-elicitation interview.
- The classic question-answer conversation that may quickly resemble a cross-examination is avoided.
- The final product can be converted into an exhibition or collage and can be included in the hospital magazine.

CASE – new paediatric ward

Staff members wondered what children thought of the new paediatric ward. Children were asked to 'take pictures of the things you like, and the things you like less.' The children received a copy of all pictures, a small book and some hobby supplies. They were requested to explain why each picture was taken.

Twelve-year-old Anne took a picture of the glass ward door. She has trouble sleeping because it allows in too much light. When this is discussed with her parents later on, they say that they like being able to see their daughter from the hall. A clear example of the fact that the experiences of parents and children can differ and that both perspectives are relevant. *perspectieven relevant zijn.*



Thirteen-year-old Marijke photographed the view from her room. Because the other building is so close and there are no curtains, people could easily look into each other's rooms. She is very uncomfortable with this. The ward was surprised when seeing this photograph. It seems obvious, but it was still missed when building the ward.

The photovoice project has resulted in a lot of surprising and valuable information for the ward. The knowledge acquired has been applied in various actions. The concerns of being able to look in and too much light shining in have been solved by darkening and covering the windows.

Facilitation and method



METHOD

When conducting photovoice, take into account that it consists of two activities: taking the photographs and the photo-elicitation interviews. Connect these two activities. The combination of taking pictures and the subsequent in-depth conversations is what results in qualitatively rich data.

TAKING PHOTOGRAPHS

The study/ the assignment

- Give the children a clear assignment. This assignment can be formulated very specifically or broadly, depending on the phrasing of the question.

Examples are:

- *Broad: 'Take photographs of those things and places you like, and those you do not like.'*
- *Specific 'Take a photograph of your favourite place in the hospital.'*
- Avoid giving them examples. This may restrict the children's creativity and inspiration. Give children the time and space to think and to discover.
- Emphasise that the children decide what they take photographs of, not their doctor, daddy or friend.

Instructions for the camera

- Explain how to use the camera. Give them a short manual so the children or their parents can reread the instructions later on.
- Make agreements with the children about the maximum number of pictures that may be taken (for example, a total of 15 - 20). This should prevent the children randomly taking pictures and losing sight of the assignment.

- Agree with the children on when they will return the camera (varying from a couple of days to at most a week).

TIP To enforce the use of photography and to add to the children's empowerment, start with a mini-course in photography (for example, a workshop by the hospital photographer).

NB To guarantee the privacy of people in the hospital, photographs of people cannot simply be taken and used. Photographs of staff members and relatives may be used (for example, one of that nice nurse) if permission is obtained.

Out and about

- Give children a note explaining the study. They can show this to curious people they meet while they are taking photographs. In the note, mention that the children decide themselves what they take pictures of.
- Listen closely to the stories and experiences children share when they return the camera and write them down. This may result in valuable information for the photo-elicitation interview.

THE PHOTO-ELICITATION INTERVIEW

Preparation

Number the pictures before the interview, so afterwards you will know which pictures were discussed and what was said about them.

TIP It is important that children have an overview of the pictures taken, can make arrangements, can choose which photographs will be discussed first, how long they want to dwell upon a certain picture, whether they want to discuss certain pictures together, and so on. This is best achieved when printing the pictures.

Set-up of the interview

- Plan the interview in the hospital (for example, in the play room or in the child's room) and as soon as possible after taking the pictures (preferably the same day or the day after). Experience shows that when the interview is done at home after the admission, the hospital already seems far away to the child.
- Restate why the pictures were taken and what is about to happen today.
- Tell the child that you are very curious about what he or she has to say about the pictures.
- Ask the child's permission to record the interview, so nothing will be forgotten. Give the recording device to the child to explore and operate (makes it safer and less unknown). When the child does not give permission or when it seems there will be too much discomfort, take notes on paper.
- Explain that everything said in the interview will be incorporated anonymously (unless different agreements were made with the child!).
- Leave it up to the child how he or she wants to show the photographs; all at once, one at a time, the most important one first, and so on. This is usually a spontaneous process of analysis, and no arrangements have to be made beforehand.

Discussing the photographs

- When the child is not very talkative at first, ask short questions: What is this? What is happening here? Through these questions, try to form a picture of the situation and the environment in which the

photograph was taken. What is happening around the framework of the photograph?

- Make a list of subjects to be discussed. Use this as a reminder when searching for depth in the children's stories.
- Give the child the space to elaborate on seemingly less relevant topics. This can result into surprisingly valuable information. Then ask questions which bring the child back to the starting point. Thus, steering is definitely allowed, but accept the children and their stories as they are.
- Ask the child if there are pictures missing because he or she did not have the opportunity to take them, for example because a specific room was closed.

Concluding the interview

- Finish the interview when the child's attention span is waning. Be attentive to the child's physical and verbal expressions, like sighing, slouching and being easily distracted. The child's interest comes first, not the research agenda.
- Ask the child which photographs may be used for further research.

TIP Make extra copies of the photographs so the child can take them home after the interview.

Variations

- After the pictures have been discussed, they can be used to make a collage, an exhibition, a patchwork book, and so on. Children can then write explanations to accompany their photographs in which they describe what they have taken pictures of and why that is important to them.
- The photo-elicitation interview can also be carried out with a group of children. Discussing the photographs in a group can lead to children engaging in a conversation with each other.
- But be aware that too many differences between

the children in a group can cause the opinion of the articulate children to be put forward as the truth, while the experiences of the quieter children are not given a chance. When this is the case, choose an individual approach.

- Replace the pictures by making a movie.

Pitfalls

- Especially for younger children, pictures may seem so self-explanatory that they do not require clarification. The researcher must then depend on his or her own conversational skills.
- Not all themes can be captured in a picture! Take this into account when formulating the assignment and when discussing the pictures afterwards.
- This method requires a lot of organisation by the health care professionals.





2. Online chats

The chat conversation occurs between one child and one interviewer communicating through electronically written text messages in a chat box. The conversation is aimed at discovering the child's experiences, opinions and ideas concerning a certain topic.



Requirements

- Two computers (respondent and interviewer)
- Recruitment letter
- Accounts on a social network, like s



Target group

- Individuals
- > 9 years



Duration

- 30 – 45 minutes



Strength of the method

- Accessibility and straightforwardness of communication with the support of images.
- Transcription is immediately recorded by the computer.
- Anonymity can reduce social desirability.
- Saves time and money (planning may require an investment of time).
- It matches the children's social environment well.



CASE – Facebook chat

In the paediatric ward, interviews were done through Facebook chat with young people aged between 16 and 18 years. The central theme was their experience during their admission in the paediatric ward. At the ward's request, they were also asked specifically about the voice of young people in the development of the policy (medical) and – in consideration of planned renovations – about the ward's interior and facilities.

The theme of having a say was considered positive by young people. They liked the fact that both they themselves and their parents were involved in the development of the treatment plan. In some cases, though, young people thought the communication and the agreement on the policy could be improved:



"What was it like to be admitted to the paediatric ward?"



"Well, first of all, you don't really feel lonely, because they often come by and ask what you would like; if you want to play a game, they join you right away."



"Sounds good"



"and they just sit with me to chat"



"And did they also explain to you what you can expect?"



"Well, that did not go very well because every three days the machine had to be replaced and that was also under an anaesthetic. And I never knew when it was my turn. When I asked one of the nurses, they didn't know either, and then you have to wait all day in suspense. And sometimes they tell you the surgeon will come by this afternoon, and when it was five o'clock I asked the nurse again, isn't the surgeon coming? and she said apparently not because he would not come after five o'clock."



"So I understand that they were not very clear to you about the procedures that had to be done, and that when you asked, you did not receive the right information."



"Yes, that's right"

(chat session, 17-year-old girl)

Facilitation and method



Setup

- Create an account for the researcher on a social media site (for example, MSN Messenger or Facebook).
- Also create an account for the child/teenager you wish to chat with.
- Make sure the child receives the username and password of the newly created account before the chat session takes place (do not use an existing account). Preferably do so through a letter in which you also notify the child of the date and time on which the chat session will take place (NB: agree on this with the child/parents and nursing staff).
- Take into account the time at which young people are free to speak to the researcher. If the child has already been discharged from the hospital, this will likely be in the evening rather than during office hours.

Facilitating the chat session

- Start the chat session by explaining the research again and introducing yourself. Also give the child the opportunity to introduce him- or herself.
- Make it clear to the child that you are contacting them because he or she is the 'hands-on' expert when it comes to hospital admission. Show clearly that you are curious about his or her experiences and stories, and that critical remarks are important to improve the health care even more.
- Make an interview guideline beforehand in which you formulate topics.

TIP Do not make a list of precisely formulated questions as otherwise you may be tempted to stick to it, as a researcher. This may restrict the children's experiences too much. During the chat session, adopt

a flexible attitude and try to encourage the child to talk as much as possible.

- Use open-ended questions (who, what, where, how), ask probing questions ('Can you give an example?', 'What exactly do you mean by that?') and avoid leading questions (Do not ask: 'Do you enjoy being in the ward?', but 'How is the atmosphere in the ward?').
- Allow the child plenty of time to think about his/her answer and to type and send it.
- Formulate simple questions as they are more likely to be answered, and it prevents the answers getting lost.

See the following example:

Interviewer: was it an emergency or planned admission? How did everything with the admission go, did everything go smoothly or were there some bumps in the road?

Boy (18 years, admitted for appendicitis): No, I went to my GP on Monday with stabbing pain in the stomach, and I was referred to the hospital for blood samples, and after that we were called at home that we had to rush to the hospital. There they performed an ultrasound, but it turned out my body had already started fighting the inflammation, and this made it dangerous to operate because they would have to take out part of the small and large intestine, and that is why they preferred to treat it with antibiotics.

In the example above, a lot of questions are asked at the same time, but the boy only answers one of them. He actually only answers the second question, giving a list of facts about his hospital admission. We do not learn how he experienced his admission (smooth, or maybe difficult).

TIP During the conversation, write down key words and themes which are covered. Thus, you make sure that you can ask probing questions about certain topics later on, or that topics are not treated twice.

Concluding the conversation

- Take plenty of time to round off the chat session. You don't want the end of the conversation to seem sudden.
- Copy the digital interview to a program and file for archiving.
- After saving the conversation in a separate file, delete the chat history to guarantee the privacy of all participants.
- NB: after the conversation, delete the account the young person worked on and finally also delete the interviewer's account in order to prevent the young person sharing important information with the interviewer when he or she is no longer using that account. This could endanger the child's safety.

Variation

- To make participation in the research even more interesting for children, consider using multimedia technology. Using iPads or smart phones can make the chat sessions accessible and more flexible. For instance, there is no need to reserve a computer room. Make sure the children have the possibility to practice before the chat session, if necessary.

- The chat method can also be used as a peer-to-peer method. This means that young people interview each other about their hospital experiences. One possible advantage is that young people dare to speak more freely to each other than to an adult.^{33 34} Especially regarding sensitive subjects, this may be a good solution. However, young people are not trained researchers. This raises questions about the quality of the collected data,^{35 36} for example, because not enough probing questions are asked.^{37 38}

Pitfalls

- The language used to communicate through social media works with abbreviations and is concise. Young people are often experts in this, which is why asking probing questions about what the respondents mean exactly is very important.
- It is difficult to create ambiance when you cannot properly judge the situation.
- There is a danger of miscommunication when interviewer and participant are typing at the same time.³⁹



3. Statement box

The statement box uses a box with stimulating decorations containing images or statements on a certain topic. By asking children to select images or statements from the box and to discuss their associations and experiences with them, the dialogue between child and researcher is encouraged without the researcher playing a dominant role.³



Requirements

- Decorated box (adapted to the target group and topic)



Target group

- Individuals or small groups of 2 to 6 children
- > 6 years



Duration

± 30 minutes (partly dependent on the number of participants)



Strength of the method

- By literally handing the children the box and having them determine the pace of the conversation, they soon feel welcome to share their story. This is why this method is also appropriate for quieter children.
- Children determine how much time is given to a certain topic. This helps us gain a better insight as to what they consider to be important and what not.
- Quiet children are also invited to share their experiences.
- It is easy to use. Children can be asked on the spot if they want to participate.

TIP 1 Do not select only good images, add some funny and provocative ones.



IMAGE 1 Are you angry sometimes? Then what do you do? Are you sometimes angry in the hospital? What happens?

TIP 2 For a change, you can also use cartoons or comics in the box of statements.



IMAGE 2 If you could make three wishes, what would they be? Or more specifically: if you receive a wand to make staying in the hospital less dreadful, what would you wish for?

CASE

Health care professionals wanted to know what young people considered important in the hospital. For this reason they presented them with various statements. Below, two examples illustrate this:

STATEMENT I am not afraid to ask the nurse or doctor any questions.

"Yes, but there is way too little time. I was not well prepared for the surgery. I did not know how long I had to stay here, whether or not I could go outside, whether or not I was allowed to take a shower. I did not have the opportunity to ask those things beforehand. I had to ask all of that yesterday, at the very last moment, in the operating room." (18-year-old girl)

STATEMENT I think a doctor comes to my bed too often.

"I think so, yes, but it is also a good thing. Because they have to know everything about you, of course. Yesterday all these doctors kept coming up to me, and I had to tell all of them the same story over and over again. That is kind of weird. Why don't they write things down?" (12-year-old boy)

A week later, the researcher visited the ward again, and a girl came to talk to her. She said: "I cannot get any fresh air in my room, and now I have a cloud

in my head. I wish the window could open, like in the room I stayed in last time." And a boy pointed out to her that they had not yet discussed the Clini-Clowns (professional clowns, also known as clown doctors, who visit and entertain seriously ill children in hospitals). Their replies showed that they felt they were being taken seriously as a conversation partner and thought about the conversation afterwards. The researcher did not limit herself to the official conversation, and later realised that these spontaneous conversations contain important data. She used these data in her report.

Examples of other statements are:

- I think it is a good thing that parents can stay the night.
- There is too little to do in the hospital for young people my age.
- I really do not like the nursing staff at all.
- When I need someone in the hospital, they always come right away.

The statements have raised several points for improvement, from the interior of the rooms and the ventilation to information and communication. The hospital is now considering other solutions. The ward has started a refresher course for nurses on communicating with patients and parents.

Facilitation and method



Preparation

- Cover a box in a stimulating and age-appropriate way. Print or draw images (small and large) or make up statements concerning the topics to be discussed, and glue or write them on separate notes. Fold the notes before putting them in the box. This boosts the enthusiasm and gives children something to do during the conversation.

TIP Give young people an empty piece of paper and let them add their own statement which they would like to discuss.

TIP A variety of large and small images will increase the fun.

Working with the statement box

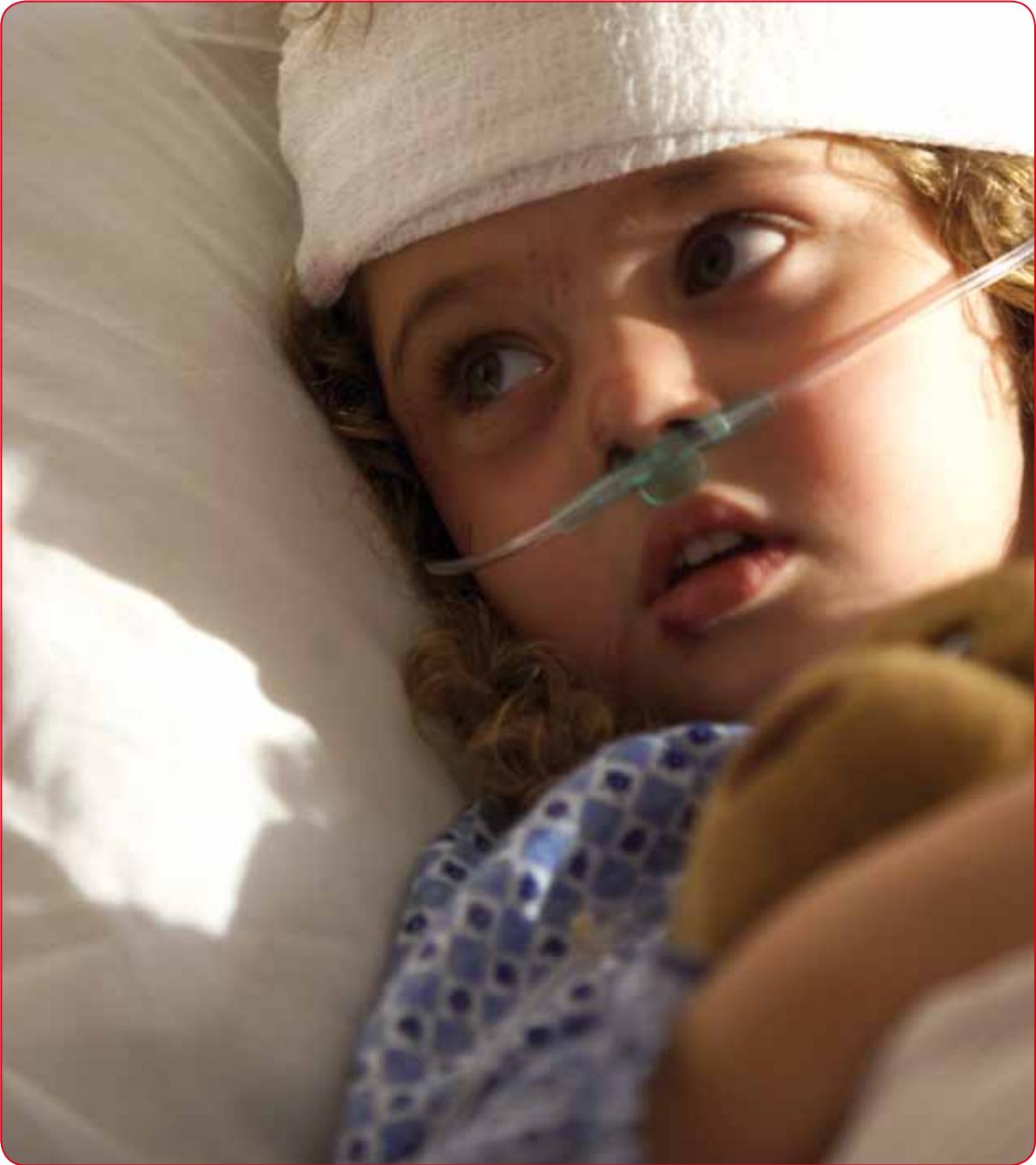
- Ask children to shake the box firmly before taking out one piece of paper at a time and saying something about it. This method gives children the opportunity to determine the order of the themes, and it leaves space for them to quickly put aside those themes they consider stupid and less relevant, and pick another image. These spontaneous actions can result in a lot of information.
- Give the children plenty of space and time to discuss the various topics with each other.
- As the interviewer, ask additional questions when necessary and possible, but do not control the conversation.

Conclusion

- Save enough time at the end to ask the children if there are any topics they would like to discuss, or if they have any additional comments or remarks.
- Pay attention to the children's verbal and physical expressions. Take a break or end the conversation when their attention span wanes.

Pitfalls

- The interviewer must be careful not to assume a central role or this method will lapse into the classic question-answer conversation. Make sure the children decide on the pace and the order themselves.
- The statements/images placed in the box strongly influence the topics of the conversation and the direction the conversation will take. Therefore, make sure to leave plenty of room for spontaneous interaction and elaboration.





4. Wish wall

This method asks children to place their wishes and ideas on a wish wall using drawings and texts. In this way they can express their ideas for hospital improvements and share them with other people.



Requirements

- Paper, cards, images, magazines
- Pens, colouring pencils, marker or felt-tip pens, tape, glue
- Large, inviting piece of paper or wallpaper with “wish wall” written on it



Target group

- Individuals or small groups of 2 to 6 children
- > 7 years



Duration

5 - 45 minutes



Strength of the method

- Can be used flexibly.
- The ideas of children are central and become visible to others.

CASE

At the moment of writing, the wishes are still being collected. What is striking is that the children's wishes are difficult to interpret if no conversation is started about the meaning behind the wish. This can be done immediately after the wish is put on the wall, or putting the wishes in context later on with a group of children.



I wish for...

"more distraction during the injections"

"more space to display your mail"



Facilitation and method



Preparation

- Make sure there is a room available where children can put their wishes on paper and hang them on the wall in peace and quiet.
- Ask the children to write/draw the wishes they have for improving the hospital. More than one wish is possible. Make sure that someone is there to guide the children during the writing and drawing (a maximum of one person for every two children), who can talk to the children to obtain in-depth information on the how, why, who, what, where and so on of the wish.
- Let the children put their own wish(es) on the wall.

Variation

- An addition to the wish wall is a mailbox or a wish cupboard with drawers that is placed on the paediatric ward. Children can place a wish in the cupboard at any time of day. Every now and then you can select the best wishes with the children (or the wishes with the highest priority) and put them on the wish wall.
- An alternative could be to make a digital wish wall (or wailing wall). In the Netherlands, for example, the website of the Dutch children's helpline (www.kindertelefoon.nl) allows children between 8 and 12 years old to send a wish anonymously via the 'dream castle' and/or pour their hearts out on the 'wailing wall'.
- Once the wall has been available to the children for a while, an in-depth workshop can be organised with the children. Have the children go over the wishes on the wall and ask them to group the wishes that belong together. This will result in categories created by the children themselves. Ask them to name the categories by sticking a title on

top. Then ask them to order the categories. Which wishes should be dealt with first by the hospital?

Conclusion

- Make sure the wish wall is accessible to health care providers and directors of the hospital. Actively invite them to visit this room so they can become acquainted with the children's wishes.
- Make sure the board/care providers notify children that they have seen the wish wall. Have them give feedback to the children on which action items will be taken from the wall and how they will be implemented.

TIP Make the opening of the exhibit to the 'public' a festive event to which the children, their parents and care providers are invited. The board could talk to the children about how the wishes will be implemented.

Pitfalls

- Wishes do not say much about the actual experiences which have led to the formulation of a certain wish, or about the way in which children would like to see their wish dealt with. Thus, looking for in-depth information on the children's wishes is of vital importance. It not only improves the data, it also strengthens the foundation of the list of action items.



Variation: wish mailbox



5. Guided tour by children

With this method, the children give a guided tour of the ward. This provides an immediate and quick view of how they use and experience their environment. It also gives them the opportunity to express their wishes.



Requirements

- Notepads
- Pens
- *Optional:* additional decor to make leadership noticeable, like a flag, jacket or hat.



Target group

- Groups of 2 to 4 children
- > 6 years old



Duration

30 minutes



Strength of the method

- By calling on the children as guides of the ward/hospital, you directly address their experiential knowledge.
- With children's experiential knowledge as a starting point, the direction of the conversation is in their hands.
- Does not require a lot of time to prepare.
- Easy to execute (if the staff of the ward/hospital cooperates)

CASE - The hospital through the eyes of children

During an evaluation afternoon in the hospital, five children aged between 10 and 13 years took the hospital play specialists on a guided tour of the ward they had been admitted to recently. During the tour, the children indicated what they experienced as comfortable or scary in the ward. They emphasised, for example, the empty walls and the lack of colour. The examination room (picture 1) was a room none of the children liked to go into.



PICTURE 1 *The examination room, photographed by Danielle (12 years)*

During the tour, the children were actually scared to walk in there, while the patient lounge (picture 2) was a place in which they felt very comfortable (during the tour, all the children jumped into that room happily). This raised the question of whether the difference in ambiance is unnecessarily large and could be improved with a few small adjustments.



PICTURE 2 *The youth room, photographed by Romy (10 years)*

During the walk, the children opened up completely in sharing their experiences about their period of hospital admission. For a moment, it was like they were admitted to hospital once again. The children felt very comfortable, and the consultation resulted into a lot of valuable information, which has been used for setting up an improvement plan for the ward. The walls in the hallway and examination room, for example, have now been made more cheerful with posters and mural paintings.

Facilitation and method



METHOD

The study/the assignment

- Clearly explain the study and ask children if they would like to participate.
- Ask a number of children (2 or 3) to give you a guided tour in the hospital/ward (make sure this has been discussed with the hospital/ward).
- Asking for a guided tour of the ward may be sufficient for the children, and further instructions are probably unnecessary. If they do require more information, ask the children to show you those places they specifically do or do not like to visit.
- Avoid giving examples when introducing the assignment. This may restrict the children's creativity and inspiration, and it might send them too much in a certain direction.
- Encourage the children to come up with solutions for possible bottlenecks.
- Take notes during the walk to record the essence of the children's input. Involve children in this process. Ask them if a certain remark is important, and if you should write that down. After this has been asked a couple of times, children will pick this up themselves.

Variatie:

- Children can also be actively involved in the research that is taking place during their exploration. Instead of the adult taking all the notes, the children can also be given notepads and pens during the tour, so they can take their own notes of the places they visit and their group members' experiences with those places.
- An addition to this method is the drawing of a map after the guided tour. Children can draw maps individually or in groups. Assignments like 'mark the places you visit most with an orange circle and the places you visit the least with a blue circle' and 'mark the places you like visiting the best with a green cross and the ones you like visiting the least with a red cross' will provide the children with plenty of material for discussion and contemplation on their experiences and opinions. But this also produces a lot of valuable information for the researcher. When selecting this variation, the researcher will not have to ask very specific questions during the tour. The tour questions can be open, along the lines of 'Can you show me this ward?' Bear in mind that you have to keep making notes about the order of the rooms and

TIP: Before the tour, agree on some behavioural rules with the children (but do not put too much emphasis on them). Have the children come up with the rules themselves (do not make too much noise, no running, knock on a door before you enter...) and supplement them as necessary. For example, do not enter rooms when red lights are on.

Out and about

- Clearly make the children feel that they are taking you, a staff member/boss, in tow. They decide where you will go.
- Ask the children questions during the walk and leave room for them to converse with each other. You could ask, for example, why they are showing you certain places. When do they come there? What do they think of that room? Who is present when they are in that room?

the children's remarks as it contains valuable information.

TIP: Ask the ward and the hospital for permission to organise this tour. Make sure the staff knows about the tour so that they know what to expect.

Pitfalls

- The hospital/the ward might experience this method as burdensome because it cannot be agreed upon in advance which rooms the children want to visit.





6. Diary room

The diary room is a small room where children can record an audio or video message. In this way they can share their experiences and opinions concerning a specific subject, question or statement.



Requirements

- 'Play house' which functions as a 'diary room'
- Small sofa or chair in the house
- Camera
- Computer



Target group

- Individuals or pairs (depending on the children's choice)
- > 6 years



Duration

A maximum of 20 minutes, depending on the number of questions or statements the child might be asked about.



Strength of the method

- The absence of a human interviewer may make this method more accessible.
- Stimulating method which arouses the children's curiosity.
- Can be a structural method to realise children's participation, if guidance can be offered.

CASE

TIP This hospital has opted to have a special house made. However, a simple play house or puppet theatre will also work.



Facilitation and method



Preparation

- Make a diary room which looks attractive to your target group. Use a play house or a puppet theatre, for example, and possibly decorate it together with the children.
- Ensure that the children can utilise the diary room on their own so that they do not need the help of a guide. This can, for example, be achieved by using a certain software package which directs audio and video in the diary room in such a way that it guides the children from question to question. You can also opt for a simpler solution by placing a number of cards with questions in the diary room so the child has something to follow when talking to the camera.
- Set up the diary room in a place where children can neither be disturbed nor heard by others. You can use the diary room just once or temporarily, or you can choose to open it for a longer period of time.
- Give the children the possibility to choose between audio or video recordings. Build this possibility into the construction of the diary room. This can be done technologically, with a button which turns off the screen, but also very practically with a curtain, for example, or a selection of masks the children can put on if they do not want to appear on screen.
- Formulate one broad question or statement, or opt to treat several specific questions on one topic. Examples are:
 - Broad: *What do you like in this hospital, and what not?*

- Specifically about the topic 'hospital admission':
Can you explain how your admission to the hospital went? Who was present at the admission? Where were you received? How long did you have to wait? What did you think of that?

In the diary room

- Make sure the children know how to operate the camera. You can give oral instructions or a simple manual.
- In principle, children enter the diary room alone, but have a flexible attitude. Pairs' recordings can deliver surprising results.
- The guide will remain near the diary room at all times so the children can ask questions when necessary. Ensure that you cannot directly hear or see what the children are doing in the diary room, to safeguard their privacy.

Subsequently

- Make sure the recordings made by children are viewed as quickly as possible after the time of recording. Children may share important and urgent information, for example in connection with their disease. When this information is overlooked, the child's safety might suffer.

Pitfalls

- The presence of a camera may have an inhibitory effect.
- Privacy and anonymity cannot be guaranteed, so great efforts must be made to obtain the participants' permission to be filmed, and the purposes for which the images will be used must be made clear.
- Technologically, the use of recording equipment requires proper preparation and further inquiries.
- Experience shows that when this method is not facilitated, children will not enter the diary room on their own. Guidance is essential.





7. Letter to the chief executive

In this method, children are invited to write a (email) letter to the chief executive of the hospital. This is a creative way to learn what children think is important, or to give feedback to the board on the most important action items which resulted from another method.



Requirements

- Official stationery and envelopes
- Name of the chief executive/board
- Pens/felt-tip pens
- Large sheets of coloured paper (green and red)
- Arts and crafts materials (paint, stickers, colouring pencils, glitter pens ...)
- Computer (optional)



Target group

- Individually or in groups of 2 to 6 children
- > 7 years



Duration

A minimum of 30 minutes



Strength of the method

- It establishes a direct dialogue between the children and the board of the hospital.
- This method is versatile and easy to carry out, both individually and with a group of children.
- The method can also be used as a supplement or in-depth method for one of the other methods described; it is a good way to give feedback to the board about the results obtained and actions implemented.

CASE – Dear chief executive...

In one hospital, 23 children individually wrote an email letter to the chief executive. Besides stating general information (like age, sex and duration of the hospital admission), the children were asked to react to three key questions through a digital format:

1. Dear chief executive, what I like very much about this hospital...

"I like that people can visit all day long (...) then it is at least a bit nice." (6-year-old girl)

2. And I would immediately change / improve this if I were the boss...

"I would appreciate if the nurses say what they are going to do when they come in, so I know what to expect. Sometimes when they bring medication, they do not say which medication that is, and I would like to know that." (11-year-old boy)

3. This is my idea for change / improvement...

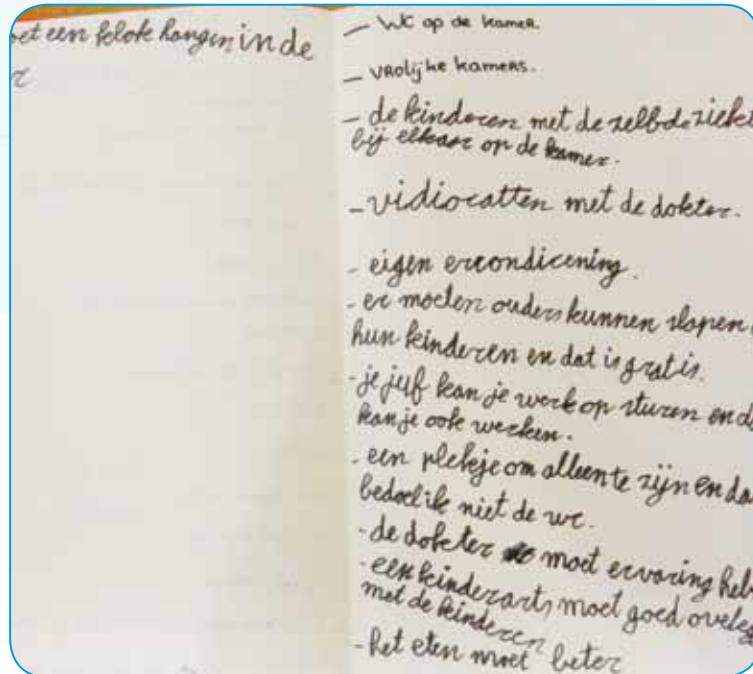
"Replace all computers, because they do not work very well anymore. The computers often freeze." (9-year-old boy)

FIGURE 1

CASE 2 – action list for the board

In another hospital, this method was used as a supplement to the photovoice activities. Based on the bottlenecks raised in the photographs, the children collectively composed a letter with action items for the board (picture 3).

In this letter to the chief executive, the children indicated what they would like to be different, for example a place to be alone other than the toilet, clocks in their rooms, better food, better consultation between doctor and child, and the possibility of doing schoolwork in the hospital.



PICTURE 3 Letter of action items for the board, including "better food", "the paediatrician should consult with children", "children with the same diseases in the same room", "possibilities for parents to stay the night", "being able to do schoolwork", "the doctor should have experience"

Facilitation and method



Method

- Inform the children about the aim, purpose and result of writing the letter.
- Let the children know that they are the 'hands-on' experts with regard to admissions to the paediatric ward. The chief executive has never been admitted to the paediatric ward, so he does not know what it is like to be there as a patient. Also mention that a chief executive cannot always change things, for example because time and money are required.

Individual letter

- Ask children to consider carefully things that went well and things that did not during the process of hospital admission and the time spent in the paediatric ward. Then ask them to put this into words in a written or email letter.
- Make sure that the letters are actually received by the chief executive. Ideally, the children hand their letters themselves to the chief executive or a board member.
- Make sure all children receive a personal reply from the board which confirms that the letters have been read, and specifies how the action items will be dealt with.
- The letters can also be displayed in a central area, provided that the children give their permission for this.

Collective letter

- Ask the children to consider carefully things that went well and things that did not during the process of hospital admission and the time spent in the paediatric ward. Ask them to write these things down (this step can be skipped when the method is used as a continuation of one of the other

methods). Then discuss the results with the children. This also constitutes a moment of feedback for the children, and an additional moment of verification of the accuracy of the data for the researcher.

- First discuss the positive experiences with the children and later the less positive ones. Who wrote down what, why, and are those things familiar to other children?
- Have the children write down the items that occur most often, or the ones on which the most consensus is reached, on a large sheet of paper. What went well goes on the green sheet, what did not on the red sheet.
- Lay down on a table or hang the red sheet on the wall in such a way that all the children can easily see it. Ask them to imagine how the things that did not go well could be improved.
- Ask the children to write down these solutions/ action items on a large sheet of paper. Allow them the time and opportunity to decorate the action list.
- Make sure the children themselves can hand over their letter to the chief executive or a member of the board.
- Hang the letter/action list on the wall together with the chief executive and the children. Hang it in a central space in the paediatric ward, so all health care providers and visitors can read the action items.

Pitfalls

- Requires the immediate commitment and time of the board.
- Might raise expectations which cannot be met.





8. Methods involving parents

Though we assume that it is best when the children themselves indicate what they do and do not like about the health care in the hospital, it is also important to consult the parents. They, too, are 'hands-on' experts and thus have a unique perspective on health care. Furthermore, they can speak on behalf of their children when they are too ill or too young to put into words what they think is important, though there are restrictions involved.

Parents can be consulted in many ways. In this chapter, we will restrict ourselves to focus groups, 'mirror meetings', and individual interviews since parent participation is not the focus of this book. These three methods are applied in the hospitals involved in the research.⁴⁰ The descriptions are concise since plenty has already been written about them.

Focus group

A focus group is a conversation in groups of four to ten participants, supervised by an experienced facilitator. This method provides parents with the opportunity to share and discuss their experiences with each other. The strength of the focus group lies in the creation of interactive data; one person's contribution will stimulate another person's contribution.^{41 42 43} Engaging in a conversation with each other results in a more nuanced idea of the health care in the hospital. The disadvantage, compared to a personal interview, is that the various parents will have to be able to get together at the same time. To prevent this problem, one could

opt for online focus groups. Parents will not have to leave their home and can join the focus group on their computer. Though the online focus group is less personal because the participants cannot see each other (and non-verbal communication is not possible), there is a higher degree of flexibility and anonymity. You could, for example, let the participants log on for a week. Thus, they can add to the discussion whenever it is most suitable for them. It also gives participants time to reflect on the responses of other people, and it provides them with the opportunity to change or nuance their opinion. The anonymous character of the online focus group has proven to be especially useful in obtaining information on sensitive subjects. When it is not possible to create an online environment yourself, you could use a private group from an existing network, like the Dutch website www.deeljezorg.nl, which is a virtual place where people can share their stories and experiences with respect to health care and welfare.

CASE

In the neonatology ward, a focus group was organised to investigate the opinions and experiences of parents concerning the health care for their newly born babies. The example from the conversation below illustrates the added value of mutual interaction:

PARENT 1 "We found out on Saturday that the twins could go home on Sunday. That kind of took us by surprise. We would have rather known this in advance, so there would have been time to prepare for everything."

PARENT 2 "The same applies to the transfer from incubator to the open cot room. That also happens very suddenly."

PARENT 1 "Yes, we experienced that too. I remember thinking, can they do that, just like that? Once they were home, everything was okay. But we would have liked to be able to prepare better, also to make it a celebration. You're not experienced yet."

PARENT 3 "We were also informed on Monday afternoon at four o'clock that our son could go home the next morning. Well, a lot has to be taken care of then. It was not how I had imagined it either."

Parent participation not only results in a list of items for improvement, it also helps gain an insight into what goes well and what is appreciated: "The day before she came home was our daughter's birthday. They had decorated the room in the hospital. That was amazing. People paid attention to us. I felt at home there." (*mother*)

In the abovementioned hospital, people were enthusiastic about the information gained from the focus group, and as a result of the research, a study group was set up to work on these points for

improvement. The parents were given feedback on their suggestions by the hospital with an accompanying letter of thanks.

Variations

- When there is an insufficient number of parents for a traditional focus group, you can choose to organise a mini focus group during the children's hour of rest with the parents who are present at that time and willing to participate. Since this takes place in the ward itself and the parents are already present anyway, participation in the mini focus group might burden them less.
- Another alternative in the case of recruitment problems is the waiting room conversation. Parents are waiting there anyway, and they will be more willing to participate than when they have to come to the hospital on a separate occasion. The disadvantages are that the parents might not have a lot of time, the conversation might have to be interrupted halfway through, and privacy cannot be guaranteed.

Mirror conversation

A mirror conversation is a variation of the focus group in which parents have the opportunity to share their experiences with health care in the presence of hospital staff members. The mirror conversation was originally developed by the Academic Medical Centre (AMC) in Amsterdam as a way of making staff members aware of the patients' perspective. In a mirror conversation, patients and staff members figuratively hold a mirror up to each other's face based on their experiences and expertise. The group for a mirror conversation consists of about 8 to 12 participants and a number of involved health care professionals.⁴⁵ The general guideline is that the number of staff members present should be smaller than the number of participants. The conversation is prepared with

the participating staff members in advance.

Thus, they can indicate in advance which specific topics they would like to emphasise. However, there will be plenty of room in the mirror conversation for parents to introduce subjects that matter to them. We recommend preparing the mirror conversations and having them supervised by an independent, external party.

A mirror conversation takes place in two circles, an inner and an outer one. Parents sit in the inner circle and start by sharing their experiences. Make the first question for the parents as broad as possible: 'What are your experiences with the care in this hospital?' The staff members are seated in the outer circle and listen. In the second round, both parents and staff members form one

circle. Now the staff members can ask questions about what they heard in the first round. Parents and staff members can converse with each other based on their experiences of the health care and services provided and suggestions for improvement.

Based on the conversation report, an overview is drawn up containing the positive points and the suggestions for improvement. They will be discussed with the appropriate directors, who will then develop an improvement plan. Experience has shown that this transparent method is experienced as very positive by both parents and health care professionals. Because care providers are directly confronted with the parents' experiences, their awareness and involvement are augmented.⁴⁶



CASUS

"Unpleasant that we had to be there, but good to be here"

In two hospitals, experience was gained with organising a mirror conversation for parents. During these meetings, five to ten parents were present, whose children who had been admitted to the paediatric ward or the neonatology ward. As listeners, several health care professionals were present: paediatricians, the chief of the ward, paediatric nurses and hospital play specialists.

Parents often share first the positive things they experienced, before turning to their concerns and points of criticism. Important eye openers for the health care professionals were that parents sometimes do not know what is expected of them, and that the communication and the concordance between the different disciplines should be improved.

"What do the nurses expect of parents? At what time should I be around? Dinner time? Bed time? Sometimes there is a paracetamol suppository. Should I just give that? Sometimes I am at home for an hour and a half and then I feel guilty about not being with my child. Does the nurse want me to be there at all times? Does the nurse want to see every filled nappy? It makes me feel awkward when I have to call. I then put the nappy in the lift, but the smell!" *(mother)*

At the end of the conversation, participants and listeners were asked what they thought of the conversation. Some examples of responses:

"... that I am reminded of what a hospital admission means to the patient and parents, 'that is how they experience it'; the information from this conversation really adds to the standard evaluations that are filled out." *(paediatric nurse)*

"I was a little nervous at first, but at some point I forgot that there were listeners." *(mother)*

As a result of the mirror conversations, the hospitals got to work on the suggestions for improvement. One of the hospitals introduced care conversations with the parents. Every two days, the mutual expectations are discussed so they can be dealt with promptly.

Individual interview

With individual interviews, the aim of the conversation is to uncover the experiences, opinions and ideas of the parent in question concerning a certain subject. During this interview, the parents are given plenty of time and room to discuss both their positive and negative experiences at length. The advantage of an individual conversation is that probing questions can be asked to reveal underlying thoughts and ideas. Moreover, the interview is relatively easy to organise. During their child's hospital admission, parents are often present in the hospital and frequently have half an hour to spare when their child is occupied. Telephone interviews are a variation of the face-to-face interview, allowing parents to speak to the interviewer at a place of their choice and at a time most suitable for them.

CASE

In a number of hospitals, we did not succeed in gathering enough parents for a focus group. So we decided to approach the parents who did sign up for the focus group for a telephone interview. The responses were very positive; all of them were willing to speak to the interviewer. The interviews were aimed at the parents' experiences during their child's hospital admission and stay. Key questions were: What went well during the admission? What needs to be better? How could this be improved? The results of the interview were submitted to the parents and the hospital in the shape of plus points and suggestions for improvement. The ward has decided to focus attention on the communication amongst staff members themselves, and towards patients and parents.

Points of interest

Which method you choose depends on the specific research question, the preference and experience of the researcher, and the time available. The points of interest below apply to all three methods:

- Whether talking to children or parents, the location, ambiance and attitude of the facilitator are key to determining the success of the

Use knowledge that is already available when it comes to what patients and parents think is important. For example, consult quality standards developed from a patient perspective² and the literature.

conversation. Try to create an open atmosphere in which the parents feel welcome to share their experiences and ideas and, as the facilitator, adopt an enthusiastic, respectful and involved attitude.

- Prepare in advance a conversation guideline or

list of topics with the themes to be discussed in accordance with the research question. Using knowledge that is already available when it comes to what patients and parents think is important. For example, consult quality standards developed from a patient perspective² and the literature.

- Do not prepare a list of precisely formulated questions as otherwise you may be tempted to stick to it, as a result of which no conversation is created in which parents feel free to introduce themes that are important to them.
- At the beginning of the conversation, give a short introduction in which you talk about yourself, the study, and the aim of the conversation. Keep in mind that the parents find themselves in a dependent relationship, and bring up this topic for discussion. Also ask the participant(s) to introduce themselves briefly. Carefully consider beforehand what you want to know: what is relevant to the research question, and what not?
- Ask parents for their permission to record the conversation with an audio recorder or a camera, to make a careful analysis possible. But never simply rely on technology: always make notes as well.
- After the conversation, send the participants a summary so that they can check whether or not their input was correctly interpreted. Afterwards, let the participants know what the hospital is going to do with the results.
- It is best to ask an external party, for example, a patient organisation or researcher, to moderate the conversation. Experience with the method helps to collect qualitatively strong data. Moreover, experience shows that patients (or their parents) struggle with their dependent position.
- Participation should not cost the parents money. Reimburse them for their expenses.

Conversational tips:

- First ask about their positive experiences: 'What went well?' and then move on to the less positive ones: 'Which things were not so successful?'
- Ask as many open-ended questions as possible. These are questions which can be answered in an unlimited number of ways. As a reminder: always start your questions with an interrogative word: Who, What, Where, Why, When, How?
- Always ask probing questions when parents give a general reply.
PARENT "Everything went well, no complaints."
INTERVIEWER "Can you tell me specifically what you thought went well?"
- Conclude the conversation with: 'What do you consider to be the most important topic that was discussed in this conversation?' This tells you what their priorities are.

Pitfalls

- In group conversations, there is always the risk that articulate people will dominate the discussion. The person moderating the conversation must compensate for this. For example, make eye contact with the quieter participants and ask questions directed at them. For example: "*Miss Jansen, how do you feel about the things your neighbour just shared?*" Keep in mind that one parent is not the same as the other and that everyone experiences and expresses things in their own way.
- Working with groups of parents may be hard to realise in a hospital setting. Experience often shows that recruiting parents is difficult because they are already heavily burdened, both emotionally and practically, during their child's admission. However, parents who do opt to participate are very enthusiastic and satisfied with their participation afterwards. A personal invitation by a health care professional with

whom the parents have a connection and a clear explanation of the aim of the gathering can help to increase attendance.

- Interviewing people or facilitating a group conversation and analysing the gathered data in the right way require specific training and practical experience.



PART 3 From method to process

Analysing, reporting and effectuating change

The experiences, wishes and stories of children and parents form the basis of the analysis. The personal observations and information obtained from third parties can help put these data into context. In this part of the book, we describe the basic principles of analysing, reporting and activating to ensure that the children's input will be utilised.

Analysing

Analysing means reducing the large amount of information obtained to several, clearly formulated themes and the accompanying exceptions. The step-by-step plan below can prove to be helpful in this process.^{47, 48}

1. Carefully read the entire report.
2. Break it down by subjects that are discussed and assign them a 'title', for example: content treatment, client interaction, information, or health care organisation. This title can be written in the margin, or use different colours. Next, carry out a second step of classifying each identified subject. Again, titles are assigned. The main category 'content treatment', for example, can be subdivided into the categories: professionalism, carefulness and quality. Review what has been said, but also what was not mentioned, take into account the emotions expressed, and note which situations or remarks deviated from the pattern.

3. Unfortunately, for organisational reasons, this next step is sometimes skipped, but it is essential to check the analysis with the target group. Do the general findings match their experiences? Do they have any remarks, additions or suggestions? Do they still have the same priorities?
4. The results of the analysis, the themes and the significant deviations are then described. It is important to explain these findings, and to substantiate them with quotations and examples.

Reporting

A report is important to justify and disseminate the findings. The following guideline may be helpful when formulating a report:

1. Introduction, how and why did the initiative come about?
2. Which methods were applied and how did the process go?
3. Who participated (and who did not)?
4. What are the results of the study?
5. Which actions are necessary?

Feedback to children:

It is important for children to see that their participation and ideas are having an effect.

Make sure that the children can see that their wishes and experiences have been noticed. For example, through an informational letter, an article in the hospital's news magazine, or by organising an informative afternoon during which actions will be discussed.

Research as a catalyst for change

A report is one of the results of a participatory project, but it should never be the only result. After all, the aim of a participatory project is broader. Collecting information on the experiences, needs and knowledge of children concerning a certain topic is just the first step. The second one is to translate the research data into action to realise change for the benefit of the children. The necessary actions can be initiated and carried out by adults. However, the children's input will be better guaranteed if they are allowed to contribute when the actions are being realised. Or they can design, implement and evaluate actions with the help of adults.

Besides local change, participatory projects require change at the level of the institution and policy.

First, to make sure that changes are actually carried out and become established, and second, so that the children's participation does not become a once-only project. For example, organise an exhibition or a work conference to gain insight into the children's ideas and to see how they can be translated into practice, or organise a 'youth participation' training course for the ward. At an internal or regional level, a children's participation study group could be established to reflect upon the possibilities of children's participation within hospitals and how it could be facilitated even better.

Experience shows that change at the level of the institution and policy requires a lot of time and effort from different players, and involves more than one project. However, change at the individual level is often easily attainable. Participation often results in positive experiences for both the children and health care providers. Through participation, care providers become more aware of the fact that the children's social environment differs from that of adults, and that children possess valuable knowledge. For the children, participation often leads to empowerment, meaning that it can help them acquire knowledge and skills, confidence and a sense of self-esteem.²⁶⁻²⁸

And what if...?

In practice, participatory projects rarely go smoothly, and internal and external barriers must be overcome to get the project going and have it be successful. In this chapter, some of these barriers and possible approaches are discussed.

What if the children do not say anything?

If children do not say much, this does not mean that they do not want to talk. Too often, quiet children are thought to be uninterested in a topic or incapable of expressing an opinion, or prefer to play. Verify whether or not you have created the right conditions: Does the child feel sufficiently welcome to share his/her experiences? Does the child know why you want to know things and what you are going to do with his/her opinions? Did you select the right method? Inviting a person they trust to join in (friend, parent, play specialist) might help, or you could first let them come along with other children. And sometimes children need more than one meeting to get used to the project. If this is the case, make it happen.

How can I deal with resistance from within the organisation?

Be aware that there may be unexpected responses to the project and its results. Listening to the children sounds great, but what happens when their ideas do not match those of their parents and professionals? It is therefore important to take into account the perspectives and interests of all parties involved, the institutional policy and sometimes implied norms. Make sure key figures are involved with the project from an early stage and preferably become co-owners of it. Ask which themes are relevant for the hospital and take them into consideration when formulating the research questions. The management's support is key to overcoming organisational barriers and conflicts. We fear the unknown, a tendency that applies here also. Share successes at an early stage. This is important to show the children and their parents that their ideas are actually being taken seriously, and also to create more support within the organisation.

Moet je de data na afloop van een project nog kwantificeren?

Participatory projects work best when the group of participants is kept small. There is no intention to produce representative statements for the entire group (all chronically ill, or all children with a certain

The management's support is key to overcoming organisational barriers and conflicts.

disease), unless the study is adapted to that. Precisely because participatory projects are small scale, the children can grow to trust the researcher, and they can be offered an active role. When it comes to surprising insights, for example, if three children say something which made you think, 'How silly that we never thought of that before', there is no need to put time and energy into supplementary research. Ho-

wever, when in doubt about whether other children feel the same, the topic is important, and the means (time, knowledge, money) are available, consider a larger, supplementary study.

Can I also perform quantitative participatory research with children?

Active methods are often chosen for participatory projects, instead of talking or filling out questionnaires. The advantages of qualitative research are that it is more flexible and allows for more intimacy with the target group, and for more discussion between the researcher and the target group. That is why qualitative research is often chosen in practice. This does not mean that quantitative research, such as questionnaires, is not possible. Children and young people can be involved in, for example, drawing up, distributing and interpreting a questionnaire.^{49 50 51}

Can children also help with the analysis?

Children are rarely given a role in the analysis. But there are some examples of children, properly guided, providing a valuable contribution to the analysis.^{3 52} Some of the methods described in this book call for a natural process of analysis. When you are classifying pictures or wishes into certain categories, you are already analysing. When children are not involved in the analysis, there is a risk that the meaning given to events may be interpreted wrongly, or be dominated by adults. Matters that are important to children will then be overlooked. When the researcher chooses to do the analysis him/herself, it is a good idea to present the findings to the children, so they can check if their input was interpreted correctly, and to give them the opportunity to make additions. Researchers working in this way found that by discussing the data with the children, the analysis and understanding of the data were improved: together you can achieve a more complete picture.

Should I reward children/parents for their participation in the research?

The most important reward that children and parents can receive for their participation in the research is that they are being heard and that their opinion is taken seriously by the hospital. Many researchers also give children a little present for their participation in the research. Keep in mind that it is the gesture that counts. What is important is appreciation of their contribution, which can be expressed with a token gift. To prevent poor people from being excluded, it is important to reimburse them for any expenses incurred, like travelling expenses.

Can I also do research with very young children?

Researchers have gained experience with involving very young children in studies, both nationally and internationally.^{53 54} They showed that very young children – including those who cannot yet speak – can share their views on themes that concern them, and that their views on their social world can benefit the policy of youth institutions (like day-care centres, schools). This method requires specific skills of the researchers with regard to inviting and recognising non-verbal signs

Can children's participation turn out badly?

Children's participation can have negative consequences, like:

1. Disappointment: when expectations are raised that cannot be met.
2. Poor quality of data: when the area of research is too far beyond the expertise and experience of the children.
3. Overburdening: when the amount of burden participants can cope with is not taken into account.
4. Tokenism: when the interest of the researcher is placed above the interest of the participants, or when one strives for the highest level of participation instead of the level that is desirable and feasible.

Especially with sick children and their families, who are already burdened a lot, it is important to take into account the strain that participation in a project can involve. However, the pitfall is to apply this consideration to the target group, instead of asking participants *what they want* and *can do*, and how this can be accommodated best.

Conclusion

In this book, various methods are described that allow children to speak about the health care they receive. The many examples illustrate that children, when carefully encouraged, enjoy giving their opinion, and that their experiences and wishes result in valuable insights.

The wishes and ideas of children are based on experiences, sometimes positive, sometimes negative, sometimes shared by adults, but more often not. They have their own experiences with health care. Both their positive and negative experiences are important for evaluating and improving the quality of health care and the children's well-being. Though this book does not aim to bring children's wishes and experiences out into the open, we would like to briefly name three of the themes which have come up repeatedly: social contacts, communication and privacy. Social contacts are very important for children. They need access to the internet to keep in touch with friends outside the hospital, while the play room or patient lounge is a nice place to take their mind off things, or to chat with other children. Communication of information is another recurring theme. Like adults, children want to know what to expect and to be informed about their treatment. They would like to know what is going to happen, and when a certain procedure will take place. Finally, privacy is a theme that worries children, and especially the lack of it: glass doors through which everyone can look, no place to just be alone, or to talk to someone in private. As one of the children expressed it so beautifully in a letter to the chief executive: "a place to be alone other than the toilet."

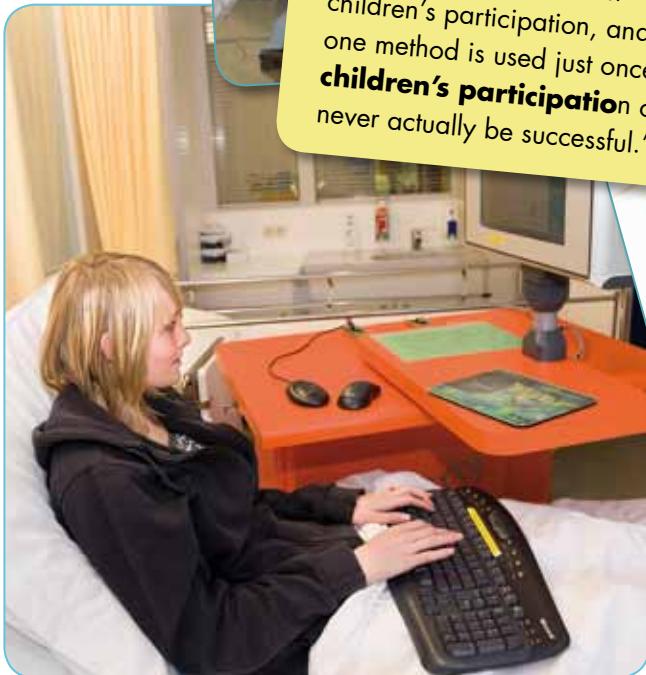
Consulting children on how they experience health care is an important step, but it is not enough. The fact that adults are listening to children does not mean that they understand their message and intend to do something with it. And if nothing happens with your input, why bother voicing your opinion the next time? In all the hospitals involved, the experiences and wishes of children were translated into plans, and in some hospitals the plans have already been put into practice. Moreover, the project and its results have encouraged participants to move forward with the theme of children's participation.

Besides enthusiasm, children's participation requires critical reflection and more professional knowledge and research skills than we could offer in this book. Why does children's participation not always work in hospitals? Why is it so hard to make the time and means available? Do we really think it is important? And how can the different perspectives – of children, parents and professionals – all be given their due in a time when health care is under a huge amount of pressure?

When we do not critically reflect upon the possibilities and difficulties with children's participation, and only one method is used just once, children's participation can never actually be successful. Children's participation is a process that requires structural attention and embedding within the process of health care and the organisation. This is a great challenge to which we are happy to contribute.



'When we do not critically reflect upon the **possibilities** and the **difficulties** with children's participation, and only one method is used just once, **children's participation** can never actually be successful.'

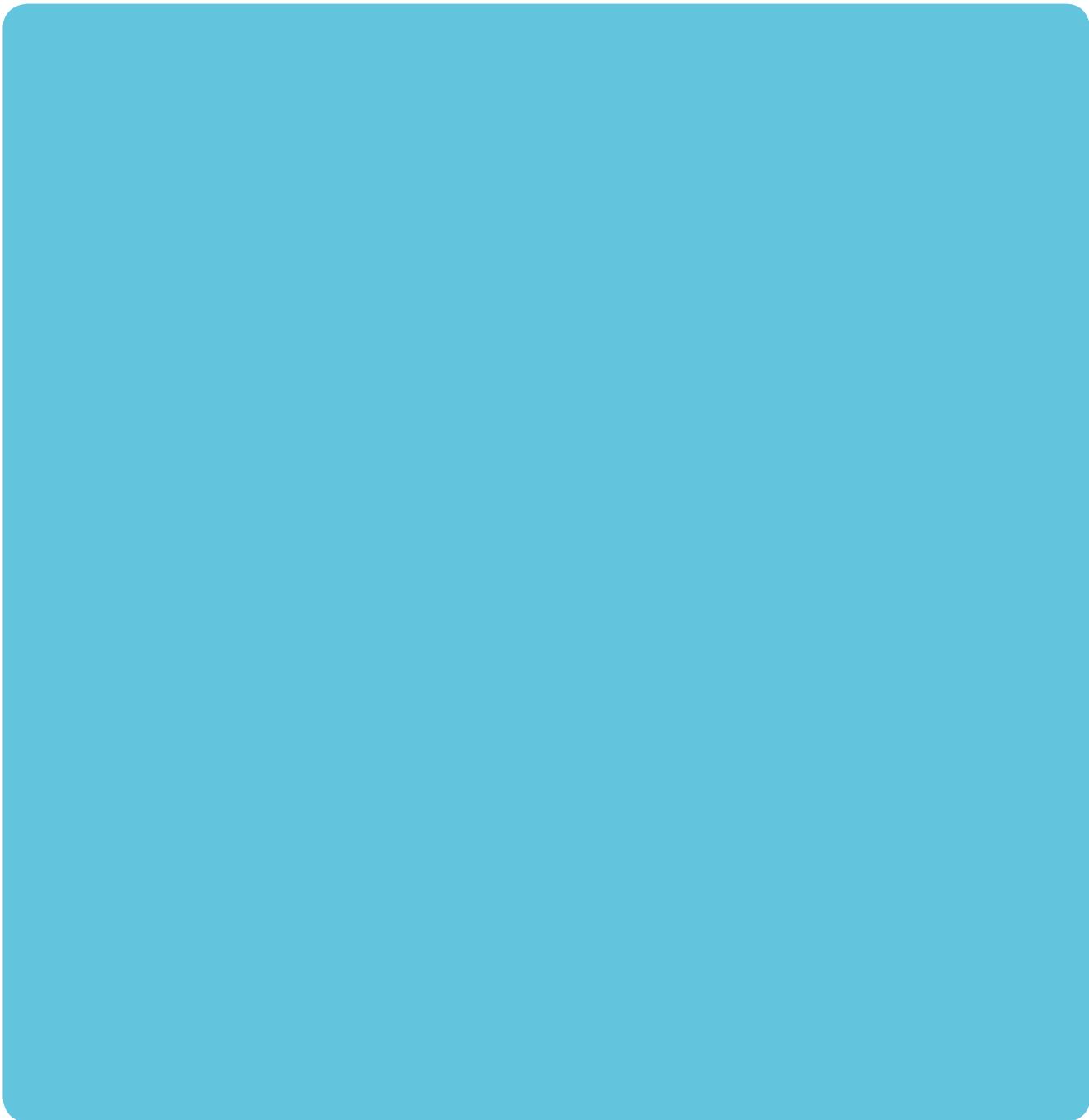


References

- 1 Hart & Vaatgroep (2011). Criteria Vaatkeurmerk Perifeer Arterieel Vaatlijden van De Hart&Vaatgroep [Criteria Vascular Quality mark. Peripheral arterial disease of the Heart & Vascular Group] Available at www.hartenvaatgroep.nl/uploads/media/Criteria_Vaatkeurmerk_2011.pdf
- 2 Kwaliteit in Zicht (2011) Basisset Kwaliteitscriteria, het patiëntenperspectief op de zorg voor chronisch zieken [Basic set quality criteria, the patient perspective on care for the chronically diseased]. Available at <http://www.programmakwaliteitinzicht.nl>.
- 3 Dedding, C. (2009). *Delen in macht en onmacht: Kindparticipatie in de (alledaagse) diabeteszorg [Sharing power and powerlessness. Child participation in the (ordinary) diabetes care]*. Amsterdam: Universiteit van Amsterdam.
- 4 Eric Emmanuel Schmitt (2010). *Oscar en oma Rozerood [Oscar and the Lady in Pink]*. Amsterdam: Atlas.
- 5 Snel, M.C., Verhelst, M. & Jansen, N.C.A. (2005). *Dokter, dit vind ik! Rapport enquête [Doctor, this is my opinion! Report questionnaire]* Utrecht: UMC Wilhelmina Kinderziekenhuis.
- 6 Alderson, P. (1993). *Children's consent to surgery*. Buckingham: Open University Press.
- 7 Christensen, P. & Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood*, 9(4), 477-497
- 8 Coad, J. E. & Shaw, K. L. (2008). Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Advanced Nursing*, 64(4), 318-327
- 9 Hart, R.A. (2002). *Children's participation: The theory and practice of involving young citizens in community development and environmental care*. London: Earthscan Publications Ltd
- 10 Hart, R.A. (1992). *Children's participation: From tokenism to citizenship*. Florence: International Child Development Centre: UNICEF.
- 11 Shier, H. (2001). Pathways to participation: openings, opportunities and obligations. *Children & Society*, 15, 107-117.
- 12 Carter, B. (2002). Chronic pain in childhood and the medical encounter: professional ventriloquism and hidden voices. *Qualitative Health Research* 12, 28-41
- 13 Coyne, I. (2006). Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, 15, 61-71
- 14 Coyne, I. & Harder, M. (2011). Children's participation in decision-making: Balancing protection with shared decision-making using a situational perspective. *Journal of Child Health Care*, 15(4), 312-319
- 15 Coyne, I. (2008). Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, 45, 1682-1689
- 16 Moore, L. & Kirk, S. (2009). A literature review of children's and young people's participation in decisions relating to healthcare. *Journal of Clinical Nursing*, 19, 2215-2225
- 17 Curtis, K., Liabo, K., Roberts, H. & Barkers, M. (2004). Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*, 7, 149-156
- 18 Alderson, P., Sutcliffe, K. & Curtis, K. (2006). Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 91, 300-303.
- 19 Alderson, P. (2001). *Research by Children: rights and methods*. *International Journal of Social Research Methodology: Theory and Practice*, 4(2), 139-153
- 20 Aynsley-Green, A., Barker, M., Burr, S., Macfarlane, A & Morgan, J. et al. (2000). Who is speaking for

- children and adolescents and for their health at the policy level? *British Medical Journal*, 321, 229-232
- ²¹ Goodenough, T., Williamson, E. (2003). 'What do you think about that?' Researching children's perceptions of participation in a longitudinal genetic epidemiological study. *Children & Society*, 17, 113-125
- ²² Sinclair, R. (2004). Participation in Practice: Making it Meaningful, Effective and Sustainable. *Children & Society*, 18, 106-118
- ²³ Lightfoot, J. & Sloper, P. (2003). Having a say in health: Involving young people with chronic illness or physical disability in local health services development. *Children & Society*, 17(4), 277-290
- ²⁴ Van Esch, S.C.M., Van de Krecke, J.J.S., De Vries, H., Batelaan, M.A. & Van der Ploeg, H.M. (2006). *Recepten voor een goed gesprek, deel 2 [recipes for a good conversation, part 2]* Amsterdam: Stichting Medische Psychologie Vrije Universiteit.
- ²⁵ Runeson, I., Hallstrom, I., Elander, G. & Hermeren, G. (2002) Children's participation in the decision-making process during hospitalization: an observational study. *Nursing Ethics*, 9, 583-598.
- ²⁶ De Winter, M. (1995). *Kinderen als medeburgers. [children as fellow-citizens]*. Maarssen: Elsevier/De Tijdstroom
- ²⁷ King, N.M.P., & Cross, A.W. (1989). Children as decision makers: guidelines for pediatricians. *The Journal of Pediatrics*, 115(1), 10-16
- ²⁸ McNeish, D. (1999). Promoting participation for children and young people: Some key questions for health and social welfare organizations. *Journal of Social Work Practice*, 13(2), 191-203
- ²⁹ Unicef (2001). United Nations Convention on the Rights of the Child. Available at <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>
- ³⁰ Available at <http://www.rbng.nl/userfiles/file/wetten/WGBO.pdf>
- ³¹ Lorenz, L.S., Kolb, B. (2009). Involving the public through participatory visual research methods. *Health Expectations*, 12(3): 262-274
- ³² Clark-Ibañez M. (2004). Framing the Social World With Photo-Elicitation Interviews. *American Behavioral Scientist*, 47(12): 1507-1527.
- ³³ Murray, C. (2006). Peer Led Focus Groups and Young People. *Children & Society*, 20, 273-286.
- ³⁴ Moore, T. & McArthur, M. (2007). We're all in it together: supporting young carers and their families in Australia. *Health & Social Care in the Community*, 15(6), 561-568.
- ³⁵ Lauwers, H. & Vanderstede, W. (2009). Kinderen als mede-onderzoekers: een verkennende literatuurstudie [*Children as co-researchers: an exploratory literature study*] Meise: onderzoekscentrum Kind & Samenleving.
- ³⁶ Jurrius, K. (2005). Participatief jongerenonderzoek maakt kwaliteitsslag [*quality improvement in participatory youth research*] *Nederlands Tijdschrift voor Jeugdzorg*, 6, 282-286.
- ³⁷ Van Staa, A., Jedeloo, S., Latour, J.M., Trappenburg, M. (2009). Exciting but exhausting: experiences with participatory research with chronically ill adolescents. *Health Expectations*, 13, 95-107.
- ³⁸ Fleming, J. (2011). Young People's Involvement in Research: Still a Long Way to Go? *Qualitative Social Work*, 10(2), 207-223.
- ³⁹ Isarin, J. (2006). *Hoor hen! Participatieonderzoek virtueel en in real life: MSN-gesprekken met dove en slechthorende jongeren [Listen to them! Participatory research virtually and in real life: MSN-conversations with deaf and hearing-impaired adolescents]* Zwolle: Van Tricht.
- ⁴⁰ Witman, Y. (2001). *Op spreekuur bij de patiënt [in consultation with the patient]* *Medisch contact*, 56(19).
- ⁴¹ Wilkinson, S. (1998). Focus Groups in Health Research. Exploring the Meanings of Health and Illness. *Journal of Health Psychology*, 3(3), 329-348.
- ⁴² Kitzinger, J. (1994). The methodology of Focus Groups: the importance of interaction between research participants. *Sociology of Health and Illness*, 16(1), 103-121.
- ⁴³ Powell, R. A. & Single, H.M. (1996). Methodology Matters: Focus Groups. *International Journal for Quality in Health Care*, 8(5), 499-504.

- ⁴⁴ Tates, K., Zwaanswijk, M., Otten, R., Van Dulmen, S., Hoogerbrugge, P.M. et al. (2009). Online focus groups as a tool to collect data in hard-to-include populations: examples from paediatric oncology. *BMC Medical Research Methodology*, 9(15).
- ⁴⁵ Binkhorst, T., Weerts, M., Schipaanboord, A. (Eds) (2005). *Patiënten betrekken bij de zorg in het ziekenhuis. Een handboek*. [Involving patients in hospital care. A handbook] Utrecht: CBO, PP/CP Utrecht & NPCF.
- ⁴⁶ De Wit, F., Mul, M. & Bal, R. (2008). Leren van patiënten [learning from patients]. *Medisch Contact*, 23, 990-993.
- ⁴⁷ Baarda, B., De Goede, M. & Teunissen, J. (2005). *Basisboek kwalitatief onderzoek [the basis of qualitative research]*. Groningen/Houten: Noordhoff Uitgevers.
- ⁴⁸ Boeije, H. (2005). *Analyseren in kwalitatief onderzoek Denken en doen [Analysis in qualitative research. Thinking and doing]*. Den Haag: Boom Lemma uitgevers.
- ⁴⁹ Huyghen, A.M.N., Von Rudnay, I., Metselaar, J. & Knorth, E.J. (2010). Assessing children's satisfaction with child and youth care: The Smiley 9-12 Questionnaire. In E. J. Knorth, M. E. Kalverboer, & J. Knot-Dickscheit (Eds.). *Inside Out. How interventions in child and family care work. An international source book* (pp. 598-600). Antwerp: Garant Publishers.
- ⁵⁰ Yang, K.W. (2009). Mathematics, critical literacy, and youth participatory action research. *New Directions for Youth Development*, 123, 99-118
- ⁵¹ Hong, J., Fongkaew, W., Senaratana, W., Tonmukayakul, O. (2010). Research Article: Development of a theory-based sexual and reproductive health promotion and HIV prevention program for Chinese early adolescents. *Nursing & Health Sciences*, 12, 360-36.
- ⁵² Foster-Fishman, P. G., Law, K. M., Lichty, L. F., Aoun, C. (2010). Youth ReACT for Social Change: A Method for Youth Participatory Action Research. *American Journal of Community Psychology*, 46, 67-8
- ⁵³ Bryson, S. (2007). Listening to the views of very young children. *Early years update*, 51(9)
- ⁵⁴ Clark, A. & Moss, P. (2005). *Listening to Young children: the Mosaic approach*. London: National's Children Bureau.

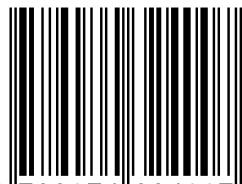


"According to the UN Convention on the Rights of the Child, all children are entitled to have a say in the matters affecting their lives. This is especially important for children in vulnerable positions, like those who end up in a hospital. In this situation, major decisions are often made about children. It is then important to attach great importance to the opinion of the child."

Marc Dullaert, Children's Ombudsman

"Paediatrics has developed enormously in the last few years. Diseases which previously could only be diagnosed have now become curable or treatable. Over 90% of the children with a chronic disorder will reach adulthood. The aim is to treat and guide these children in such a way that later on they will be able to take part and secure their own place in our competitive society. For that purpose, an understanding of their condition and their participation in its treatment are indispensable. But how can that be realised? This book offers a practical guide for doctors, nurses and other health care professionals; a manual to all those who wish to look after the paediatric patient of the present aimed at the future."

Prof. Dr. Hugo Heymans, Paediatrician, EKZ/AMC



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"We want the best health care for our children. Children are well aware of how their care can be improved. That is why it is important to listen to them and to turn their signals into concrete actions. This book offers useful guidance to designing children's participation in a thorough manner. Highly recommended to all hospitals who really want to take their young patients seriously."

Pia Dijkstra, D66 House of Representatives

"It is our mission to realise demand-driven health care from a patient's perspective. We start from solidarity, freedom of choice and preservation of personal autonomy. Children are a highly specific group of patients, and discovering their perception of care requires a different approach compared to adult patients. The Federation of Patients and Consumers in the Netherlands (NPCF) is glad that the Dutch Child & Hospital Foundation is making this case for the child and parent perspective. With this book, any hospital can immediately start to make its care of children match their social environment better, thus improving its quality."

Wilna Wind, Director, NPCF