

# If I were the researcher...

Children about ethics in research with and by children



# Colophon

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Children about ethics in research with and by children

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#### Design

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With the support of Bernard van Leer Foundation



Young people active in research and youth policy



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## **Foreword**

Conducting research in collaboration with children and young people is important for children themselves and for the adults around them. By involving children we can find out more about how they feel about their environment. Children who have an active role in research are gaining knowledge and can use this to improve their social environment. Children can also learn a lot from a survey.

Ethics, when conducting a survey, are important. What is allowed and what isn't? Involving children is in itself worth an ethical discussion: we, for example, feel that children have the right to be involved in research and that exclusion of children is, in itself, unethical.

We are not alone in this. The International Children's Rights Treaty includes two articles that make it obligatory for governments to involve children in research that concerns them. Articles 12 and 13 read:

"Article 12: The child has the right to give his or her opinion with regard to all matters that concern the child. The government ensures that the child can express its opinion and that he or she is listened to. This applies to legal and governmental procedures as well."

"Article 13: the child is entitled to freedom of speech; this also includes the freedom to collect, receive and spread information and ideas. In this the rights of others must be taken into account."

Yet there are all sorts of issues concerning ethics in research with children which are important to address before you start doing research with children.

There are, however, ethical guidelines for involvement of children in (medical) research. These guidelines offer a certain level of guidance, yet there are still practical questions and bottlenecks in social scientific research. It is good to continue to take these into consideration; for example, asking for the consent to participation from young children and issues around ownership of the end products.

In the quest for (international) ethical guidelines for research into and with children, oddly enough it is usually the opinion of the children themselves that is ignored. What are important ethical directives according to children? How do they feel that they should be treated within a research setting? We believe that children can make an important contribution to the debate on ethical guidelines, and that their opinion should even be central when drafting the guidelines.

In this brochure we offer a number of concrete methods to cope with ethical issues within social scientific research. There are not always ready-made solutions, but a good start is the conversation about ethics between researchers and, importantly, between researchers and children.

On behalf of Team Stichting Alexander Kitty Jurrius, directeur, Adimka Uzozie, senior projectleider

## Ethics, what exactly are they?

Ethics concern the question: what is it that is good to do, and what is not good? They are about moral principles, about what the best course of action is morally. Ethics concern the way values such as 'fair', 'correct', 'respectful' and 'good' are put into practice.

# View on children: Children as competent partners in research

The view on children determines the attitude of the researcher during the study. When children are seen as vulnerable objects that must be protected, researchers talk about children. When children are seen as social players with their own rights, researchers can speak with children (Morrow, 2009).

A study by Childwatch amongst 257 researchers worldwide shows that 26% of them state the perception of the competencies of children by adults as a reason not to involve children in a study. Children are supposedly vulnerable and must be protected; they would not be capable of indicating their feelings, knowledge and ideas and therefore are not able to participate actively in research. (Powell a.o, 2011).

The exclusion of children from research provides results to which children have not contributed their views. This is in itself an ethical issue: that it is good and fair to give children a voice in research means that the research is conducted and designed in a specific way.

#### Who determines what is ethical?

Researchers can consult with each other as to whether they find the research ethical. They might agree to ethical guidelines.

An example of a document with ethical guidelines for involving children in research is the document "Guidelines for research with children and young people" (2011) National Children's Bureau Research Centre.

As far as ethics are concerned we speak about two aspects:

#### Informed consent

This means consent on the basis of good information. Not only at the start of a project, but continuing to ask, throughout the duration of the project, whether they are still finding it fun, whether they want to continue and always offering the option to stop. Children must be well informed about each step that is taken during the research and what the result of that is.

#### · Child protection and safeguarding

This means that children are protected during the process. It must be clear how data is dealt with (confidentiality of data) and researchers must have a protocol for what they do, for example, in the event that abuse is discovered. Children must not be placed in difficult, dangerous positions in research; it needs to be easy for children to reach a researcher.

It is also possible to discuss with children what they feel ethical means. We will elaborate on this later on.

# What does literature say about ethics?

## Subjects

A handy overview of ethic subjects is offered by Virginia Morrow:

Morrow. V. (2005). *The ethics of social research with children and young people - an overview* Institute of education, University of London.

In this article there are 10 subjects that should be dealt with in an ethical children's survey, with a number of questions that the researcher must answer so that the investigation is indeed carried out ethically.

#### The objective of the research

At the start of the research the question must be asked what the purpose of the study is, whose interests it concerns and what position children take in the research. Researchers must consider why questions are asked and which questions are asked.

#### Costs and desired outcomes

At the start of an investigation it should be considered what benefit a child gains from participation and what it costs. Are there any risks for children (in the field of physical, psychological or social safety) and what is done to prevent that? Are these risks ethically justified or not? What are the consequences for children if they are not involved in the research?

#### **Privacy and confidentiality**

When it comes to privacy and confidentiality, there are several matters of importance. How do you obtain names and data of children, and are they told who has passed on their name? What options do you give children/parents who participate?

Also necessary to consider in advance are matters such as: where is the research with the respondents taking place? Is this a familiar spot for the children? Children may indicate that they prefer to have their parents present. How do you deal with this?

If a researcher thinks it is possible that he will need to report something (such as abuse) he must first decide whether he will discuss this with the child before reporting it and also whether he wants to warn children in advance that this could happen.

The researcher must find a way to guarantee anonymity in reports. Furthermore it is necessary to think about the storage of the research material (recordings, transcripts, videos etc): where can you keep them safely? Who has access to this material? Who is the owner of the end product?

#### **Selection of participants**

With regard to the selection of participants there are a number of questions: how to select your participants? Is the research accessible to all children? It is also important to think about the representativeness of the research. Is the survey data representative of a certain group? Is there space within the research setup for the drop-out of children throughout the process?

#### **Available finances**

With regard to finances it actually comes down to two matters: on the one hand the available finances for the research - is there sufficient money for proper implementation and guidance? On the other hand, the fees for those taking part in the project - are children/parents getting their expenses paid, and if so, how much and what impact does this have on voluntary participation?

#### Assessment and checking of the research methods

With regard to the research methods a number of matters are important: what do children and parents/carers think of the plan? In addition to this it must be examined whether the research setup is child friendly and whether it can be adapted. Are methods in line with the capacities of the children? Should researchers be accountable to third parties?

#### **Information**

There should be information available to all respondents in language understandable to them as regards the objective and nature of the research. There should be an explanation about the method, the timetable and possible outcome (both positive and negative) of the research. Other conditions are: clear description in language understandable to the children, personal explanation, with encouragement to ask questions,

names of the research team/the researcher, including accessibility data and contact options.

#### Consent

As far as consent is concerned it is about the question whether children really wish to participate in an investigation.

Permission to participate in a study about children is often asked from parents, or from teachers and other authorities, but children themselves must also give consent to wanting to collaborate.

Asking permission from children to collaborate in research is trickier than with adults. One must realise that children are more obedient to an authority than adults, and thus more likely to agree to collaborate in research because they feel they are not allowed to refuse. In addition, children find it more difficult to understand the consequences of the research.

#### Good to consider:

- Is it also possible for children to refuse to participate?
- Can they ask questions or consult before they give their consent?
- Do children know that they are allowed to stop the research?
- What will you do if a child wants to participate but doesn't have permission from his or her parents?
- To what exactly is the child giving its consent?

The question that often comes up for discussion is whether a child is capable of giving assent to participation in a study. According to the Guidelines of the NESH, in the event of participation of children under 15 years the consent of parents is needed. The Guidelines for Research with Children and Young People suggest that the consent of parents should be asked for children under 16 years (Shaw, Brady & Davey, 2011). The opinions about a suitable age for independent consent by the child to participate in a study are divided.

(NESH stands for: The National Committee for Research Ethics in the Social Sciences and the Humanities. The NESH is located in Norway.)

#### Spreading the message

In preparation for the period after collecting the research data it is important to reflect on a number of issues that need to be organised in advance. Is there enough time reserved in the research plan for reporting and publishing the results? How do you ensure balanced reporting? How and when will the feedback to children be organised?

How do you get started with sharing the knowledge with society (publish in the scientific or popular arena)? When are conferences taking place which you could join or can you organise a conference yourself? How do you use the media?

#### Impact on children

Be aware of the impact that your message has on the population of your research. How do you portray your children in the research? How does this affect the method of data collection and data analysis? Are researchers acting in a thoughtful manner? Do researchers critically view their own prejudices? Make sure that stigma and discrimination is prevented. Children are the starting point; examine their environment, listen carefully to the children, and speak with them in their own terms. Keep a balance between good research and sufficient respect for the dignity of the children.

### Read more

Many authors have written about ethics in research with children. For example:

- Alderson, P. and Morrow, V. (2011) The ethics of research with children and young people. London: Sage Publications Ltd.
- Hill, M. (2005) Ethical considerations in researching children's experiences in: Greene, S. and Hogan, D. (Eds.) Researching children's experience. London: Sage Publications Ltd
- · Morrow, V. (2005) The ethics of social research with children and young people an overview Institute of Education, University of London.
- Morrow, V. (2009) The ethics of social research with children and families in young lives: practical experiences. Oxford: Young lives, University of Oxford
- Powell, M.A. and Taylor, N. (2011) Building capacity for ethical research with children and young people.
   Otago: University of Otago Centre for research on children and families.
- · Save the Children (2004) So You Want to Involve Children in Research? A toolkit supporting children's meaningful and ethical participation in research relating to violence against children. Stockholm: Save the Children.
- Shaw, C., Brady, L.-M. and Davey, C. (2011) Guidelines for research with children and young people. London: NCB Research Centre.

# How can you discuss ethics with children?

When discussing ethics with children there are a number of matters you need to consider. For example, it is important to ensure that all children that you involve are well aware of what you mean by ethics. It is also important to choose a good time to talk about ethics. Make sure to bring it up in the conversation before you really get started with the research, but first of all it is important to create a good atmosphere, for example by doing an introductory game.

Start with an open attitude. Stay as close as possible to the thoughts of the children by first letting them say what they feel is important when they conduct a survey (for example, ask them the question what someone should or indeed should not do when asking someone questions). You do this by asking directly what comes up in their mind and not filling this in yourself with examples.

#### Discussing ethics with very young children

It is important in the interaction with children to take their age and abilities into account. For very young children (up to about eight years) sometimes a different approach and methodology is required than for older children and young people. Children under eight years old are often more visually minded than older children. In order to make it possible to discuss ethics with young children it may be best to make use of imagery, games and role-playing. Later In this essay there will be an example of a role-playing game about ethics (the 'ethics game').

#### Explanation of ethics in research with children

A researcher can discuss ethics with children and young people at the start of the research. For example, the researcher says:

"Before we start the research we're going to think about all the things we must be aware of when we do the research. How are we going to deal with the data? What can we, as researchers, do and what can't we do? We are going to make some agreements about that. And you can now also come up with other things that we must take into account when carrying out the research. The agreements that we make regarding this are called 'ethics'.

Ethics are specifically about you dealing correctly with the people you encounter in your research."

#### Discussing ethics with children: Ethics game

You can for example discuss ethics with children through the ethics game. This means the following:

By means of a number of small role plays where the children themselves will portray the role of researcher and respondent, there will be a discussion about what is and what is not ethically responsible behaviour. This way, together with the children, ethics rules are drawn up, to which they then commit themselves. This method has proved to be successful because it appeals to children: they can watch the scenario acted out and are well able to tell which behaviour is good or not and why. They find it fun, it stimulates them to think and matters previously taken for granted are scrutinized. Children can think up rules precisely because they can imagine what a situation could look like if the relevant rule is not observed.

#### Working method Ethics game

In the ethics game children learn to assess how a researcher should behave with respect to other children. We are then talking about ethics. In this method, the children themselves act out a number of situations in the form of a role play. After each role-play the children who are watching assess whether the reaction of the researcher is a bad or a good example of how you should behave as a researcher when you consult children.

#### **Working method:**

- 1. Two children act out a role play in front of the group. They are shown their assignment on a card where they can read a description of a situation. One child takes on the role of researcher, the other child that of the respondent.
- 2. The two children will act out the described situation. They can add and make up whatever they want so that it becomes a fun short 'theatre play' (of 1 minute).
- 3. After the brief performance the two children will sit down again. The mentors first ask (cooling down) the two children how they felt it went.
- 4. Then the audience will explain what they saw. The mentors will ask a few questions about the play:
  - · Was the researcher right or wrong?
  - · Why was this good or bad?
  - Which rule(s) with respect to the behaviour of a researcher can we think of with reference to this short play?
- 5. The rules are laid down on a sheet.
- 6. Then another duo will stand in front of the group to act out a different situation.

#### Discuss ethics with young people

It is also important in a conversation with young people firstly to ensure a good relaxed atmosphere before you can discuss ethics.

However, with young people, after acquaintance and the creation of a familiar atmosphere, go into the theme of ethics more directly. In this context a group conversation is a very suitable method, because ethics is a theme that lends itself pre-eminently to dialogue and exchange. You can record the conversation and elaborate afterwards, so that you can try to formulate guidelines on the basis of the statements. You can then give feedback about these directives to the young people and in this way continue to develop the discussion.

# Discussing ethics with young people: summary of themes

#### What would you do if you were a researcher?

- What, as a researcher, do you have to take into account when doing research with children?
  - What is allowed and what isn't?
- What, as a researcher, do you have to take into account when doing research with children?
  - What is allowed and what isn't?
- How do you inform children and possibly the parents?
  - What information must children have with regard to the research?
- What can you and what can't you promise?
- What other issues are important to mention?
- How do you make sure that children want to participate in the research?
- How do you start?
- How do you introduce a sensitive subject?
  - What is the right moment to do so?
  - How do you deal with anonymity?
  - What is the best location for the research to take place?
- · Is the presence of someone the children know necessary?
  - What can you offer children?

# What are children and young people saying?

Within various conversations with children the theme of ethics in research with children has been discussed. Below follow pointers to possible guidelines which can be formulated from this, substantiated with quotes from children.

 Taking the input of children seriously, actually use them and make them visible

Yes, but then something needs to happen with that, I don't have very good experiences that when telling things something is actually done with that. (Girl, 17 years old)

2. Stress that it is good to participate in the research because other children in a similar situation can then be helped

So that you really give the child the feeling that they are now also truly helping other children who have experienced things, etc. (Boy, 13 years old)

3. Guarantee anonymity

When someone shares something then I presume that the other person keeps this to him or herself and if he or she wants to do something with that, he should simply indicate that. (Boy, 16 vears old)

4. Do not go straight to your objective but firstly create a relationship of trust, in particular with a sensitive subject such as, for example, child abuse

I honestly think it would be best if you simply meet up a few times just to talk about various subjects (such as playing outdoors, eating). Yes, just go talk topics (playing outside, eating) and then you, at some point, slowly work towards the theme. (Girl, 16 years old)

- 5. Make it clear at the beginning that they don't have to answer everything if they don't want to
  - That you then simply say: If you find it difficult to answer the questions you don't have to feel obliged at all. Then you can simply say that you don't want to talk about it. (Boy, 13 years old)
- 6. Explain what you want to do with the information obtained from the children and ask their permission to use it for those purposes
  - If you then want to tell this to someone else, you have to ask permission. Not just saying I'm going to tell such and such and that's it, but you must also ask: are you OK with that, you have to consult about that. (Boy, 17 years old)
- If the children are under treatment, involve the practitioners and inform them about the research and deploy them when needed
  - It may of course be the case that children will tell you things which were not yet known, that is why I think it would be good that, suppose you are doing this with a group of children, you also are in touch with the aid workers in a careful way. And you yourself are of course not the aid workers of the children, but things could come up that are pretty heavy. (Girl, 16 years old)
- 8. Telling the child in advance that it is possible that the things that he or she is sharing could be passed on if these are very important things for other people to know, for example because the child is in danger
  - I do think they need to know in advance, but that they also know that this is only the case when it really cannot be done differently, that the information is only passed on when they themselves are really in danger. (Girl, 17 years old)

- 9. Help/guide the child if he or she tells you things during the research that were unknown to the practitioner
  - Or at least give the child the opportunity to talk first, like yes, you know, it is not going to be behind your back or something like that, because then you feel screwed, to put it bluntly, but if you say to such a child: do you know that you're in danger and that it is better if you tell someone, the child might think about it and decide: hey, maybe it is good if someone else knows about it. (Girl, 17 years old)
- 10. Continuity in the research; when there is more than one contact session, keep deploying the same researcher
  - Actually it should be someone, in my opinion, that you know and who you can trust. Because after the first time I've met someone, I don't immediately completely trust that person. Because how can I know that 100% sure, you are from Amsterdam, I don't know you so how can I be 100% sure that you will keep it a secret. (Boy, 13 years old)
- 11. Getting into a conversation in a relaxed way, not in a very formal setting

But also simply do something while you are talking (playing football, baking biscuits). If you just sit down at a table on a chair opposite each other then you immediately get a sense of being interviewed, but when you are playing football outside and you are just chatting a bit in a relaxed manner, getting to know each other, then it is already totally different. (Boy, 13 years old)

The preceding points are also based on the statements of children from various studies and a conversation with the Youth Council of Jarabee. The latter conversation was about the theme of ethics in research with children into child abuse.

# Talking about themes that are 'taboo'

Children are not afraid to discuss sensitive themes. Adults can sometimes have a certain fear of talking openly about a difficult theme.

Where it concerns making sensitive themes open to discussion children have a number of tips:

#### Child abuse

It can feel awkward or even threatening for children if asked directly about their child-abuse past. Children therefore advise starting the conversation by means of reference to cases. It then remains up to the child whether they choose to talk about their own past, or whether the fictitious person from the case remains the topic of conversation.

"You can also just tell a simple story, like once there was a girl and this and that happened. Then you can, for example, ask: have you guys ever heard or seen something like this with someone? Then it may very well be that such a child says yes: that happened to me once. Then you don't even have to use the term child abuse, but you have just told a story and might recognise it.

When talking about difficult subjects a relationship of confidence is of great importance. Taking the time to get acquainted, to build a relationship and creating trust in the researcher are preconditions for talking about child abuse and also about other 'taboo' subjects.

"I honestly think that what's best is that you simply go and meet up for a few times, just talk about random subjects a few times and that you then, at some point, start working towards the subject gradually..."

#### **Poverty**

When making the theme of poverty open to discussion, stigmatization plays a role. The question: 'what is it like to grow up in poverty?' can bring about a lot of resistance. The term can come across as rather insulting and once a certain atmosphere has been created, it is often tricky to improve the situation. Try to discuss the subject in a different manner. For example, say: growing up in a family with little income/a family that doesn't have much money to spend. First talk about the subject in general terms and ask whether they know other people who find themselves in a similar situation, so that it doesn't necessarily have to become personal.

Researcher: 'Maybe you know children where there is very little money for the family?'

Children: 'Yes...'

Researcher: 'How do you notice that there is little money at

home?

Child: 'Well, because you are not going away on holiday. Or that you are always wearing old clothes, or that you don't get any presents on your birthday...'

Child: 'Or that you are not allowed to join a sports club'

Then the researcher can discuss the issue of what it is like for a child if it doesn't get any gifts, is wearing old clothes or is not allowed to join a sports club. The personal experience is not central in this conversation (at least, it is not named as such), but the own experience is.

# Finally

Many books and articles have been written about ethical research with children. Preceding all the considerations relating to the implementation, we can ask the question whether you must involve children in research. Children are entitled to express their opinion in matters that concern them, and many situations can be improved, if solutions are sought together with children.

The involvement of children in research creates obligations, with respect to the children and the research. As with any research, ethical considerations in the fields of the objectives, costs and findings are important. The list of 10 topics by Virginia Morrow is a handy tool for this.

Researchers should be aware of the consequences of their choices with respect to the research process, on the position of children and young people. In order to be able to assess these consequences, the dialogue about this with children is of great importance. This brochure shows a number of tools for conducting a conversation with children about the ethical approach within research.

Above all, every situation is different, and requires a different approach to the target group, the subject or the methodology. It is therefore especially important to enter into conversation about ethical issues with each other and with children so that it is possible to determine a tailor-made approach as to what is the 'right' thing to do.

Ethics in research are incredibly important. At the same time, we want to ensure that the discussion about ethics in advance is not a reason to exclude children from participating in research because then their ideas and experiences are not known at all. We therefore advocate considering the importance of children in research and to find ways to involve them in the most meaningful way.

# Stichting Alexander

Young people active in research and youth policy

Stichting Alexander is a nonprofit institute for youth participation and youth oriented action research. Supported by 20 years of experience in all life domains of young people - like leisure, youth care, health care, education, culture, employment - we are able and enable others to bring participation to a higher level. Our research approach results in genuine involvement and stronger social ties in the communities we work with.



Researching with children and young people is important, for them, and for adults in their environment. By involving children in research, we discover more about their ideas. Children who are involved in research, gain knowledge which they can use to improve their environment. They also improve several capabilities. The Convention of the Rights of the Child states that children have the right to be involved in decisions and have the right to obtain information.

Research with and by children leads to various ethical questions. In this brochure, we offer concrete tools to handle ethical dilemma's in social research. No final solutions, but the dialogue on ehtics is an important starting point: among researchers, but also among researchers and children.

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