

THE PARTICIPATION OF CHILDREN IN SCIENTIFIC RESEARCH

GENERAL GUIDANCE



Guðrún Kristinsdóttir
Professor Emerita



HÁSKÓLI ÍSLANDS

Guðrún Kristinsdóttir 2020

Published at the behest of the University of Iceland Science Ethics Committee

Foreword

The work of the UI Science Ethics Committee brings up a wide variety of dilemmas around issues that are important, but about which it is difficult to establish hard and fast rules. It is vital to guarantee respect and consideration for the subjects of research and other affected parties, as well as ensuring that all reasonable ethical standards are met. However, it is equally important to encourage researchers not to shy away from pressing and sometimes difficult subjects that expressly call out for research. The UI Science Ethics Committee strives to tread the middle path between these two perspectives. It is the view of the Committee that the best strategy is to ensure that the scientific community is well informed on the dilemmas that may arise and take them into account when designing research projects, in such a way that the Committee's regulation framework is seldom tested. The Committee's experience is that this is usually the case, although there are occasionally applicants who are not aware of various issues that must be considered.

The Committee decided to ask experts who are highly knowledgeable in areas where there are a lot of contentious issues to put forward their views and reflections, which would then serve as a useful source of ideas for applicants on what they should bear in mind. The first research area we identified, which is admittedly a very broad area, is research into matters of children and young people, especially where the research topics concern sensitive subjects. We enlisted the help of Dr Guðrún Kristínsdóttir, Professor Emerita at the UI School of Education, who is credited as probably the most experienced Icelandic scholar in such research.

She was asked to write down her own thoughts on this area of research without significant guidance from the Committee, except pertaining to scientific ethics such as they appeared in the rules of the Science Ethics Committee. The resulting document would be entirely her own work and would be published on the Science Ethics Committee website under her name. The Committee would not take a position on the document beyond selecting Guðrún to complete the work. Guðrún has, as we all do, asked various colleagues to proofread and comment on her work, including members of the Committee. It has been suggested that a discussion thread should be available, where people could express their own perspectives on this document or related issues.

On behalf of the Committee, I would like to thank Guðrún for her work and the eloquence with which she has managed to express her ideas.

Jón Torfi Jónasson, Chair of the UI Science Ethics Committee

Table of Contents

THE PARTICIPATION OF CHILDREN IN SCIENTIFIC RESEARCH GENERAL GUIDANCE 0

 Guidance for researchers – the participation of children in scientific research 6

 This guidance discusses:..... 8

 Introduction..... 9

 Rights and protection 11

 Introductory information, permission and informed consent 13

 Consent of the child – criteria and competence 15

 Information letters and consent forms 20

 Harm, stress and risk 20

 Individual confidentiality 22

Confidentiality in institutional context..... 24

 Sensitive research topics 24

 Children's attitudes towards the research methodology..... 26

 Preparing projects 27

 Communication with institutions 29

 Ethics committees 31

 Changes that may be beneficial in Iceland 32

Sources 33

 Appendix I Information for parents..... 38

 Appendix II Example of consent form 39

 Appendix III Request for assistance with a survey questionnaire 40

Guidance for researchers – the participation of children in scientific research

This document is intended as guidance on the participation of children in scientific research. It was compiled at the request of the University of Iceland Science Ethics Committee, to whom I am grateful for the initiative and their helpful comments. I would like to thank my colleagues who proofread the text and gave up their time to discuss issues with me for their assistance.

This document is first and foremost based on research in the social sciences, in a broad sense of the term, rather than other fields. Hopefully it will inform researchers on standard working procedures in research, in particular that which focuses on children.¹ It is intended to advise and guide researchers and students in finding solutions to ethical problems and help them adhere to the accepted values of the scientific community.² These values include precision, consistency and order in research, but no less important are respect and consideration for the research participants and any ethical dilemmas that may emerge. These guidelines can be used to evaluate contentious issues in the implementation of individual research projects and to help design research plans. They focus on research and, in part, teaching and administration regarding cooperation with institutions.

Research involves the quest for new knowledge. In the humanities and social sciences, empathy and interpretation are inextricable elements of the research process, not least for qualitative research. Different approaches and academic perspectives can lead to different, but equally valid, interpretations of the same material. This means that researchers must explain the impact of their own values and opinions on material, data and interpretations. It is incumbent upon scholars to account for the acquisition and publication of data and ensure consistency in their reasoning. Work surrounding scientific ethics, i.e. the establishment of regulations and the committees who discuss these matters, is not conducted in a vacuum and is relative, limited, subject to time constraints, context and culture. This can concern, for example, qualitative research whereby knowledge is acquired by examining social realities and human interaction (Silverman, 2013; Flick, 2009; Charmaz, 2008). It is not possible to identify clear solutions or definitive guidance that are unanimously accepted when it comes to ethics. Ethics are first and foremost a tool to evaluate and increase understanding of contentious issues. This guidance focuses on research involving children, but much of it can be applied to other situations. Research on or with children can raise issues which

¹ Research standards from the Icelandic Centre for Research: <https://www.rannis.is/media/sidareglur/Vidmid-um-vandada-starfshaetti-og-sidferdi-i-visindum-og-rannsoknum.pdf>

² UI Code of Research Ethics see the website for the UI Science Ethics Committee.

researchers are obliged or feel compelled to disclose to others. In such cases, it is important to guarantee that scientific and communication standards are met, as well as ensuring that participants are treated with due consideration. This is a very broad topic and the discussion presented here is not exhaustive. Here follows a summary of the main topics covered in this article.

This guidance discusses:

- The rights of children, especially regarding the UN convention on this subject, including the right to seek, receive and impart knowledge and ideas of all kinds.
- Child protection and special considerations regarding children in research to do with privacy, confidentiality and communication. It is reasoned here that the participation of children in research has increased and that their competence to do so has been established.
- An introduction to research plans and requirements regarding the supply of information before the child can consent. This addresses approval, informed consent, and a critique of passive consent.
- Children's consent to participate in research, age limits and children's competence, and the requirements of researchers regarding the way in which they obtain a child's consent.
- The chapter *Harm, stress and risk* discusses the avoidance of potential stress that participation in research could cause.
- Confidentiality, which must often be upheld in research and may pertain to both individuals and institutions. The limits placed on confidentiality and how to ensure a balance between confidentiality and the duty to report.
- Research into sensitive topics that may require all kinds of decision taking.
- Children's attitudes toward research methods have been investigated to a certain extent and here I summarise a few relevant findings.
- On the preparation of projects, provision of information, storage of data and personal safety of the researcher. It is important to ensure that children who are asked to take part in research understand what this involves.
- Researchers who conduct research with the participation of children via institutions must seek their permission to do so. These guidelines discuss communication with institutions for this purpose. Reluctance to provide permission for research among children is discussed – it is a matter of justice to avoid excluding children or a certain group of children from research.
- Science ethics committees should protect the rights of participants and are responsible for quality assurance. They can guarantee the quality of the research and protect participants from poor academic practices. The committees are discussed, including some challenging issues regarding their operation.
- Finally, a mention of desirable reforms of current procedures. The universal age limit for children to participate in research is currently 18 years of age. A lowering of this is suggested as well as introduction of flexibility based on foreign models.

Introduction

Increasing levels of participation of children in research have created new knowledge in many fields over the last 25 years (Hill, 2006; James and Prout, 1997). A new discipline, generally called childhood studies or children's studies, has been developed, in which attention is increasingly directed towards children and influences on their lives, on children as people, on their perspectives and their active participation in research (James and Prout, 1997; O'Kane, 2001; Christensen and James, 2002). This development is taking place in many fields (Lenzer, 2001; Qvortrup, Corsaro and Honig, 2009).

Writing on these issues has increased over the last decades (Esser, Baader, Betz and Hungerland; 2016; Alderson and Morrow, 1996). This has been accompanied by extensive discourse on the ethics of science and methodology (Alderson and Morrow, 2004; Hill, 2006) and qualitative research has become common (Øverlien, 2007).³ This has led to different approaches (Hammersley, 2012) which will not be covered in detail here, since the aim of this document is to provide general guidelines rather than a scholarly review.

Children use many services provided by the state, municipalities and organisations. Research into institutions that serve children shows that despite an increasing emphasis on rights and independence, children are subject to one of the highest levels of governance of all service users (Hill, Davis, Prout and Tisdall, 2004). Rules within such institutions have wide-ranging impacts on the lives of children – school attendance is an easy example. The way in which children's participation in research is handled is therefore very important and we might argue that this matter is one of the most recent aspects of governance of children's interests.

The findings of research in which children actively participated have strengthened people's trust in the value of children's contributions to research (Vis and Fossum, 2013; Robinson and Kellett, 2004; Cashmore, 2002). It is now a mainstream position to consider children generally as active citizens who participate in shaping their own lives and society (Cater and Øverlien, 2014; Hill, 2006). It has been pointed out that the participation of children in scientific research should not only be discussed on researchers' terms – it is also worth looking at children and teenagers' own perspectives (Christensen and Prout, 2000; Qvortrup, Bardy, Sgritta and Wintersberger, 1994; Qvortrup, 1991). Several people have begun to do so (Ellonen and Pösö, 2011a-b; Mossige and Backe-Hansen, 2013; Hill, 2006). The direct participation of children in research or children as co-researchers have also attracted attention. However, this development has not been accepted wholesale by scholars. For

³ This last point certainly applies to Nordic publications.

example, some have asked whether this is a realistic approach, wondered what ethical questions are raised by such participation and, not least, pointed out the unequal power relations between children and adults (Solberg, 2014; Robinson and Kellett, 2004, Mc Laughlin, 2005).

Regarding research methodology, Greene and Hill (2006) discuss the subject and say that people are divided into different schools of thought. Christensen and James (2000) believe that research into the lives, experiences and perspectives of children do not require special methodology and we should not assume a difference between research among children and research among adults. Many people, however, have developed special methods tailored to the understanding, knowledge and status of children, looking primarily to developmental psychology. It is beyond doubt to deny that there is a difference between a young child and a teenager, for example with regard to their cognitive development and ability to understand complicated and/or subjective questions and subjects. Greene and Hill (2006) point out that age is a very strong indicator in society and adults often believe that the experiences of children of the same age must therefore be the same. This is, however, dependent on context and circumstances. It is easy to oversimplify the status of children based on age and overlook their diversity regarding competence and interests. Hill (2002) emphasises that younger children are generally more affected by external factors (e.g. reactions to stress) but older children are more guarded about their own identity or private life. From a sociological perspective, other scholars highlight the subordination of children based on the power that adults have over them. They argue that this necessitates special research methods in order to reduce the imbalance in status and empower children (Kellett, Forrest, Dent and Ward, 2004). Punch (2000a) traces the deep-rooted attitudes of adults on the difference between children and adults to the fact that some adults tend to underestimate children's competence and treat them with arrogance. Solberg (1996, 2014) also discusses the attitudes of adults towards children and highlights the difficulties researchers have with interviews designed to explore the experiences and opinions of children. Researchers often need to become more conscious of their own ideas about children and their lives in childhood. Solberg believes that some adults are unable to understand that their knowledge is not worth more than children's knowledge and that their age is not the main issue. The key to gathering reliable data lies in defining the project as a *joint* creation of knowledge. The researcher is certainly at the helm, but must think carefully about his or her own ideas about children and childhood by giving equal consideration to how things are said as what is said (Solberg, 2014).

The tendency for children to try to win the approval of adults has also been the subject of considerable discussion and debate (Alderson and Morrow, 2004; Punch, 2002a). There were significant disagreements about the credibility of children in light of these new trends increasing the participation of children in research. People have long cast doubts over children's accounts and

believed that they tend to try to please the researcher by reflecting the accounts and assertions of adults. Others point out that maturity comes with experience and believe that although children generally have different abilities than adults, they are not necessarily "worth less" (Kellett et. al., 2004; Solberg, 1996; Alderson, 2000; Christensen and Prout, 2002). It is worth remembering that adults have a lot of experience in tailoring their answers to current norms. This discussion does not address the question of how, or whether it is possible, to evaluate the maturity, ability and experience of the children involved. That issue is discussed in the chapter on consent.

Rights and protection

Research into children's lives and circumstances is important and so are children's contributions. Children have legal rights to protection and privacy in accordance with international as well as Icelandic regulations (Convention on the Rights of the Child, 1989; Samningur SP um réttindi barnsins, 19/2013). Children 's needs and interests can require different safeguarding than those applied in research on adults, since children are subordinated in society and reliant on adults. Researchers must have sufficient knowledge of children to be able to ensure quality working practices in this regard. They must be able to adapt methods and provide information in a format appropriate for the children participating. Despite the increasing inclusion of children in democracy in our part of the world, children are more often than adults expected to comply with the instructions of authority figures. They might even feel that they are not allowed to decline to participate in research and may find it more difficult to fully understand the consequences of providing researchers with information (NESH, 2016; Alderson and Morrow, 2004; Punch, 2002a). With regard to research topics which may be emotionally difficult, children have proven that they can handle this better than previously thought, as long as the appropriate methods are used (Mullender, Hague, Imam, Kelly, Malos and Regan, 2002). In light of this, the special status of children is therefore comparable to that of marginalised adults, e.g. people with developmental delays or people who are very reliant on their environment and/or have become used to being controlled in their daily lives. Since their competence has been confirmed and their contributions have revealed important new knowledge, the stereotype of the passive child has generally been rejected in more recent writing on the subject (Woodhead and Faulkner, 2000). Nevertheless, researchers must avoid the pitfall of generalising about children in this regard: their assertiveness and circumstances are highly variable, as with all people.

The increased focus now placed on children's participation in research can be traced to a general development of democracy and a desire to guarantee the rights of children in various areas

of society. The most obvious example is the impact of the UN Convention on the Rights of the Child, cf. Article 12 and 13. When asking people to share their knowledge, the most important thing is to listen to them. However, this document does not discuss universal rights, but rather rights connected to specific knowledge interests in each case. Member states of the UN shall ensure that children who are able to form their own opinions have the right to express them freely on matters that affect them. The opinions of children shall also be given fair consideration in accordance with the child's age and maturity. The rights of children include the right to seek, receive and impart information and ideas of all kinds (Act on the UN Convention on the Rights of the Child, no. 19, 2013). The Convention has led to several studies of the meaning of concepts such as *participation, protection and freedom of expression* (Shier, 2001). This research has focused on the value of different methods which has clarified and refined applications, i.e. when a child is genuinely participating, when participation fulfils the stipulations of the UN Convention, when it is tokenistic or so minimal as to be insignificant.

There are ethical questions about the acquisition, analysis, publication and application of research data for all kinds of research, but especially when there are conflicts between cultural and social values. There are several incentives to discuss the participation of children in research from the perspective of scientific ethics. A broad consensus on the protection and welfare of children in scientific research requires a definition of the term *protection*. Legally, this refers to the idea that, as indicated in the Convention of the Rights of the Child, the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth (UN Convention on the Rights of the Child, 1990). Protection also stipulates support, based on the principle that all decisions shall be taken with the child's best interests in mind. However, many people have been unsure how to define having "the child's best interests in mind". Child protection and special considerations regarding children in research concern privacy, confidentiality and interaction. The matter also concerns the obtaining of permission for research and children's consent (Cater and Øverlien, 2014; Graue and Walsh, 1998; Greig and Taylor, 2007, Mauthner, 1997).

The duty to protect sometimes conflicts with the right of the child to participate and this may have negative consequences (Guðrún Kristinsdóttir, 2014a; Eriksson and Näsman, 2008). It is important to bear in mind that it is in the best interests of children to have their perspectives heard on as many topics as possible that concern them and on which they are able to express an opinion. At the same time, we must remember that the researcher is in pursuit of knowledge. Researchers interpret and evaluate the validity of data considering different viewpoints and facts, which entails examining the perspectives expressed by the children (Hammersley and Traianou, 2012). It is important to bear in mind that adults are responsible for taking due care when defining the best

interests, competence and circumstances of children. This concerns the evaluation of applications for children's participation in research here in Iceland. Keeping children away from involvement in scientific research is not always tantamount to protection as is sometimes claimed (Guðrún Kristinsdóttir and Hervör Alma Árnadóttir, 2015).

We should also consider power, which is related to the status of the individual; adults generally have stronger position than children. Researchers can be assumed to have considerable power as a result of their status. This means that they must strive to minimise the impact of their influence. However, it can be difficult or impossible to completely eliminate it (Hill, 2006). Children and adults have the same right to receive information on the nature, goals and purpose of the research. People are generally more likely to take part in research if they are treated with respect and consideration. In ideal conditions and contexts, both children and adults should be able to express themselves, answer questions and recount narratives in a similar way. It was previously mentioned that the special status of children is based on the fact that they are subordinated in society, have less influence than adults and are subject to decisions made by people responsible for their welfare. Such requirements and issues in the ethics of research apply not only to children, but also to marginalised adults (Alderson and Morrow, 2004; Hanna B. Sigurjónsdóttir, 2003). The requirement to protect children should be judged in each case and weighed against children's right to express themselves.

Introductory information, permission and informed consent

The general rule in research involving human subjects is that consent of participants is required. Informed consent is at the fore of scientific ethics. This document will not go into the history of research ethics in any great detail, but there was a major awakening on this issue following the Second World War due to the inhumane experiments and treatment conducted by the Nazis. Research institutes in Europe and the United States have been required to establish ethics committees which review research plans in consideration of ethical issues (Ástríður Stefánsdóttir, 2013). The level of authority differs between ethics committees. Some committees play an advisory role while others are authorised to shape and even prohibit the implementation of research if they do not believe it meets certain ethical standards. Ethics committees base their work on international declarations which have been developed with a series of amendments (Forsman, 1997). The best known are the Declaration of Helsinki from the World Medical Association (2014) and guidelines from the Council for International Organizations of Medical Sciences (2002). The first draft of the Declaration of Helsinki was produced after the Nuremberg Trials at the end of the Second World

War, when doctors from the Nazi concentration camps were tried for war crimes. The declaration composed by the World Medical Association aimed first and foremost to ensure the protection of participants. An important aspect was the idea of informed consent.

In all cases where researchers work with personal information⁴ and data which may be of sensitive nature (e.g. race, origin, political and world views, religion, health, sexual and gender identities, genetic and biometric information)⁵, they are required to obtain the consent of people participating or being researched. An exemption from this is research conducted in an open setting (e.g. on the street, in public, open website), unless personally identifiable data are recorded (e.g. video or audio) and saved in a register of participants. All processing of such registers shall be in accordance with laws on data protection.⁶ *Permission* is often required from a workplace or institute in order to access the setting for the research. *Consent*, on the other hand, refers to the participants themselves. It is recommended that researchers draw a distinction between these two terms, *permission* and *consent*.

The main rule is that consent from participants must be *informed*, which means that prospective participants must be provided with detailed information about the research on which to base their decision.⁷ This information should describe the goals, purpose and application of the research. Prospective participants need to know what methods will be used, what topics or areas are being investigated, what participation involves, e.g. how long the research will take and about possible stress, harm or risk it could cause. Participants must be informed of their right to withdraw their involvement at any stage of the research. They should know if confidentiality applies and to what extent, who will have access to information and how data will be stored. They must be informed of how the findings will be used and where they will be published and presented. They need to know who is responsible for the project and how it is funded. For more information on voluntary participation, see the chapter on consent in this document and Article 2.4.1 in the UI Code of Research Ethics. The information provided to prospective participants needs to be clear,

⁴ Personal information: Information on personally identifiable individual. An individual is considered identifiable if he/she can be verified by means of authentication directly or indirectly, such as with reference to one or more factors which characterise him/she, i.e. by name, ID number, location, online identity, physically, biologically, physiologically, mentally, genetically, culturally or socially (Lög um Persónuvernd, 90/2018, 3.gr.2. [Act No. 90/2018 on Data Protection and the Processing of Data, only available in Icelandic, author's transl.].

⁵ Personal sensitive data: Severe learning or emotional difficulties may also be included. Researchers must familiarise themselves with the difference between sensitive personal data (Article 3 of the same Act) and other information that may be sensitive even though it is not specifically mentioned in the law.

⁶ See more on the difference between the duty to report and data processing which requires a permit (Chapter V of the same Act).

⁷ See also Article 2.4.1 in the rules for the UI Science Ethics Committee.

researchers should use everyday language. Researchers ought also to ensure that information is communicated in a language that participants fully understand. For some participants researchers should therefore consider the need to use both oral and written language (e.g. drawings, easy reading texts etc.)

There has been much discussion of the concept of informed consent, including debate on whether and when to deviate from this as the main rule (Sigurður Kristinsson, 2011; 2013; Vilhjálmur Árnason, 1993). The medical sciences have been at the forefront of this development, ever since the original Declaration of Helsinki.⁸ Researchers are responsible for implementing research and monitoring can be difficult, even if the necessary permission is obtained (Doylan, 1997). As pointed out above, informed consent concerns respect for individuals and is not merely a technical point, any more than other aspects of scientific ethics. It has been pointed out that sometimes the principle of informed consent must be discounted, e.g. for covert research (Hammersley and Traianou, 2012). In some cases, it may also be impossible to acquire informed and written consent for practical or cultural reasons. One example of the former might be covert original research into bullying among children on the school playground (Raundalen and Raundalen, 1979) and an example of the latter might be a situation where people are frightened to sign a document due to fear of the authorities (Silverman, 2013).

Consent of the child – criteria and competence

In Iceland, the consent of the legal guardian is required before a child below the age of 18 may take part in research, as long as the child is considered competent to do so. This procedure is a general rule and is based on the age of majority in the Children's Act, but it is not specifically stipulated in law. The Ombudsman for Children points out that deviations from the right of children to express themselves must always be interpreted as being in the child's best interests.⁹ The UN Convention on the Rights of the Child supports seeking consent from children, which is a mark of respect for the child as an autonomous individual (Samningur Sameinuðu þjóðanna um réttindi barnsins, 19/2013). A child's consent requires a statement from the Science Ethics Committee (University of Iceland, 2014). The main rule is that both the legal guardian and the child must provide consent individually. Here in Iceland, it is permissible to deviate from the general rule of requiring consent from the legal guardian in certain circumstances, cf. Article 2.4.4 of the UI Code of Research Ethics. The Code,

⁸ <http://www.laeknabladid.is/tolublod/2014/03/nr/5112>

⁹ See in Icelandic, "Barn fær ekki að tjá sig við sýslumann" (a child is not allowed to talk to the district commissioner) <https://www.barn.is/spurt-er/barn-faer-ekki-ad-tja-sig-vid-syslumann/>

however, is unclear on who shall make such a decision. Hill (2006) points out that the consent of the legal guardian may not be required in certain circumstances: in cases of neglect or abuse of the child, if it is very difficult to find the legal guardian, or if participation is considered to have no negative impact on the child.

It is notable that age limits for a child's consent to participate in research differ between countries and even within the same country (Health Canada, 2012). Norwegian children aged 15 or older may consent to researchers collecting personal data on them without the consent of a parent, although not if this data is of a sensitive nature (NESH, 2016). In Norway, researchers are required to provide information on the research to children aged 7 or older – or even younger children – who are able to form their own opinions. Researchers must also give these children the opportunity to express themselves. Alongside formal consent from a legal guardian, in Norway it is considered essential that children themselves consent if they are competent to do so. In England, Wales and Northern Ireland, there are no legal requirements regarding age limits other than for clinical experimental research on drugs and medical equipment (NHS, Health Research Authority, e.d.). There the so called 'Gillick competence' rule applies, i.e. children are permitted to make their own decisions if they have the required understanding and intelligence to fully comprehend what the research involves. This is provided that the child is able to use and evaluate the information provided in order to make a decision.¹⁰ A strong emphasis is placed on the provision of information when seeking consent.

Much supports the application of flexibility of criteria for children's consent to participate in research (Hill, 2006).¹¹ However, opinions are divided on this subject. The study of Meaux and Bell (2001) showed if that if they were provided with appropriate information using the right language, children as young as five could understand what (medical) research is and voluntarily consent. At this age, however, a child is not considered to be formally competent to consent and the word 'assent' is used instead. Ford, Sankey and Crisp (2007) believe that there are four arguments in favour of seeking the child's assent: respect for the child; to encourage maturity, self-determination and autonomy; to remind parents and researchers to consider the best interests of the individual child; and to provide an example for the child of showing others respect.

Children's ability to express themselves (verbally), understanding and maturity are hugely variable even among same-age peers. As well as the child's maturity, researchers must think about

¹⁰ This is what in English is called the child being 'Gillick competent', which is based on a court ruling that established the basis of the rule.

¹¹ Hill (2006) mentions the British Psychological Society, federal laws in the United States and the rules in Canada that differ from province to province.

other factors, e.g. origin, religion, gender, gender identity, physical abilities, health, disability, family structure, place of residence and another context. Such diversity has ethical (and methodological) consequences. A thorough understanding of diversity makes for informed decisions and can prevent generalisations about a child's situation when determining the structure of the research. There are many indications that children are generally competent to make their own decisions about participating in research, even from a very young age.

Still, there remains a valid question of how to assess the competence of a child to participate and to form an opinion on participation in research. Alderson (1995) discussed the competence of children in terms of weighing and assessing the benefits and downsides of their participation, asking: When should children be consulted? She mentioned the three following criteria: *Understanding* – the competence to understand relevant information. *Reason* – the competence to form a rational opinion with their own best interests in mind. *Self-determination* – the ability to make voluntary and unforced decisions. Alderson believes that the validity of a child's assent should be assessed based on the presence of these three factors. Researchers must evaluate whether children are capable of protecting their own best interests and provide them with an opportunity to decide whether to participate or not, for example by giving them time to think and make up their minds. Children must be assured that saying no will not have any negative consequences for them. The researchers may give examples that are meaningful for the child, e.g. explaining that saying no will not affect their grades or the opportunities open to them.

The question of competence applies to the researcher no less than to the child. Researchers must be able to provide clear, satisfactory information, help the child reach a rational conclusion, respect the child's position, and avoid applying any kind of pressure. The attitude and ability of the researcher to assess responses to a request for participation therefore have a significant impact. The attitude of the person responsible for assessing the child's competence is also important. Some key persons believe that children are generally not competent to take part in research. The way in which competence is assessed makes a difference. The child's attitude can also make a difference, such as when children are set a test or task that they are unhappy about, or when they don't trust the examiner. One way to deal with this problem is to assume that school-age children are competent. It is then up to adults who disagree to prove a child's incapacity. For example, this applies to the evaluation of applications for the participation of children in research conducted in institutions that concern children (Guðrún Kristinsdóttir and Hervör Alma Árnadóttir, 2015). Most children probably discuss serious decisions with their parents or other trusted adults. Their attitudes are clearly important here in Iceland. As age guidelines regarding consent are higher than in our neighbouring countries, it is important to lower them and revise here in Iceland in light of best evidence.

Otherwise a group of children are unreasonably excluded from scientific knowledge production.

Alderson and Morrow (2004), who discuss consent to the medical treatment of children, point out the contradiction in English law that means that a child's consent shall be respected even if the parents refuse, but on the other hand a parent's consent may override a child's refusal. These authors point out that the discussion also applies to all research involving children, not just medical treatment. It is clear that the reluctance to allow children to take part in research can stand in the way of important knowledge production. If a legal guardian consents to a child's participation without consulting the child, it can prove difficult to implement this decision. If the child refuses, participation goes against best practice in research with regard to individual self-determination and can also lead to poor results. Some ethics committees define the requirements for a child's consent in some detail in accordance with the child's age and the level of stress involved (NIH, 2016). Then the projected benefits of the research and the potential stress and risks of participation are evaluated.

Various factors determine how the child's consent should be obtained, e.g. the form and content of the research. Generally, it is recommended to get permission and consent in writing, but other formats may be more suitable in line with the age, maturity and competence of the child. When information is provided, language must be tailored to the child's maturity and definitions of the terms used must be considered, as well as the child's thinking and ability to express themselves and comprehend ideas and conversations. Here it is worth mentioning Bruner (1960), who reminded teachers to adjust their language to suit the child's logical thinking and communicate with them on their level. Another point to consider is the situation from the child's perspective. Some children find it difficult to be alone with an unfamiliar person, while some children want to be able to express themselves without a guardian present. Children differ as to whether they want a parent present, e.g. during interviews. It may be easier for some children to express their opinion at school without their guardian's present, e.g. if the guardians or the child's home circumstances are a source of upset or stress for the child. This is especially true if the research involves sensitive issues. Asking a child to express an opinion at school can elicit (undesirable) obedience, or the other way around – it may be that at school the child does not have the freedom or leeway to refuse to participate. Giving the child a choice whether to speak to the researchers alone or with a peer or peers has proven a successful approach (Mauthner, 1997). If there is a potential conflict of interest, the presence of others is usually negative.

In many cases, researchers should provide the child with information verbally, perhaps even reading the introductory material together, as well as in written form. This allows the opportunity to explain and ask questions about anything that is unclear. Researchers should not routinely assume

that a participant is able to read and understand the written material in the researcher's presence. There are a lot of things that can affect reading comprehension other than reading ability – concentration matters. In the case of qualitative research into a topic that could be emotionally challenging, this time with the child (this may also apply to an adult) can lay the foundation for a good relationship based on trust.

It has been pointed out that informed consent cannot always be final, since it is not always possible to predict how the research will develop, despite all the formalities (e.g. in the case of long-term observation of children). This may mean that consent needs to be reviewed while the research is still underway. It is then viewed as "iterative and uncertain ... and open to revision and questioning" (ESRC, 2005). Renold, Holland, Ross and Hillman (2008) encourage discussion of these points and what a contract on informed consent for research involving children entails. If a participant shows signs of unhappiness or reluctance to answer questions in an interview, it may be appropriate to ask the participant if one would like to take a break. This is also an opportunity to reiterate that the participant is free to withdraw from the research, in any case information on this point are to be included on the consent form (Hollway and Jefferson, 2005).

Research involving children often takes place in schools in an environment which is familiar to the school children, which can be an advantage for them. However, researchers must not abuse the easy access to children in schools, where it is possible to reach many children at once. Kellett (2004) points out that the power balance in schools is heavily weighted against the children and may even be the place where children are least able to benefit from their right to participate.

There are various things to consider here, including the impact of the school environment on the child's decisions. Children are used to complete tasks of quite various character. Researchers must ensure that the child understands what is meant by research and that the project in question is not regular school task. Researchers must clearly state that children can decide for themselves whether they participate. In a school, the staff are in a position of power over the children. As appropriate, researchers may need to explain to the children that the research has nothing to do with the teachers or the school and design the implementation around that, not least when children are asked to answer questions about difficult topics. In many cases, it is therefore best if a member of the research team is responsible for gathering data rather than a member of staff at the school. Children who are unwilling or unable to participate must be given options to prevent them standing out, e.g. by providing other interesting projects as alternatives. Generally speaking, children who refuse to participate should be working in a classroom while data is collected, to avoid singling them

out.¹² It may also be appropriate to offer a special room for children who need assistance (e.g. with reading), which may be distracting for them or others. The experience of the author is that some children find it difficult to not be included when their parents decline participation on their behalf at the same time as most of their classmates take part. If the child is in private care or at an institution, particular care must be taken when seeking consent (Alderson and Morrow, 2004).

In Iceland, large surveys conducted in schools have often operated on a model of passive consent from parents. Then an informative letter is generally sent home with pupils and parents are asked to get in touch if they decline consent to their child participating. If no refusal is forthcoming, consent is presumed. This system does not ensure that information reaches parents and it is therefore possible that children participate in surveys and other research projects without their parents' or their guardian's knowledge. This is not compatible with the standards of informed consent and violates the rights of both parents and children. It is vital to seek the informed consent of all children when looking for participants (e.g. in research conducted in schools) and move away entirely from passive consent.

Information letters and consent forms

It would be possible to provide many examples of information letters and consent forms for children and parents / legal guardians. Such examples can be found in textbooks and on some websites for ethics committees and foreign public institutions. There are examples concerning both written and oral consent from guardians and children, simplified language and accommodations of other differences depending on the maturity and competence of the child and the form of the research, e.g. survey, interview, field observation (University of Chicago, e.d.)

Harm, stress and risk

In medical research, there is considerable discussion of the potential harms or risks that may result from participation in research. Negative consequences are weighed against the possible positive outcomes of the research to judge whether the direct and obvious benefits clearly exceed the downsides. It can be difficult to define and evaluate the concepts of harm and risk. For example, we could ask: How many people will we affect by including them in the research? Will the research elicit discomfort and worry or joy and hope in these people? In the social sciences, risk is probably based

¹² Here the author of this document is writing based on her own experience.

on mental stress and refers to potential or definite harms, costs or discomfort. There are several points to discuss here. The possibility of violence or abuse directed towards children is now given increased attention. Sometimes (e.g. in interviews or field observation) it is worth considering whether it is appropriate to be alone with a child, although this may often be acceptable. When it comes to collecting data, it may be reasonable or important to inform family and/or colleagues about the time and place, not least with the wellbeing and safety of the child in mind.

There are not many examples of procedures in research which directly cause stress to children, but it has been known to occur (Woodhead and Faulkner, 2000). However, some research projects focus on topics that can lead to stress and bring up difficult memories. If there is any expectation that this could be the case, the researcher must take particular care in designing the project.¹³ If the research requires the child to recount difficult experiences, researchers must take care to ensure that the child is not retraumatised by answering the questions. In such cases, the presence of a guardian should be considered and determined in consultation with the child. Some children want to take part in research on difficult topics, if they believe that their participation will help others (Guðrún Kristinsdóttir, 2014a; Mullender, et. al., 2002). Researchers must be prepared for emotional responses and should of course support the child with thoughtfulness and kindness (Solberg, 2014). If a child should be harmed or feel bad as a result of participation, the researcher is obligated to ensure temporary help from an appropriate professional and have information on these services on hand. There are examples of participants being offered a free consultation with an appropriate professional. Generally, it is not recommended that researchers engage in long-term support of the child – instead they should turn this responsibility over to someone else if such support is required.

If researchers witness or are informed of harmful behaviour from the child directed towards themselves or others, the appropriate response must be carefully considered. This could be physical or emotional abuse. By reacting with overly strong emotions, the researcher may cut the child off in the middle of the account and thereby the possibility for further research. Researchers must explain contentious issues regarding stress, risk or harm in permit applications. Special consideration must be given to plans for the publication of findings on sensitive topics, with a view to potential harm or

¹³ See various perspectives from Ellingen, Arstad Thorsen and Størksen, 2014; Jóhanna Einarsdóttir, 2007; Greene and Hogan, 2006; Fraser, et. al., 2004; Punch, 2002; Lewis and Lindsey, 2000; Graue and Walsh, 1998; Butler and Williamson, 1994 and various other sources cited here.

stress. It is possible that findings will be misused if not presented very carefully. On the other hand, researchers must be honest about the bad news that some research may reveal, not least if the purpose of the research is to bring about improvements (Bournon – Trites and Belanger, 2005).

The risk of emotional stress due to difficult topics also applies to researchers. It can be challenging to hear accounts of or witness people going through serious difficulties. This is particularly true of qualitative research, which is often based on direct communication with participants. Researchers may need to ensure that they have the support they need to process their emotions while the research is underway. Researchers must have the appropriate background, knowledge, education or experience to handle these kinds of research topics. Supervisors of postgraduate students should evaluate and discuss this issue with the students before approving research plans that can be expected to involve particular stress.

Individual confidentiality

The confidentiality of participants must be respected in research. This applies especially to medical information and other sensitive personal data that the researcher may have access to in the course of the research.¹⁴ Confidentiality means that any personally identifiable information that may be disclosed will not be passed on without the participant's consent.¹⁵ Care must be taken over all information about confidentiality provided to participants; researchers must beware promising too much. To ensure confidentiality, names must be encrypted and identifying details deleted such that the material cannot be traced in any way to a specific place or person. Sometimes it is necessary to change more than just the names of people and places, but changes must not affect the actual content. This applies particularly to qualitative research based on field observations and oral accounts, not least when the research is conducted in a small community. In fact, various people can trace such cases if they make the effort. Guenther (2009) points out the other side of the coin, i.e. that making changes to identifying details and place names is an act of power over participants who want to make their voices heard and can sometimes cover up the facts in a negative way. The use of anonymity must be considered, reasoned and implemented with care (Guðrún V. Stefánsdóttir, 2008).

Researchers must also remember that a breach of confidentiality may be a punishable

¹⁴ See the chapter Introductory information, permission and informed consent

¹⁵ For more information on focus group research, see the chapter on preparing projects.

offence according to Article 230 of the General Penal Code no. 19/1940 or, according to the circumstances, the provisions of other laws, e.g. chapter IV in the Act No. 90/2018 on Data Protection and the Processing of Data.

Other aspects of confidentiality pertain to limits set by certain laws. People who work with children are obligated to pay particular attention to the behaviour, upbringing and care of children. They are mandated to notify the authorities if they suspect that the child is being raised in unacceptable conditions, subjected to violence or other abuse or living with serious threats to health and development (Child Protection Act, 80/2002). This duty to report is unambiguous and applies widely in Iceland (Guðrún Kristinsdóttir et. al., 2004). When conducting research into children's circumstances, academics must be aware of their responsibilities in this regard. Researchers are ethically and legally obligated to pass on confidential information about such issues, either to the parent or legal guardian, a professional or the child protection authorities. Note however, that it may be harmful for the child if such information is passed on to a legal guardian if there is a conflict of interests. Researchers may therefore need to take care regarding the balance between confidentiality and the duty to report. This applies, for example, if children and teenagers report circumstances where they are or have been in danger due to harmful behaviour, violence or abuse. It also applies if the researcher suspects such behaviour or harm. One should consider whether the child realises the consequences of disclosing such information. If the researcher does not respond, the problem still exists. By doing nothing, the researcher could lose the child's trust. On the other hand, the child may experience the researcher's reaction (discussing the matter with or notifying a legal guardian or a professional) as a betrayal. Experts recommend discussing the matter carefully with the child before reporting – or, depending on the circumstances, discussing with both the child and a legal guardian (Hill, 2006; Alderson and Morrow, 2004; Thomas and O'Kane, 1998; Butler and Williamson, 1994).

Limits to confidentiality also apply in other circumstances. For example, if research reveals information about an incident or behaviour that involves breaking the law, the level of confidentiality the researcher can offer may be limited.¹⁶ Regardless of promises about confidentiality, those who become aware of an alleged crime are obligated to try to prevent it or its consequences, which includes the duty to report to the authorities (General Penal Code, 19/1940). This applies to everyone, children as well as adults. In accordance with this, confidentiality is overruled by the duty to report in the case of preventing or reporting a crime. There could be room for interpretation here,

¹⁶ This could apply to certain research topics, e.g. relating to drug use in children and teenagers, children of people serving a sentence, people living in Iceland illegally – to name just a few.

e.g. whether the matter concerns the interviewee or someone else. An example could be overbearing behaviour or violence from one parent towards the other, or the sale of illegal substances to a third party. It is difficult to define any general rule on this issue, but it is clear that different interests need to be weighed against each other – the self-determination of the participant and the harm of potential steps the researcher may take.

A conflict between a confidentiality agreement and the duty to report can obviously cause problems for a researcher. A situation may arise where it is untenable for a researcher to respect a participant's confidentiality. Of course, researchers must keep the interests of the research participants in mind as well as remembering not to cause harm to others. It may be sensible to think carefully about such matters and discuss them with other people, including, in certain circumstances, more experienced people before deciding.

Researchers must also take care to ensure they are not dependent on an informant. This can be avoided by informing prospective participants on the *limits of confidentiality* and discussing this issue with them. It is best to do this when obtaining consent or later in the process, if the researcher expects information like this to come up.

Another point to consider, which weighs against the above, is whether laws and regulations should be followed unequivocally. Such rigid compliance could certainly hinder or prevent research. This is obvious for some research into crimes but could also apply to other fields where researchers look at irregularities. Hammersly and Traianou (2012) warn against absolute conformity to ethical rules and standards, as mentioned above in connection with the requirement for informed consent.

Confidentiality in institutional context

An institution that permits access for research may be guaranteed a specific level of confidentiality. This must be formally organised. There may be limits to the level of confidentiality offered to an institution that grants researchers access. Issues may arise concerning alleged offences on the part of the institution against a third party or service user. If researchers receive information on such misconduct, they may be unsure of how to proceed. Researchers must be aware of and discuss their position with the institution and point out that they are neither in a supervisory nor a judicial role. They are, however, responsible for the information they acquire and may not hide behind confidentiality, prudence or impartiality if they become aware of or suspect illegal or inappropriate activity. This affects, among others issues, the contract with the institution and the information provided before the data collection starts.

Sensitive research topics

Research into sensitive topics requires several kinds of decision taking. In the case of large samples and topics that may be difficult to talk about, it can be much more challenging to comprehend the impact of the research, both before and while data collection is underway. The general rule is that researchers should familiarise themselves with works written about potential impact, including discourse on the research topic and writing about the ethics and concerns for the researcher that sometimes accompany it. In the case of a student project, students should discuss the matter very carefully with their supervisors and seek advice. For example, let us think about a prospective project researching bullying in schools. This could take the form of interviews or surveys conducted in schools. In this case a participant may be very interested, and all necessary permits be in place. Nevertheless, the researcher may still be surprised by the emotional pain that can be elicited (or exacerbated) during the participants' account. This can be explained as bullying has a significant and often long-term impact on children and teenagers and indeed anybody (Schott and Søndergaard, 2014; Ársæll M. Arnarsson and Þóroddur Bjarnason, 2009). Researchers must carefully consider how to react, e.g. when an interviewee shows signs of being upset, be able to handle emotional responses and wind up the interview. This should be done preferably in such a way that the interviewee leaves with his or her head held high or at least having received support and recovered somewhat. In the case of surveys, where data is collected from a large group all at once, it is generally very difficult or even impossible to detect such responses. In this case, the points discussed in the chapter on introducing the project to participants become particularly important.

Sometimes it is likely that some children will report (potential) dangers that they are exposed to – children may be living in difficult circumstances or be worried about another person and keep these worries secret. We can look at an example of how researchers prepared such a project. A difficult research project was planned in Iceland into the knowledge that school children have of domestic violence (around 1100 pupils at Icelandic compulsory schools responded, a general cohort). A great deal of work went into the preparation. Despite the sensitive topic, of which some gatekeepers had serious doubts and concerns in the process of getting the project approved, this extensive school survey went well. Response rates were good, as was the cooperation with schools. School staff took part in educational meetings before the survey was conducted. At least two researchers were present to collect data, along with assistants where necessary. Student counsellors were informed of the topic and that children might require assistance afterwards. The survey was completed by the children in classrooms, subject to the consent of parents who were assumed to have discussed the matter with their children. Teachers were not present in the classroom so that the children would understand that the research had nothing to do with the school. The session began with those children who wanted to take part signing a consent form to underline the fact that

participation was voluntary. Each child then received an information booklet about the topic, tailored to the age of the child. The booklet included information on where to get help. Children were allowed to decide for themselves whether they took the booklet home with them. Participation levels were good; 72.8% of parents consented to their children taking part and 68.4% of the sample responded. Response levels good – for example, a quarter of respondents took the option of drawing or writing on the blank page at the end of the survey (Guðrún Kristinsdóttir, 2012). The findings showed that the children had a general knowledge of domestic violence that varied depending on their age. For example, many were able to define the term in their own words (Ingibjörg H. Harðardóttir, Steinunn Gestsdóttir and Guðrún Kristinsdóttir 2014). Although responses were diverse, the answers of both children and teenagers showed an understanding that domestic violence was the use of power by the person in charge in the household.

Staksrud (2013), who discusses research into children's internet use, mentioned various examples of how to prepare research into difficult topics, e.g. interviewers must be well prepared to listen to oral accounts, that they have been set rules, that they are informed of the duty to report or replaced if they do not accept this duty. In an US anonymous survey on internet safety, children whose answers indicated that they could be in danger were later asked to supply telephone numbers where they could be contacted.

Children's attitudes towards research methodology

This document is not intended to provide a thorough discussion of research methodology, although the topic certainly involves ethical debates and challenges. Many of the sources cited here cover this ground. This chapter focuses on the attitudes of children to methodology, including examples. The attitudes of children towards answering surveys have been investigated to a certain extent (Mossige and Backe-Hansen (2013). For an example, we can look at a research project by Stafford, Laybourn, Hill and Walker (2003) which involved asking 200 children of various ages, with different background and location, about their attitudes towards research methods. The children reported that they didn't mind answering surveys if they weren't long and the language was easy to understand, but some children found them boring. The project also found that children wanted researchers to come to them with such surveys, if they were well designed, if the topics concerned them and if they thought that the research would help other children and young people. This is in line with the findings of the author of this document and her colleagues, which showed that children want to take part in research that they believe could help other people in similar situations (Guðrún Kristinsdóttir, 2014b). Hill (2006) nevertheless points out that we do not have sufficient knowledge about the reasons behind these attitudes. Another example of the attitudes of children towards research

methods comes from Ellonen and Pösö (2011a-b), who asked children their opinions on answering electronic surveys. Around 1100 pupils (a general cohort) from grades 6 and 9 took part. The survey concerned experiences of crimes and violence both within the home and outside it. The results for the participants' attitudes towards responding were compared to their answers about their own feelings and experiences concerning the nature of violence. There was no trend based on age or other common background factors. Respondents who had experienced the most serious violence differed as to whether they felt positive or negative about the survey. Some described anxiety or boredom but others reported feeling stronger as a result of answering the questions. There was a link between respondents' wellbeing and a negative experience of answering the survey. Those who had the most negative attitudes towards the survey also described more emotional distress than others. The authors, who approach the discussion both from a protective and a participatory perspective,¹⁷ do not recommend against surveys in schools on research topics that may be emotionally challenging for ethical reasons, but they do point out that the school environment is complex. The methodology requires a lot of work to ensure voluntary participation and obtain informed consent, but there is a lot of support available in the school community, both from staff and peers.

Preparing projects

Presenting introductory information on research plans is the first step towards a contract on participation. This information sets out a certain framework, creates expectations and, if successful, forms the foundation for connections, trust and collaboration. As previously discussed, the basic principle is that researchers shall take care to ensure that participation in the research does not cause any harm. Precise information is part of good preparation and can support systematic decision making. Information must be provided to children and legal guardians in writing in advance, including with the introductory letter when consent is obtained. The information must include various points discussed in the chapter on consent. Whether the information is delivered verbally as well is a matter of judgement and depends on the methodology, research topic and the prospective participants. The chapter on difficult research topics provides examples of how to prepare and organise a survey with a large sample. Check this chapter to see how many issues need to be considered in such cases.

When preparing a project on a topic that is considered difficult, the choice of methodology

¹⁷ On these perspectives, see Guðrún Kristinsdóttir (2014a).

must be made even more carefully than otherwise (Punch, 2002b). Qualitative individual interviews are generally more suitable than other methods (Silverman, 2013; Kvale and Brinkmann, 2009). This applies to research among children, people with various forms of disability or marginalised people (Guðrún V. Stefánsdóttir, 2008; Clarke and Braun, 2013), or when the research focuses on personal issues (e.g. trauma, grief) or socially controversial topics (e.g. the use of drugs or criminal behaviour). Interview research on sensitive topics has frequently revealed that interviewees feel positive about accounting their own difficult life experiences. As far as children are concerned, this is based on not least on their sense of being recognised and asked for their input (Graham and Fitzgerald, 2011).

At this stage, consideration must be given to the storage of data and safety issues. Once data has been collected, the database must be organised and everything well labelled. This can save a lot of time in the future and ensures high standards at the data processing stage. If participants are to be anonymous, the data must be well cleaned by removing identifiable information (names, locations, etc.). It is best to work exclusively with these edited files during data analysis and the write up, because otherwise there is a risk that errors (e.g. real names) could find their way into lectures and slides. Print outs of confidential files must be stored in locked containers, computer files must be password protected and codes created to store real names and pseudonyms separately.

In focus group research, care must be taken in the preparation phase to ensure that participants do not discuss information that other participants provide in confidentiality (France, Bendelow and Williams, 2000). Confidentiality is provided as a condition for consent to participate. Researchers must be careful to rule out the possibility of accidental confidentiality breaches, here as with other kinds of research.

Although individual interviews are well suited to study difficult topics, qualitative questionnaires (i.e. with open-ended questions, visual material and vignettes) can work well because then participants do not have to respond in person. Questionnaires do not demand physical proximity or so much experience with collecting data, although the questions and all other arrangements certainly need to be considered carefully. This method does not raise as many ethical questions regarding the researchers' experience as the individual interview and therefore may be better suited to students and for projects with small funding. Supervisors should bear this in mind for postgraduate students.

It has been pointed out that researchers need to take care with their own personal safety when preparing to collect data (Clarke and Braun, 2013). This applies particularly to research about difficult personal topics. A good rule of thumb is to make colleagues aware of places and times while data collection is underway. Researchers may also need to consider the best location in consultation with the participant. Above, this document discussed research conducted by the author and her

colleagues into children's knowledge of domestic violence, some of which took the form of individual interviews with children and mothers (Guðrún Kristinsdóttir, Margrét Ólafsdóttir and Ingibjörg H. Harðardóttir 2014). Children and mothers were always shown both interview rooms, which were near to each other, before the interviews started, so that they were familiar with the environment. This is something worth thinking about, because participants must feel secure for the research to yield good results.

Communication with institutions

Researchers who wish to conduct research with the participation of children via institutions must seek the institution's permission to do so. Great care must be taken over preparing such applications, as they can make all the difference to the success of the project (Johl and Renganathan, 2010). Obtaining access and permission required to conduct research is generally not a simple task. It can demand systematic planning, a great deal of work and even luck (Van Maanen and Kolb, 1985). For pedagogical studies, researchers need permission not just from parents, but also teachers, school administrators and school office staff. These staff act as gatekeepers, i.e. they determine whether researchers are granted the access they need to conduct their research (Johl and Renganathan (2010). Other gatekeepers could include the participants themselves, other authorities and ethics committees. At service institutes that work with children, researchers must contact the administrators and other staff as appropriate. Experience has shown that many institutions entrust a single member of staff with the authority to handle such permit applications and some workplaces have established regulations on the subject. Experienced researchers and teachers in this field know that these matters have been increasingly formalised in recent years, but there is limited supervision of the process here in Iceland.

When researchers apply to an institution for permission to conduct research that requires access to information about service users, ideally the two parties will be on the same page regarding understanding of confidentiality and copyright. Researchers must ensure that their independence is not compromised in this relationship. Researchers may need to explain to administrators at the institution that they are not there to monitor the standard of service. The general rule is that researchers own the research data that they collect, are bound to confidentiality regarding this data, may make independent decisions about how to process and publish the data, and own the copyright

to the findings.¹⁸ Institutions sometimes believe that they have an automatic right to access data collected within their walls, but this is not the case. Research is, by its nature, independent of an institution's operations, though it may sometimes concern these operations to some extent. If this is not made clear from the outset disputes may arise, e.g. if an institution requests access to the research data. Such access may be detrimental to the goals of the research. Conflicts may rise if the terms surrounding the content of interviews and handling of data are not discussed as they are agreed. Unclear terms can cause delays or even corrupt the research. Notwithstanding, the researchers are obliged to fulfil their duty to report, which was discussed in the chapter on confidentiality – this is a separate issue. Supervisors should help their students with such matters.

The communication between researchers and institutes that grant permission to conduct research is a part of the gatekeeping process. The results of a study here in Iceland indicate that there is a need to simplify the formal application process for obtaining permission from committees and institutions. Currently, the process is complicated and time consuming (Guðrún Kristinsdóttir and Hervör Alma Árnadóttir, 2015). This was focus group research among seasoned researchers at UI in the fields of social and health sciences with extensive experience of research involving children. It is worth mentioning that this investigation was conducted at a single point in time and it is impossible to generalise on basis of the findings. The results do, however, draw attention to the communication with institutions and the power of gatekeepers working for institutions. It emerged that it seemed to be individual people rather than the institution who determined what information was required in applications. Institutions and professionals were too reluctant to allow the researchers access, even though other formal permission (e.g. reviewed approvals by funding bodies) was in place. Several reasons were mentioned, e.g. doubts about the researchers' ability to talk to children and concerns that children should be protected from difficult questions. For example, one response to an application had expressed doubts about the interviewing skills of a participant which had more than a decade's experience of talking to children. Therefore, it seems appropriate to mention how important it is not to exclude certain groups of children from research. Gatekeeping is discussed to some extent in works about research findings, but often not in depth (Johl and Renganathan, 2010). There are several discussions of gatekeeping in connection with the work of ethics committees, which are among many gatekeepers (Varma, 2014).

¹⁸ Of course, specifics may vary, and agreements may be reached, e.g. for contract research.

Ethics committees

Ethics committees have long operated in the health sciences but were adopted much later in the social sciences. This document previously mentioned how the Nuremberg Code on research on human subjects shaped science ethics in light in of the horrific violations of human rights committed in the name of science before and during the Second World War. The history of scientific ethics codes, not least for medical research, goes back further than will be explored here. The focus of the code was on self-determination for individuals, their freedom to withdraw from research and provisions for avoiding unnecessary pain or harm. The Declaration of Helsinki from the World Medical Association created a recognised foundation for medical research ethics and has been reviewed and updated several times (Declaration of Helsinki from the World Medical Association, 2014).

Ethics committees may be established for a specific case or operate at a certain university or at the national level. They are intended to protect the rights of research participants, monitor quality and remind researchers of points they may overlook. Many regulations, standards and checklists have been created to this end. Quality assurance work in research is, however, more closely related to attitudes rather than regulations.

Ethics committees can ensure the quality of the research and protect participants from poor academic practices. They draw attention to ethical codes and quality criteria. These committees have raised awareness of research ethics. They can encourage providing clear information to participants, act as a safety valve, and raise awareness of various points that may have been overlooked when a research plan is presented. It is to be expected that people sometimes disagree with the rules and requirements of ethics committees. The discussions these disagreements inspire may lead to open and reasonable discourse and improved procedures (Alderson and Morrow, 1996).

The work of ethics committees and other related committees in a gatekeeping position have been criticised for overly rigid bureaucracy with increasingly strict requirements for the application process and monitoring. This criticism mainly comes from those conducting social and cultural research and those using qualitative methodology (e.g. ethnography), (Unger, Dilger, Schönhuth, 2016; Gerber, 2004). It is claimed that criteria emanate from quantitative, clinical or medical research. These can compromise the freedom, quality and diversity of methodology in the social sciences and cultural studies. It is more important to focus on giving matters more consideration in teaching and research work, rather than appointing ethics committees.

Other discussed issue of the monitoring of research by ethics committees is that it proves difficult to answer various questions from the ethics committee before the research is complete, that

PhD students' time is wasted in the application process, that there are difficulties conducting research in disability studies, and that there are disagreements regarding intentions to let the voices of participants be heard (Gerber, 2004). Similar point has been directed at gatekeepers in child protection institutions (Guðrún Kristinsdóttir and Hervör Alma Árnadóttir, 2015). Hill (2006) states that rules for research involving children make too much of a distinction between "normal" children and children in special circumstances, as a way of simplifying the issues.

To conclude, it is worth mentioning that research with child participants usually takes longer than research with adult participants; the consent of legal guardians is required and there are usually several gatekeepers. As previously stated, children must be given plenty of time and explanations and, in some cases, require detailed discussions. This can make it challenging to follow good research practices if the right conditions (time, money) are not in place. It is not acceptable to cut corners here, though.

Changes that may be beneficial in Iceland

The age limit for children participating in research should be reviewed in Iceland by lowering the minimum age for consent and introduce flexibility. As previously stated, researchers must obtain the consent of a legal guardian for children younger than 18 years to participate in research. This procedure is general and based on the age of majority in the Children's Act, although not specifically stipulated in law. Experience and foreign research recommends to base the rule on the child's maturity and competence rather than on age (Hill, 2006).¹⁹

Moreover, it is important to ensure that, just like anyone else, children who consent participation in research understand what this involves. It is vital to seek informed consent of all children when looking for participants (e.g. in research conducted in schools) and move away entirely from the aforementioned 'passive or presumed consent', commonly applied for survey research.

Here in Iceland, it is permissible to deviate from the general rule of requiring consent from the legal guardian in certain circumstances, cf. Article 2.4 of the UI Code of Research Ethics. However, the Code does not make it clear who is authorised to grant such permission. This indicates also that the participation of children in research should be explored in more detail and specific provisions established.

¹⁹ Hill (2006) mentions the British Psychological Society, federal laws in the United States and the rules in Canada that differ from state to state.

Sources²⁰

- Alderson, P. and Morrow, V. (2004). *Ethics, social research and consulting with children and young people*. Ilford: Barnardo's.
- Alderson, P. (2000). School students' views on school councils and daily life at school. *Children & Society*, 14, 121-134.
- Alderson, V. and Morrow, M. (1996). The Ethics of social research with children. *Children and Society*, 10, 99 – 105.
- Ársæll M. Arnarsson and Þóroddur Bjarnason. (2009). Einelti og samskipti við fjölskyldu og vini meðal 6., 8. og 10. bekkinga. *Tímarit um menntarannsóknir*, 6, 15–2.
- Ástríður Stefánsdóttir. (2013). Eigindlegar rannsóknir og siðferðileg álitamál. *Netla – Veftímarit um uppeldi og menntun*. Special issue. Rannsóknir og skólustarf.
- Bournon – Trites, M. and Belanger, J. (2005). Ethical dilemmas facing action researchers. *The Journal of Educational Thought*; Autumn 2005; 39, 2, 197 – 215.
- Bruner, M. (1960). *Beyond the information given. Studies in the psychology on knowing*. London: George and Allen and Unwin.
- Butler, H. and Williamson, I. (1994). *Children speak, Children, trauma and social work*. London: Longman, NSPCC.
- Child Protection Act no. 80/2002. <http://www.bvs.is/media/verklagsreglur/Child-Protection-Act-as-amended-jan2018.pdf>
- Cashmore, J. (2002). Promoting the participation of children and young people in care. *Child Abuse & Neglect*, 26(8), 837–84.
- Cater, Å. and Øverlien, C. (2014). Children exposed to domestic violence: a discussion about research ethics and researchers' responsibilities, *Nordic Social Work Research*, 4,1, 67-79.
- Charmaz, K. (2008). *Constructing grounded theory*. London: Sage.
- Christensen, P. and Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood*, 9, 477 – 497.
- Christensen, P. and James, A. (2000). Researching children and childhood: cultures of communication. In Christensen, P. and James, A. (eds.). *Research with children*, (pp. 1–8). New York: Falmer Press.
- Clarke, V. and Braun, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage.
- Convention on the Rights of the Child. (1989). United nations, Office of the High Commissioner.
- Council for International Organizations of Medical Sciences (CIOMS). (2002). *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Genf: CIOMS.
- Declaration of Helsinki from the World Medical Association. (2014).
- Doylan, I. (1997). Informed consent in medical research. *BMJ*, 314, 1107 – 1125.
- Ellonen, N. and Pösö, T. (2011a). Children's experiences of completing a computer-based violence survey. Ethical Implications. *Children and Society*, 25, 470 – 481.
- Ellonen, N. and Pösö, T. (2011b). Violence experiences in care: Some methodological remarks based on the Finnish child victim survey. *Child Abuse Review*, 20, 197 – 212.
- ESRC. Economic and Social Research Council. (2005). *Research Ethics Framework*, http://www.esrc.ac.uk/ESRCInfoCentre/Images/ESRC_Re_Ethics_Frame_tcm6-11291.pdf
- Eriksson, M. and Näsman, E. (2008). Participation in family law proceedings for children whose father is violent to their mother. *Childhood*, 15, 2, 259–275.

²⁰ Some Icelandic titles yet not translated to English.

- Esser, F., Baader, M. S., Betz, T. and Hungerland, B. (2016). (eds.). *Reconceptualising agency and childhood: New perspectives in childhood studies*. New York: Routledge.
- Fern, E. and Kristinsdóttir, G. (2011). Young people act as consultants in child-directed research: an action research study in Iceland. *Child & Family Social Work*, 16, 3, 287- 297.
- Forsman, B. (1997). *Forskningsetik. En introduction*. Lund: Studentlitteratur.
- Flick, U. (2009). *Introduction to qualitative research*. London: Sage.
- Ford, K., Sankey, J. and Crisp, J. (2007). Development of children's assent documents using a child-centred approach. *J. Child Health Care*, 11, 19, 19 – 28.
- France, A., Bendelow, G. and Williams, S. (2000). A "risky" business: Researching the health beliefs of children and young people. In Lewis, A. and G. Lindsay, G. (eds.), *Researching children's perspectives*, (pp. 150-162). Buckingham, UK: Open University Press.
- Fraser, S., Lewis, V., Ding, Kellett, M., Robinson, C. (2004). (eds.). *Doing research with children and young people*. London: Sage.
- General Penal Code. 1940 No. 19. Government of Iceland.
https://www.government.is/library/Files/General_Penal_Code_sept.-2015.pdf
- Gerber, R. (2004). Will van den Hoonaard. W. (ed.). (2002). Walking the tightrope: Ethical issues for qualitative researchers. Review. *Forum; Qualitative social research*, 5, 2.
- Graham, A. and Fitzgerald, R. (2011). Supporting Children's Social and Emotional Well-being: Does 'Having a Say' Matter? *Children & Society*, 25, 6, 447 – 457.
- Graue, E. and Walsh, D. J. (1998). *Studying children in context. Theories, methods, and ethics*. Thousand Oaks, CA: Sage Publications.
- Greene, S. and Hill, M. (eds.). (2005). Researching children's experience: Methods and methodological issues, In Greene, S. and Hogan, D. (ed.). *Researching children's experience. Approaches and methods*,(1-21). London: Sage.
- Greig, A., Taylor, J. and MacKay, T. (2007). *Doing research with children*. (2nd edition). London: Sage.
- Guðrún Kristinsdóttir and Hervör Alma Árnadóttir. (2015). Hliðvörður hvert er hlutverk þitt? Þátttaka barna í rannsóknum. [Gatekeeper – what is your role? Children's participation in research.] *Netla – Veftímarit um uppeldi og menntun*, <http://netla.hi.is/greinar/2015/ryn/002.pdf>
- Guðrún Kristinsdóttir. (2014a). Ofbeldi á heimilum. Leitað til barna og unglunga. In Guðrún Kristinsdóttir (ed.), *Ofbeldi á heimili. Með augum barna*, (17–59). [Violence at home, Children's views and perspectives]. Reykjavík: University of Iceland Press.
- Guðrún Kristinsdóttir. (2014b). (ed.), Appendix I. Ráð barna til annarra barna um viðbrögð við ofbeldi á heimili [How to respond to when there is violence in your home. Children's advices to other children]. In Guðrún Kristinsdóttir (ed.), *Ofbeldi á heimili. Með augum barna* (pp. 275–276). [Violence at home, Children's views and perspectives]. Reykjavík: University of Iceland Press.
- Guðrún Kristinsdóttir, Margrét Ólafsdóttir and Ingibjörg H. Harðardóttir. (2014). Frásagnir barna og mæðra af ofbeldi á heimili. In Guðrún Kristinsdóttir (ed.), *Ofbeldi á heimili. Með augum barna*, (pp. 89–167). [Violence at home, Children's views and perspectives]. Reykjavík: University of Iceland Press.
- Guðrún Kristinsdóttir. (2012). *Þátttaka barna og unglunga í rannsóknum. Vingjarnleg stjórnun fullorðinna?* [Children's participation in research. Caring parental guidance?] Poster at Menntakvika, conference at the UI School of Education.
- Guðrún Kristinsdóttir. (2004). (ed.), Co-authors: Freydís J. Freysteinsdóttir, Guðrún Frímansdóttir, Gunnar M. Sandholt, Hrefna Friðriksdóttir and Ólöf Finnsdóttir. *Barnaverndarmál. Skilgreiningar hugtaksins og samanburður við nágrannalönd*. [Child protection case. The concept compared to neighbouring countries]. Reykjavík: Félagsþjónustan í Reykjavík, 2004.
[http://www.bvs.is/media/rannsoknir-i-bv/Barnaverndarmal_skilgreining_hugtaksins\(1\).pdf](http://www.bvs.is/media/rannsoknir-i-bv/Barnaverndarmal_skilgreining_hugtaksins(1).pdf)
- Guðrún Kristinsdóttir. (2007). (ed.) Ingibjörg H. Harðardóttir, Margrét Ólafsdóttir and Steinunn Gestsdóttir. *Það er ljótt að meiða. Þekking og skilningur barna á ofbeldi á heimilum. Helstu niðurstöður könnunar*. [It is bad to hurt someone. Children's knowledge and understanding of domestic violence]. Reykjavík: Kennaraháskóli Íslands.

- Guðrún V. Stefánsdóttir. (2008). *Ég hef svo mikið að segja. Lífssögur Íslendinga með þroskahömlun á 20. öld.* Unpublished doctoral thesis. Reykjavík: University of Iceland, Faculty of Social Sciences.
- Guenther, K. M. (2009). The politics of names and places. *Qualitative research*, 9, 411 – 421.
- Hammersley, M. and Traianou, A. (2012). *Ethics in qualitative research. Controverses and contexts.* London: Sage.
- Hanna Björg Sigurjónsdóttir. (2003). Rannsókn um seinfæra foreldra: Hugleiðingar um siðferði og ábyrgð rannsakanda. [A study of parents with learning difficulties]. In Friðrik H. Jónsson, (ed.). In *Rannsóknir í félagsvísindum IV*, (pp. 365 – 375). UI Faculty of Social Sciences, Reykjavík: University of Iceland Press.
- Harcourt, D., Perry, B. and Wally, T. (2011). (eds.). *Researching young children's perspectives.* London: Routledge.
- University of Iceland, (2014). *University of Iceland Code of Research Ethics.*
http://www.hi.is/sites/default/files/admin/meginmal/skjol/vshi_sidareglur_16_1_2014.pdf
- Health Canada. (2012). *Requirements for informed consent documents - Research Ethics Board - Health Canada.* Ottawa, Ontario: Health Canada: Public Health Agency of Canada.
<https://www.canada.ca/en/health-canada/services/science-research/science-advice-decision-making/research-ethics-board/requirements-informed-consent-documents.html>
- Helsinkiyfirlýsing Alþjóðafélags lækna. (2014). Siðfræðilegar meginreglur fyrir læknisfræðilegar rannsóknir á mönnum. *Læknablaðið*, 3. tbl., 100. árg.
- Hill, M. (2006). Ethical considerations in researching children's experiences. In Greene, S. and D. Hogan (ed.), *Researching children's experience*, (pp. 61–86). London: Sage.
- Hill, M., Davis, J. Prout, A. and Tisdall, K. (2004). 'Moving the participation agenda forward', *Children and Society*, 18, 77–96.
- Hill, M. (2002). Effective professional intervention in children's lives. In *Effective ways in working with children and their families*, (pp. 7-47). London: Jessica Kingsley.
- Hollway, W. and Jefferson, T. (2005). *Doing qualitative research differently.* London: Sage.
- Ingibjörg H. Harðardóttir, Steinunn Gestsdóttir and Guðrún Kristinsdóttir. (2014). Hugmyndir barna og unglunga um ofbeldi á heimilum. In Guðrún Kristinsdóttir (ed.), *Ofbeldi á heimili. Með augum barna*, (pp. 61 – 87). [Violence at home, Children's views and perspectives]. Reykjavík: University of Iceland Press.
- James, A. and Prout, A. (1997). *Constructing and reconstructing childhood. Contemporary issues in the sociological study of childhood.* London: Falmer.
- Johl, S. K. and Renganathan, S. (2010). Strategies for gaining access in doing fieldwork: Reflection of two researchers. *The Electronic Journal of Business Research Methods*, 8(1), 42–50.
- Jóhanna Einarsdóttir. (2007). Research with children: methodological and ethical challenges *European Early Childhood Education Research Journal*, 15, 2, 198-211.
- Kellett, M., Forrest, R., Dent, N. and Ward, S. (2004). Just teach us the skills. Please, we'll do the rest': Empowering ten-year-olds as active researchers. *Children and Society*, 18, 329–343.
- Kvale, S. and Brinkmann, S. (2009). *Interviews. Learning the Craft of Qualitative Research Interviewing.* London: Sage.
- Lenzer, Gertrud. (2001). Children's studies. Beginnings and purposes. *The Lion and the Unicorn*, 25, 2, 181-186.
- Lewis, A. and Lindsey, A. (2000). (eds.) *Researching children's perspectives.* London: Open Univ. Press.
- Lög um samning Sameinuðu þjóðanna um réttindi barnsins, 19, 2013. [Act on The UN Convention on the Rights of the Child, 19/2013].
- Mauthner, M. (1997). Methodological aspects of collecting data from children: Lessons from three research projects. *Children & Society*, 11, 16 – 28.
- McLaughlin, H. (2005). Young service users as co-researchers. Methodological problems and possibilities. *Qualitative Social Work*, 4, 2, 211 – 227.
- Meaux, J. B. and Bell P. L. (2001). Balancing recruitment and protection: children as research subjects. *Issues Compr. Pediatr. Nurs.* Oct-Dec; 24(4):241-51.

- Mossige, S. and Backe-Hansen, E. (2013). For sensitivt for ungdom. In Fossheim, H. og Hølen, I. (eds.), *Barn i forskning. Etiske dimensjoner*, (pp. 73- 108). Oslo: De forskningsetiske komiteerne.
- Mullender, A., Hague, G., Imam, U., Kelly, L., Malos, E. and Regan, L. (2002). *Children's perspectives on domestic violence*. London, Thousand Oaks, CA: Sage.
- O'Kane, C. (2001). The Development of participatory techniques: Facilitating children's views about decisions which affect them. In Christensen, P. and A. James (ed.), *Research with children: Perspectives and practices*, (pp. 136 – 159). London: Falmer.
- NESH. (2016). *Forskningsetiske retningslinjer for samfunnsvitenskap, humaniora, juss og teologi*. Oslo: De nasjonale forskningsetiske komiteene.
- NHS. Health Research Authority. (ed). *Medical Research Council. Consent and Participant Information Sheet, Preparation Guidance*. <http://www.hra-decisiontools.org.uk/consent/principles-children-EngWalesNI.html>
- NIH. National Institute of Health. (2016). *Research involving children*. <https://humansubjects.nih.gov/children1#OHRP>
- Punch, S. (2002a). Research with Children: The Same or different from research with adults? *Childhood*, 9, 321 – 42.
- Punch, S. (2002b). 'Interviewing strategies with young people: The "Secret box", Stimulus material and task-based activities'. *Children and Society*, 16, 45 – 56.
- Qvortrup, J., Bardy, M., Sgritta, E. and Wintersberger, H. (1994). (eds.) *Childhood matters: Social theory, practice and politics*. Avebury: Public Policy and Social Welfare, vol. 14.
- Qvortrup, J. (1991). *Childhood as a social phenomenon. Introduction to a series of national reports*. Eurosocial report no. 36. Vienna: European Centre for Social Policy and Research.
- Raundalen, T.S. and Raundalen, M. (1979). *Er du på vår side?* Oslo: Universitetsforlaget.
- Renold, E., Holland, S., Ross, N. J. and Hillman, A. (2008). Becoming participant. Problematizing 'informed consent' in participatory research with young people in care. *Qualitative Social Work*, 7(4): 427–447.
- Robinson, C. and Kellett, M. (2004). Power. In S. Fraser, V. Lewis, S. Ding, Kellett, M. and C. Robinson (eds.), *Doing research with children and young people*, (pp. 81-96). London: Sage.
- Schott, R. M. and Søndergaard, D. M. (2014). (Eds.). *School bullying. New theories in context*. Cambridge: Cambridge University Press.
- Sigurður Kristinsson. (2013). Siðfræði rannsókna og siðanefndir. In Sigríður Halldórsdóttir (ed.). *Handbók í aðferðafræði rannsókna*, (pp. 71-88). Akureyri: Háskólinn á Akureyri.
- Sigurður Kristinsson. (2011). Hvaða máli skiptir upplýst samþykki? In Salvör Nordal og Vilhjálmur Árnason (eds.). *Siðfræði í samfélagi*, (pp. 189-206). Reykjavík: University of Iceland Press.
- Shier, H. (2001). Pathways to participation. Openings, opportunities and obligations. *Children & Society*, 15, 107 –117.
- Silverman, D. (2013). *Doing qualitative research*. London: Sage.
- Solberg, A. (2014). Reflections on interviewing children living in difficult circumstances: courage, caution and co-production. *International journal of social research methodology*. 17, 3, 233-248.
- Solberg, A. (1996). The challenge in child research: From 'being' to 'doing'. In J. Brannen and M. O'Brien (eds.). *Children in families: Research and policy*, (pp. 53–65). London: Falmer Press.
- Stafford, A., Laybourn, A., Hill, M. and Walker, M. (2003). Having a say: children and young people talk, about consultation. *Children & Society*, 17, 5. 361 – 373.
- Staksrud, E. (2013). *Children in the Online World. Risk, Regulation, Rights*. Farnham: Ashgate.
- Thomas, N. and O'Kane, C. (1998). The Ethics of participatory research with children, *Children and Society*, 12, 336 – 348.
- Unger, von, H., Dilger, H. and Schönhuth, M. (2016). Ethics reviews in the social and cultural sciences? A sociological and anthropological contribution to the debate. *Forum; Qualitative social research*. 17, 3, 20.
- University of Chicago. (ed.). *Social behavioural institutional review board. Consent form templates and examples*. <https://sbsirb.uchicago.edu/page/consent-form-templates-and-examples>

- Varma, R. (2014). Questioning professional autonomy in qualitative Inquiry. *IEEE technology and society magazine*, 57 – 64.
- Van Maanen, J. and Klob, D. (1985). The Professional apprentice: Observations on fieldwork role into organisational settings. In *Research in sociology of organisations*, volume 4 (pp. 1-3). Greenwich: Con Jai Press.
- Vilhjálmur Árnason. (1993). *Siðfræði lífs og dauða. Erfiðar ákvarðanir í heilbrigðisþjónustu*. Reykjavík: Rannsóknastofnun í siðfræði.
- Vis, S. A. and Fossum, S. (2013). Representation of children's views in court hearings about custody and parental visitations. A comparison between what children wanted and what the courts ruled.
- Ward, L. (1997). *Seen and heard: Involving disabled children and young people in research and development projects*. York: Joseph Rowntree Foundation.
- Woodhead, M. and Faulkner, D. (2000). Subjects, objects or participants? Dilemmas of psychological research with children. In P. Christensen and James, A. (eds.), *Research with children: Perspectives and practices*, (pp. 9-35). London: Falmer.
- Øverlien, C. (2007). Barn som opplever pappas våld mot mamma – vad säger forskningen? *Nordisk Sosialt Arbeid*, 27(4):238-250.

Appendix I Information for parents

Information for parents

Fictional example of interview research involving children

Logo or symbol for the institution, as appropriate, and date/year

Title of research project

The goal of the research is....

The research applies to children born in the years XXX

About the interviews

Parents will receive a telephone call to arrange a time that suits the child,

the interviews will take place in the home and taken about (20 minutes - 1 hour, as appropriate for the child's age), depending on how much the child has to say,

a researcher will talk to the child in private,

interviews will be recorded if the child consents,

(if applicable) at the end of the interviews with the child, a discussion will be held with a member of staff at,

neither the child nor the member of staff will be informed of what the other has said,

the child will be asked about.....(main points listed),

the child may withdraw participation at any point, without further explanation, including in the middle of an interview,

the child is not required to answer all questions. The child may say that they do not wish to discuss a certain topic and this will not have any negative consequences,

tact will be guaranteed in interviews on this subject and the intention is not to pass judgement on ...

Oral reports will be treated as confidential and discretion is guaranteed. Only the researcher and assistants will have access to the data, which will be stored in locked containers and destroyed once the research project is complete. The names of children, parents or other people or addresses will never appear in the findings and efforts will be made to describe situations such that nobody can be identified. The data will only be used for research and the findings will be used to try to improve procedures (if applicable). The findings will be published in a report and scientific papers.

If you desire any further information, please contact xxx by telephone xx or email XXX -- NAME OF RESPONSIBLE PARTY.

Appendix II Example of consent form

A realistic example of a consent form for a literate school-age child. The child would be given a verbal explanation before reading the form, filling it out and returning it into a closed box.

Logo or symbol for the institution, as appropriate, and date/year

[Information on research.....]

CONSENT from the child

I consent or do not consent to take part in the research ... (title of research project)

I know that there are no right or wrong answers

I don't have to answer all the questions, nobody will be angry if I miss some out

I can stop whenever I want, and I don't need to say why. Nothing bad will happen to me if I decide to stop.

I consent or do not consent to take part by ticking Yes or No

Yes

No

Appendix III Request for assistance with a survey questionnaire

It is assumed here that the child's parent / legal guardian has received a detailed introduction in a separate letter.

Logo or symbol for the institution, as appropriate

Request for assistance with a survey questionnaire[**Information about the research project.....**]

CONSENT FROM THE PARENT / LEGAL GUARDIAN

I, the parent / legal guardian of

have read the letter about the research project and understood its contents. I consent to allow my child to take part in the survey questionnaire.

Place and date)

signature of the parent / legal guardian

N.B. The child's name is included on the consent form so that we can keep track of responses, but will not be used in any other way.

(For the person who designs this form: Remember to have a line for the child's name. It is best to write the name in advance, otherwise it is easy to forget).