

Informed consent in child research

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Abstract in Norwegian:

Denne artikkelen beskriver og diskuterer de etiske aspektene vedrørende barns informerte samtykke når de deltar i vitenskapelig forskning. Den beskriver den historiske bakgrunnen for de lover og retningslinjer som er gjeldene i Norge og hvilke vilkår som må være oppfylt for å oppnå deltakernes frie og informerte samtykke. Videre forklarer den hvem som må informeres og gi samtykke, og gir praktiske råd til samfunnsforskere som forsker sammen med barn. Forfatterne argumenterer for at informert samtykke fra barn vil berike og gi mer valide resultater i forskningen.

Abstract in English:

This article describes and discusses the ethical aspects concerning children's informed consent when they engage in scientific research. It describes the historical background of the laws and regulations that are applicable in Norway and the conditions that must be met to achieve the participants' free and informed consent. Furthermore, it explains who should be informed and give consent and gives practical advice to social scientists who research with children. The authors argue that children's informed consent will enrich and provide more valid results in scientific research.

Introduction

The ethics of dealing with children as informants in scientific research is important and can be challenging for social researchers. One of the most fundamental issues in this area is informed consent which often raises difficult and irresolvable questions (Alderson, 2004). Researchers need to be aware that children often have no experience with meeting scientists and know nothing about scientific research (Davis, 2010). When children participate in research, scholars should ensure that the children *know* that they have a choice to participate or not, that they *know* that they have the right to withdraw from the research at any given moment and that they *know* exactly what their role in the research is and which consequences it might have for them (Greig & Taylor, 1999). This paper explores what informed consent actually involves in child research and gives some practical advice for social scientists conducting research with children. We want to convince researchers that ethical guide-

lines are not only a time consuming necessity, but that high standards in ethics may complement scientific work.

Historical review

The notion of informed consent in scientific research is fairly new. In order to understand why we have ethical guidelines it is important to know about its history. After the Second World War it was discovered that a large number of captives had been a part of a series of medical experiments by the Nazi German regime (Greig & Taylor, 1999). The captives were forced into participating; they did not willingly volunteer and there was never informed consent. The experiments often had tragic outcomes for the prisoners resulting in death, disfigurement or permanent disability. One of the most extreme cases illustrating this is the horrific experiments done by the German SS officer and physician Josef Mengele. In Auschwitz, thousands of adults and children were subjected to research that in-

volved painful operations and deadly diseases. In order to make the superior race multiply at twice the natural rate, Mengele was fascinated by the mystery of multiple births. On these grounds pregnant women and young twins were damaged for life or killed. After the war Mengele escaped to South America and was never put on trial (Eckert & Teixeira, 1985). Other Nazi scientists, attempted to excuse themselves by arguing that there were no explicit rules guiding medical research on humans (Vollmann & Winau, 1996). In retrospect, it is easy to regard these scientists as monsters or madmen, but we have to remember that they were a part of a regime where obedience was overriding and where the superiority of the Aryan race was not questioned (Katz, 1992). The experimentations were aimed at advancing knowledge for the benefit of the Aryan community at the expense of adults and children who were considered inferior. During the Nuremberg Trials it was concluded that there was a need for regulation which did not allow any subjective interpretation of what is or is not ethical research. The Nuremberg Code (1947), written by lawyers, stressed the dangers of research and insists that willing unpressured consent should always be asked for when conducting empirical research.

At the time the Nuremberg Code was established, children were expected to be too immature to be able to consent to research (Alderson, 2004). By this reasoning children were seldom part of research projects. However, in the early 1960s there was growing concern about children born with deformed limbs after their mothers had been taking the drug thalidomide against morning sickness. Doctors insisted on the value of child research and discussed the dangers of using under-researched treatments. By the Declaration of Helsinki (WMA, 1964), doctors set out more detailed ethical research standards involving particularly vulnerable populations, such as children. Despite the declaration, there were still reports of medical researchers

exploiting children as "guinea pigs", such as the Tuskegee Syphilis study of African Americans up to 1972 (Freimuth *et al.*, 2001; Seidelman, 1988). During the 1970s American lawyers and philosophers began to establish new medical ethical guidelines. Since then, their ideas have been spread around the world into networks of research ethics committees involving multiple academic disciplines. In the 1990s social scientists' began to involve children more seriously in research and began using more innovative methods helping children express their views in their own terms (Bell, 2008; Greig & Taylor, 1999). In line with the United Nations Convention on the Rights of the Child, researchers are now beginning to change how they conduct research with children (Marshall, 2010). There is a growing trend to use interpretive approaches and projective techniques in order to make children participants in research by including them as "co-creators" in the design and data collection.

Norwegian regulations

In most countries research ethics are regulated both by legislation and research guidelines. Chapter four in the Norwegian Health Research Act (Helseforskningsloven, 2008) has explicit rules for informed consent. In studies involving humans, human biological material and health information, research subjects must give their informed, voluntary, explicit and verifiable consent to participate in research (Helseforskningsloven, 2008; §13). The consent must be based on specific information about the particular study unless it is permitted to give a broad consent. A broad consent is used for studies where they use human biological material and health data for specific, broadly defined research purposes (Helseforskningsloven, 2008; §14). Subjects giving broad consent need to be periodically informed about the project.

The Norwegian Personal Data Act (Personopplysningsloven, 2000) gives legal regulations for projects which use personal

data. Personal information is data which may be linked directly or indirectly to specific persons. A person is identifiable by name, social security number, or other personal characteristics, such as pictures and videotape. A person is indirectly identifiable when background information, such as municipality of residence or school is combined with information about the person's age or sex. Information and assessments that may be linked to an individual (Personopplysningsloven, 2000; §2) can only be used if the person has given their consent (Personopplysningsloven, 2000; §8). The law gives some exceptions, such as when use of personal data is necessary to safeguard the person's vital interests or to exercise public authority. Additional regulations appear when the information can not only be linked to an individual, but is sensitive as well, such as racial or ethnic origin, political or religious beliefs or health conditions (Personopplysningsloven, 2000; §2). There are several conditions for using personal and sensitive data (Personopplysningsloven, 2000; §9), but it is important that the subject give their consent. If the rules in these laws are not followed, governmental agencies, such as the Data Protection Authority, have the power to demand that researchers correct ethical deficiencies or to bring the research to an end. If researchers do not follow through, they may have to pay economic daily penalties or fines. The most extensive violations of the law are punished with prison sentences of up to three years.

In some cases one may find similar regulations both in the legislation and guidelines. Researchers breaking the rules for informed consent are both considered as criminal by law (Helseforskningsloven, 2008; Personopplysningsloven, 2000) as well as being unethical by the Norwegian Research Guidelines (NESH, 2010). Unlike laws, guidelines do not have any formalized power. The guidelines are meant as a tool for researchers to illuminate relevant factors researchers should take into account when conducting research on hu-

mans. Still, there is room for weighing guidelines against each other and make other important considerations.

A study of children's chat rooms on Internet (Tingstad, 2007) may work as an illustration of how researchers may assess the need for informed consent. Tingstad found that when she introduced herself as a researcher in the chat rooms all communication stopped. However, when she tried to act as a participant, by using a nickname and not telling why she participated in the chat room, the children "talked" with her and expected her to answer. She chose the latter approach, which meant that the children could not be informed about the study and could not give their consent to participate. She concluded that it was not possible to explore children's chat rooms if the participants felt they were observed by an adult stranger. In addition, she argued that communication in chat rooms actually goes into a public space, since the chat rooms she explored were open and accessible to anyone.

Some journals refuse to publish reports of projects that have not had research ethics approval. All research projects in Norway which use personal information must be reported (NESH, 2010). Health research projects must be registered and approved by a Data Protection Officer for research and the Regional Committee for Medical and Health Research Ethics (REK, 2013). In addition, research within social science which collects personal or sensitive information must be submitted and approved by Norwegian Social Science Data Services (NSD, 2013). One of NSD's main tasks is to ensure that research projects are conducted according to law and ethical guidelines and to safeguard the rights of research subjects.

Free and informed consent

Research projects using personal data should always ask for the persons' free and informed consent (NESH, 2010). A *free* consent is given without external pressure

or limitations of personal freedom. Informants have the right to cancel their participation without any negative consequences. An *informed* consent must keep the informant oriented about the facts relevant to his or her participation in the research project. The information must be understandable for the informant and researchers must ensure that information provided is understood. Children are considered as one of the groups which have reduced competence to give their consent. Researchers have a particularly strong responsibility to maintain children's integrity. Children should only be included in research when the research cannot be conducted on older persons who are more able to consent *and* when the research gives the child or the child's group direct or significant advantages. In cases where the research does not involve any advantages or one is unsure about which advantages it may give, it is important that the risk and burden is insignificant for the child. In research projects which do not include physical contact with the child, the information is not sensitive *and* when the benefits of the research clearly outweigh the burdens that may apply to the child, informed consent is not necessary.

Who should consent?

According to Norwegian law children are not considered competent to consent to research until they are 18 (Backe-Hansen, 2009). This implies that guardians must consent on behalf of minors. However, Norwegian guidelines only recommend informed consent from their parents when the children are up to the age of 15 (NESH, 2010). British guidelines may give us further guidance when researching adolescents between 16 and 18 (Shaw *et al.*, 2011). Researchers should ask for parents' consent if they, for example, conduct interviews in a family home or the youths are considered as particularly vulnerable, such as having learning disabilities. In other cases parental consent may be waived for

children under 16. Such cases may be when the research is integral in a larger project, service or intervention that the child is already involved in and the parents have already given their consent. Other cases may occur when seeking parental consent would potentially breach a child's right to confidentiality, such as a drug treatment or sexual health service. Backe-Hansen (2009) argues that parents of children aged 12 and older do not necessarily need to be informed depending on what the research is about. For most studies, the consent of one parent is adequate (Shaw *et al.*, 2011). Parents should give their consent prior to their children, to avoid situations where a child has agreed to participate and their parents refuse later on.

Researchers should not separate children's legal competence from the ability to understand what research entails. Parents cannot consent on behalf of the child as long as the child is able to understand the basic principles of research (Shaw *et al.*, 2011). The child should give the ultimate consent to participate in research, while parent's give consent for the researcher to invite his or her child to participate in the study (Backe-Hansen, 2009). The Norwegian guidelines recommend obtaining children's consent when they are *old enough* to express it (NESH, 2010). It is important to notice that the guidelines do not operate with specific age. Age has often been used as an influential factor to determine children's competence to consent (Lambert & Glacken, 2011). Still, there appears to be no consensus as to when children might be competent to articulate their consent to participate. Suggestions have varied from 14 years (Wendler & Shah, 2003) to as young as 2 years (Twycross *et al.*, 2008). Some argue that children and adolescents in the same age group may have different cognitive development (Roedder John, 1999). In this respect, children who are more cognitively mature are expected to have a greater understanding about participation in research than less mature adolescents. Researchers may measure chil-

dren's stage of development by using different Piagetian tests (Dorn, Susman, & Fletcher, 1995).

Others argue for less prescriptive age and cognitive appraisal, proposing a developmental, individualized and context specific evaluation of children's ability to consent (Lambert & Glacken, 2011). In the study by Dorn and colleagues (1995) they discovered that emotional factors, such as anxiety and perceived control, influenced children's knowledge of research participation more than developmental factors, such as age and cognitive level. They argued that emotions interfered with the ability to process information. Children who perceived more control over their life had a higher tendency to understand vital information about participation in research, such as purpose of research, voluntary participation and freedom to ask questions and withdraw. Adolescents in their sample did not necessarily understand more than younger children. The study illustrates the importance of providing children with environments that decrease anxiety and increase perceived control (Dorn *et al.*, 1995). When asking young children for their informed consent we emphasize that researchers should empower children by including them in the research process. Children who have participated in the data collection might be more competent to understand what the research is all about, thereby be more informed to consent.

Further, researchers need to consider if there are relevant third parties that should be informed and give consent to research (Kvale & Brinkmann, 2009). Qualitative data collecting methods with children, such as interviews, pictures and drawings, may involve information that relates to family matters (NESH, 2010). Even though it is not the researcher's intention, children might give information about persons which are close to them. Questions involving the home environment might involve information about parents, siblings, friends and grandparents, while questions about kindergarten or school can provoke infor-

mation about teachers and peers. The Norwegian guidelines emphasize that considerations for third parties should be weighed against the research critical function and the search for truth.

What information?

Informed consent is decisive for projects approval or disapproval from Norwegian Social Science Data Services (NSD, 2013). Researchers should formulate an information letter to guardians that includes an inquiry regarding participation and information about the project. It should emphasize that participation is voluntary and inform how personal data will be stored and used by the researchers. Further it should describe which methods will be used and how participants are kept anonymous. The information should entail the overall purpose of the study and the main features of the design (Kvale & Brinkmann, 2009). It should include information about the possible risks and benefits participation may represent. Both parents and their children can resign at any time during the research process and demand all information to be deleted without any explanation. Participants should be guaranteed confidentiality and all data will be presented in a way that ensures that it cannot be traced back to them or their family. Voice recordings, observation material and other personal data ought to be stored out of reach of unauthorized persons and deleted after the conclusion of the project. An example of written information to guardians is presented in Appendix 1.

The principle about access to information in research is one of the few fundamental rights that the human rights share with the ethical guidelines (Bell, 2008). Further, Article 12 and 13 in the UN Convention on the Rights of the Child emphasize that children have the *right* to get information and freedom to express their views about decisions that affect them (Unicef, 2013). This stresses the importance of giving children information when they partici-

pate in scientific research and to consider their opinions. Young children are specifically vulnerable since they are dependent on adults and have fewer opportunities to protect themselves (Tingstad, 2007). This emphasizes the importance of informing the children about the possible risks of disclosing personal information, and being informed in a manner which leaves no uncertainty about what will happen to the results and how and where they might be published. The Norwegian guidelines require that children are presented with age-appropriate information about the study (NESH, 2010). Children shall be informed about possible consequences of the research. The nature and purpose of the research should be explained clearly: Why is it being done? What are the main questions? Who might benefit from the findings? What might the children and parents gain in participating in the research? A brief summary of the methods, timetable and activities participants will be asked to do, should be presented as well.

Based on advice from Alderson (2004) the children should receive a simple clear leaflet that their guardians can read and explain for them, presented in Appendix 2. The leaflet should use large print, simple language and pictures. The leaflet should be in the first language of the recipients. It should be an A4 sheet folded into an A5 leaflet, since it looks more reader friendly than a simple A4 sheet. A first draft should be tested with a couple of children to get their critical view and to make possible changes of the leaflet. Before data collection the researcher should go through the leaflet with the child, who may not have read or remembered the leaflet when their parents presented it. The researcher should invite questions in order to pick up common worries or questions that can be resolved. In addition, the leaflet should explain how and where to contact the researchers if they have further questions.

How to consent?

With the information given to the guardians there should be a consent form attached, similar to the one presented in Appendix 1. They should fill in information which the researcher feels is necessary to conduct the study. To keep options open for further studies, the researcher can ask them to check a box if they agree to be contacted on a later occasion. Children can be asked to check a box in the information leaflet or give their consent orally if they want to participate. If data are collected over longer periods of time, researchers should ask children for continuing consent (Alderson, 2004). This implies giving the children information presented in the leaflet and asking for consent before conducting interviews or other data collecting methods. In cases where the researcher feel that the children or parents are uncomfortable about the research, but don't want to say so, we consider they should be excluded from the study for ethical reasons. In former child studies we have experienced that some children might want to participate without their parents' consent (Alm, 2010). If they see their friends are participating in the study, they might feel unfairly treated. This is most likely because the parents may forget to return the consent form. It is our experience that such a dilemma can be solved by giving the child a new information package with the advice to encourage their guardians to sign the consent if they think they want to participate.

Concluding remarks

As history tells us, scientific research can be dangerous for young people. Even though research within social science, may not kill or dismember the children, it might still harm them (Alderson, 2004). Researchers may upset and worry the children and parents. They can make deliberate or intentional promises that may be perceived as false, making children feel embarrassed or betrayed. The ethical risks

of greater participation appear if children contribute and reveal far more about themselves than they intended. Later they might feel regret, shame or anger if researchers make a disrespectful report. Researchers have the power to produce misleading findings that result in policies which can harm children's lives. One issue that is rarely discussed is the risk of published research reports that may increase shame, stigma or disadvantages for whole groups of children and young people (Guttman & Salmon, 2004). One such example is research on school-based weight loss programs which may serve to stigmatize overweight children. Researchers have to be aware of their authority as they analyze data and write reports, and keep in mind their reliance on the public: to take part in research, to fund research and to respect and use research findings (Alderson, 2004). In order to maintain this co-operation, researchers need to keep, and have to be seen to keep, high ethical standards.

As discussed, there are many pitfalls one may experience when researching with children. Ethics guides researchers to be

more aware of hidden challenges even if they do not provide easy answers. As in the study by Tingstad (2007), scholars' who conduct research with children may be confronted by seemingly conflicting opposites: science or ethics. Researchers must decide whether they should encourage children to participate or to protect them by excluding them from research (Alderson, 2004). The UN Convention on the Rights of the Child emphasizes that children have the *right* to be heard in research that may affect them (Unicef, 2013). This means that even though children have to be considered as a vulnerable group, researchers have the obligation to include them in research. By informing and inviting children in the research process researcher's exhibit a lot of confidence in children and allow them to be heard (Abebe, 2009). In this paper we have discussed practical and ethical issues for ensuring informed consent from children in social science. We believe ethics may strengthen research by respecting children's rights and the use of transparent methods will provide more interesting and worthwhile findings.

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Vedlegg 1



Forespørsel om deltakelse i forskningsprosjekt: Sunn mat for barn og unge

Forskningsinstituttet Nofima ønsker kontakt med 10 familier med barn på 2.klasstrinn som vil delta i prosjektet "Hva styrer barn og unges valg av middagsmat?". Hensikten med prosjektet er å forstå hva barn vil ha til middag og hvorfor, slik kan man gi råd for å få barna til å spise sunnere mat. Undertegnede vil avlegge doktorgrad på dette temaet ved Universitetet i Tromsø.

Deltagelse i prosjektet innebærer at barnet ditt vil delta i et fotointervju. Han/hun får da utlevert et digital-kamera og skal ta bilder av middagsmåltidene og handleturer i matbutikken. Etter en uke med fotografering møter jeg barnet på SFO for intervju. Bildene danner utgangspunkt for intervjuet som vil handle om hva barna liker og ikke liker og hvordan de oppfatter middagsmåltidene. Intervjuet vil bli tatt opp med opptaker og skrevet ned. Som takk for deres deltakelse får barnet beholde fotoapparatet de har brukt i gave. Personalet i SFO vil bare hjelpe til med praktisk tilrettelegging og vil ikke være involvert i intervjuene.

I tillegg ønsker jeg at den som vanligvis lager middagsmåltidene i hjemmet skal delta i et intervju. Intervjuet kan bli foretatt i deres hjem eller et annet sted som vi blir enige om. Jeg vil blant annet spørre om hvilken opplevelse den foresatte har av middagsmåltidene og hvilken middagsmat den foresatte og barnet liker/ikke liker. Vedkommende vil få anledning til å se og kommentere barnets bilder, men vil ikke få vite hva barnet selv har fortalt om bildene. Intervjuet er forventet å vare i en time.

Det er helt frivillig å delta i prosjektet og du og ditt barn kan når som helst trekke dere fra deltagelse i prosjektet og kreve at deres informasjonslattes uten å måtte begrunne dette nærmere. Alle personopplysninger vil bli behandlet strengt konfidensielt og anonymisert ved publikasjon.

Doktorgradsprosjektet forventes å være avsluttet våren 2014, men datamaterialet og personopplysningene vil bli beholdt ut året 2015, med tanke på videre bearbeidelse av data og publisering. Det er imidlertid mulig at det vil bli aktuelt å gjennomføre en oppfølgingsundersøkelse for å undersøke hvordan barnas matpreferanser utvikler seg med alderen. Vi ber deg derfor krysse av på samtykkeerklæringen om du er interessert i å delta på senere studier. Etter at prosjektet er avsluttet vil personopplysningene bli slettet og bilder der ansikter vises bli sladdet.

Dersom du og ditt barn ønsker å delta i undersøkelsen, må du signere vedlagt samtykkeerklæring og returnerer den til SFO så snart som mulig. Når studien er avsluttet vil jeg presentere forskningsresultatene for familiene som deltok i studien via SFO. Har du spørsmål i forbindelse med denne henvendelsen, eller ønsker å bli informert om resultatene fra undersøkelsen når de foreligger, må du gjerne ta kontakt med meg.

Med vennlig hilsen

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Samtykkeerklæring

Vi har mottatt informasjon om prosjektet ” *Hva styrer barn og unges valg av middagsmat*” og er villig til å delta i studien.

Signatur

Navn i STORE bokstaver:

Telefonnummer

E-post:

Navn på barn i STORE bokstaver

Barnets kjønn og alder:

Jeg kan kontaktes for oppfølgingsundersøkelser. Ved et slikt samtykke vil personidentifiserende informasjon beholdes ut året 2022.

Ja

Nei

Signert erklæring returneres til en av de ansatte i SFO senest fredag 1. februar 2013.

Vedlegg 2



Vil du være med å forske på middagsmat?

For å få en frisk og sterk kropp er det viktig at man spiser riktig mat. For at barn skal spise riktig mat må de voksne få vite hvilken middagsmat barn liker. For å få svar på dette må man forske og det er forskere som undersøker slikt.

Sirilil er en slik forsker og hun kommer snart til din SFO. Hun ønsker å snakke med 10 barn og deres foreldre for å vite mer middagsmaten som barn pleier å spise.

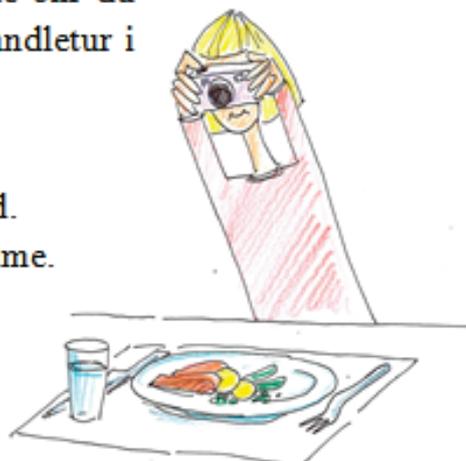


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Fotografering

Dersom du blir med på undersøkelsen vil du få utlevert et digitalt kamera. I løpet av en uke blir du bedt om å ta bilder både hjemme og på handletur i matbutikken. Sirilil ønsker at du tar bilder av:

- ✓ Middagsmat som dere spiser hjemme.
- ✓ Personer du spiser middag sammen med.
- ✓ Personer som lager middagsmaten hjemme.
- ✓ En handletur i matbutikken.



Intervju

Etter at du har tatt bilder må du svare på noen spørsmål om mat som Siril vil spørre deg om. Dette kalles for intervju. Når du blir intervjuet møter Siril på SFO og sammen ser dere på bildene som du har tatt. Du vil bli bedt om å fortelle hva du har tatt bilder av og hvorfor du tok bildene. Siril vil også spørre om hvordan middagsmåltidene pleier å være hjemme hos dere og hvilken middagsmat du liker å spise. Siril vil ta opp intervjuet på en opptaker.



Siril vil også komme hjem til deg en gang for å snakke med en av foreldrene dine. Siril vil la mammaen eller pappaen din se på bildene som du har tatt, men *ikke* fortelle hva du har fortalt i intervjuet på SFO. Kameraet som du har tatt bildene med får du i gave etter at du er ferdig med intervjuet.

Dokumenter og bilder

Det som du og mammaen eller pappaen din forteller Siril er viktig informasjon. Siril må derfor kunne skrive om undersøkelsen slik at flere kan få vite hva barn liker å spise til middag.



Når Siril senere snakker og skriver om undersøkelsen, vil hun alltid beholde navnet ditt hemmelig. Bilder som viser ansiktet ditt eller andre familiemedlemmer vil ikke vises.



Dersom du vil være med i studien må du huske at:

- ✓ Du bestemmer om du vil snakke med Siril.
- ✓ Du må si akkurat hva du mener. Det er ingen svar som er riktig eller feil.
- ✓ Selv om du er med i studien, må du ikke være med på hele intervjuet eller ta bilder du ikke ønsker.
- ✓ Vi kan ta pauser eller avslutte når du vil.
- ✓ Dersom du ikke ønsker å svare på alle spørsmålene gir du bare beskjed om det.
- ✓ Du kan be om at enkelte bilder ikke skal tas med i undersøkelsen.

Vil du være med? Sett kryss for ditt svar:Ja Nei **Ditt navn:** _____

Vennlig hilsen Siril Alm.

Dersom du har spørsmål om undersøkelsen kan du kontakte meg:

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E-post: siril.alm@nofima.no