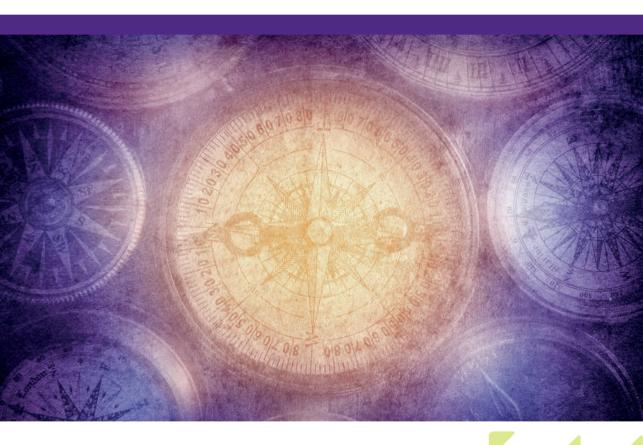


Guidelines for Research Ethics in the Social Sciences and the Humanities



GUIDELINES FOR RESEARCH ETHICS IN THE SOCIAL SCIENCES AND THE HUMANITIES

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PRFFACE

The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) is an independent advisory body responsible for developing national research ethics guidelines. The first edition of NESH's guidelines was published in 1993, and revised editions have been published in 1999, 2006 and 2016. For more information on NESH and the guidelines, see the attachment.

In this edition, NESH seeks to emphasise and clarify the fundamental norms of research ethics. The purpose is to highlight NESH's guidelines as an independent source of ethical reflection and continued discussion in the research community. NESH also highlights that research increasingly is under pressure, and different parties, including commissioners, funders, and collaborators, are co-jointly responsible for ensuring compliance with research ethics. Furthermore, the distinction between ethics and law is underscored to clarify the legal basis for the investigation of scientific misconduct and for dealing with personal data.

The revised draft of national guidelines was circulated for public consultation in the autumn of 2020. NESH received input from more than 60 researchers, research institutions, and other research actors. A working group consisting of Elisabeth Staksrud (Chair of the Committee), Ivar Kolstad (Deputy Chair) and Vidar Enebakk (Director) has reviewed the comments and authored draft formulations, which in turn have been thoroughly discussed and approved of by all NESH members. NESH would like to thank all involved parties for their contribution to the revision of the guidelines.

Oslo, December 2021

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INTRODUCTION

Research is a collective and systematic search for new knowledge using different scientific methods. Research has intrinsic value as a source of new and better insights, and it is useful to society in various capacities. The purpose of research ethics is to promote free, reliable, and responsible research. Research ethics contributes to fostering good scientific practice.¹

Research ethics

Research ethics consists of a core set of scientific norms, developed over time and institutionalised in the international research community. *The truth norm* is indispensable to all scientific activity: The search for truth, commitment to truth, integrity, and honesty are preconditions for quality and reliability in research. Research is also based on *methodological norms*, such as factuality, accuracy, transparency, and accountability. These norms dictate that scientific methods must be used in a responsible manner. Furthermore, research is regulated by *institutional norms*, which ensures that research is open, collective, independent, and critical (known as 'the ethos of science').² Together these norms constitute good scientific practice and foster integrity in research.

Research ethics also consists of common norms, derived from society's demands and expectations to research in a broad sense. Human dignity constitutes the core value in this context, and it is protected by three principles: *respect* for equality, freedom and autonomy, *beneficence* and protection from the risk of significant harm and unreasonable burdens, and *justice* in procedures and the distribution of benefits and burdens.³ These norms ensure responsible research.

A well-functioning, knowledge-based, and democratic society relies on research as a source of reliable knowledge. All human beings are entitled to share in scientific advancement and its benefits.⁴ Dissemination of research is therefore an important part of research ethics. Researchers must be open about risks and scientific uncertainty, and they must avoid damaging human beings, society, nature, and the environment by their research.

¹ See the attachment for more on NESH and the guidelines.

² 'The ethos of science' was formulated by Robert K. Merton in 1942; see also Knut Erik Tranøy (1986), *Vitenskapen – samfunnsmakt og livsform*.

³ The three fundamental principles were formulated in the Belmont report (1979).

⁴ UN (1948), The Declaration of Human Rights, article 27 (1).

Research institutions ought to ensure integrity and responsibility in research. They should furthermore secure researchers' freedom of speech and their individual academic freedom so that they, in turn, may freely disseminate reliable knowledge to the rest of society.⁵ This is particularly important when the values and norms of the research are placed under pressure.

The freedom of research, both individually and institutionally, is contingent on responsible self-regulation and good scientific practice.

Responsibility for research ethics

Research should be responsibly organised and practiced, and research ethics is a tool for this purpose. Researchers and research institutions are both responsible for ensuring compliance with research ethics, and other research actors too ought to behave in accordance with ethical norms and guidelines. The Research Ethics Act (*forskningsetikkloven*) presupposes that research conducted by public or private actors takes place in accordance with recognised norms of research ethics.⁶

Individual researchers are *always* responsible for behaving responsibly. Researchers are responsible in a broad range of capacities and contexts, for instance, as teachers, supervisors, project leaders, and experts. Researchers are individually responsible for research ethics in commissioned work or when they participate in collaborations with external partners. The responsibility for research ethics applies to *everyone* who conducts research, including students, PhD candidates, and other actors. Researchers have a statutory duty to exert caution to ensure that research takes place in accordance with recognised norms of research ethics.⁷

Research institutions should ensure that research ethics are considered and that various parties' responsibilities for ensuring this are clearly defined. This includes training students, PhD candidates, and employees, and ensuring that everyone conducting or participating in research has knowledge of research ethics. The institutions must ensure that research, teaching, training, supervision, project leadership, administration, and governance are conducted in accordance with recognised norms of research ethics.

The institutions should facilitate training and supervision in research ethics and have routines for handling ethical questions and cases. The institutions are legally responsible for ensuring that the research carried out under their purview is conducted in accordance with

⁵ The Norwegian Constitution § 100; Universitets- og høgskoleloven § 1–5.

⁶ The Research Ethics Act § 1.

⁷ The Research Ethics Act § 4.

recognised norms of research ethics.⁸ The institutions are obligated to have committees for the investigation of research misconduct and to handle cases of possible breaches of recognised norms of research ethics.⁹

Other research actors have a responsibility to comply with research ethics as well, for example, commissioners, funders, and collaborators in the public or private sectors. The balance between independence and governance should be ethically responsible, which presupposes arrangements that secure the real independence of the research. Both institutional autonomy and individual academic freedom must be protected. To avoid unclear divisions of roles and responsibilities, openness must characterize relations between commissioners, research institutions, and researchers. There should be no attempts to influence the conclusions of the research, and researchers cannot be asked to withhold unwanted results and conclusions.

NESH's guidelines

These guidelines are advisory and are intended to contribute to developing ethical judgement and reflection, clarifying ethical dilemmas, promoting responsible research, and preventing misconduct. They elaborate on various considerations and obligations, and they specify the responsibility of researchers, research institutions, and other research actors. In research projects, the guidelines should be considered throughout the entire process – from planning and execution to publication and dissemination.

The guidelines are developed by researchers, in collaboration with researchers, and are intended to aid researchers. They have been developed over a period of time, and they are based on input from different actors concerning their experiences and challenges. The guidelines are a codification of the research community's own values and norms, seeking to ensure academic freedom, responsibility, and integrity in research. The guidelines also apply to research-based activities such as teaching, dissemination of research, and institutional management.

NESH's guidelines have been developed for research in the social sciences and the humanities in a broad sense, which includes fields such as law, theology, educational science, psychology, and community medicine. They may be employed in work with artistic development and museum practice, and they may also be of relevance to other disciplines and interdisciplinary collaborations.

⁸ The Research Ethics Act § 5.

⁹ The Research Ethics Act § 6.

The guidelines apply to all research, whether publicly or privately initiated and directed. There may be grey areas between research and other forms of knowledge production, which may have different purposes, levels of independence, systems of quality control, and routines for publication. Therefore, researchers and research institutions should specify what constitutes their research and what constitutes knowledge production and communication. If analyses, reports, and evaluations are research based, they must comply with research ethics norms.

Research ethics judgements must be justified with reference to recognised norms, for instance, those embodied in the NESH guidelines. Researchers must often weigh different concerns against each other. Therefore, their choices and priorities should be explicitly conveyed. At times, different norms are intimately linked; for example, accountability is a precondition for verifiability. In other cases, different parts of the guidelines may be opposed to each other; for example, when one considers societal benefits against the risk of harm or disadvantage to singular individuals. During the research process, ethical questions may also arise that are not accounted for in the guidelines. Researchers must identify and consider ethical dilemmas and exhibit reflective and articulated judgement. The guidelines can contribute to this practice by emphasising concerns and obligations that should be taken into consideration.

The guidelines consist of five parts (A–E), which concern different ethical obligations:

- A) The research community: Researchers have a shared responsibility towards each other within the research community. They should behave truthfully, treat each other with respect, and recognise each other's contributions in projects and publications. Researchers have a collective responsibility for promoting the values and norms of research ethics in their teaching, supervision, dissemination, and publication.
- B) Research participants: Researchers have responsibilities towards all persons involved in or affected by research. Researchers should respect the participants' human dignity and consider their personal integrity, safety, and well-being. Participation in research should, as a rule, be based on information and consent.
- C) Groups and institutions: Disadvantaged and vulnerable groups have a particular need for protection Specific attention may be required in research across cultures or on cultural

heritage. Public offices and private organisations have a joint responsibility to ensure that their participation in research is in accordance with recognised norms of research ethics.

- D) Commissioners, funders, and collaborators: Researchers and research institutions have obligations towards commissioners, funders, and collaborators. Similarly, other research actors have obligations towards researchers and research institutions. Research ethics balance the norms of openness and independence against demands for social utility and relevance.
- E) Dissemination of research: Researchers and research institutions have a responsibility to disseminate scientific results, methods, and attitudes from their own and others' research to the society at large. Dissemination of research includes dialogue across disciplines, interaction with different actors in society, and participation in public debates.

Finally, this publication contains an attachment with some additional information on the Norwegian National Research Ethics Committees (FEK) and other institutions with responsibilities for research ethics. The attachment elaborates on the difference between ethical guidelines and legal acts, both with respect to the handling of personal data and the investigation of scientific misconduct. It also refers to international resources that may be useful in working with research ethics and research integrity.

A) THE RESEARCH COMMUNITY

Researchers have a shared responsibility towards each other within the research community. They should behave truthfully, treat each other with respect, and recognise each others' contributions in projects and publications. Researchers have a collective responsibility for promoting the values and norms of research ethics in their teaching, supervision, dissemination, and publication.

1. Free and independent research

Researchers shall enjoy individual freedom and have real independence. Institutional self-regulation shall be ethically responsible and cannot violate norms of good scientific practice.

Research in accordance with good scientific practice and recognised research ethical norms ought to be free. Both individual freedom and institutional autonomy are preconditions for research integrity, and relate to scientific norms, such as honesty, accountability, and openness. The freedom, independence, and critical capacity of research are crucial for ensuring social trust and credibility. Society depends on reliable research, which is not ruled by other interests, whether they be political, economic, religious, strategic, or organisational interests.¹⁰

The individual freedom of researchers presupposes integrity, and researchers are obligated to comply with recognised scientific and ethical norms. The norms of good scientific practice are embedded in the international research community, and the freedom of science ought to be respected. Researchers must defend the fundamental norms of science when these come under pressure.

Research institutions are responsible for protecting free, independent, and critical research. Institutional autonomy and responsible self-regulation presuppose research institutions that protect both the individual freedom of researchers and the collegial culture of the research community.¹¹ Research institutions must not limit or stifle individual freedom of speech with reference to duties of loyalty, demands for obedience, or economic or

¹⁰ UNESCO (2017), *Recommendation on Science and Scientific Researchers*; Ministerial Conference on the European Research Area (2020), *Bonn Declaration on Freedom of Scientific Research*.

¹¹ Universitets- og høgskoleloven § 1–5.

strategic concerns.¹² The freedom of the research should also be respected in teaching and dissemination of research (see part E).

2. Obligations of the research community

Researchers shall contribute to building academic communities characterised by openness, factuality, and collegiality.

The research community exerts stewardship over the fundamental scientific and ethical norms that constitute research ethics, in line with principles of institutional autonomy, professional independence, and academic freedom. The research community is international and is made up of different academic cultures that span institutions and national borders. These different cultures have their own methods and norms securing scientific quality and research integrity. The publication of scientific results and critical assessment through peer review are fundamental to all research.

The research community must promote a collegial environment promoting high-quality research in line with recognised scientific and ethical principles. Researchers must develop an open and non-discriminatory culture where there is room for academic disagreement, constructive critique, and ethical deliberation. Researchers should not withhold substantial critique or avoid addressing research questions from various angles, and they should be transparent about the legitimate use and limitations of different methods and modes of analysis. Lecturers, supervisors, and project leaders must include students and PhD candidates into the scientific community and for introducing them to research ethics.

3. Academic assessment

Researchers must be open about roles and interests in relation to academic assessments.

Academic assessment of student papers, dissertations, applications, publications, or academic positions should be characterised by openness, factuality, and integrity. While conducting academic assessments, researchers must be willing to consider arguments and modes of thinking that are recognised in other research traditions and be conscious of the limitations of their own competence.

¹² The Norwegian Constitution § 100.

Researchers must disclose relevant roles and ties when they are to approve, review, or assess research or the consequences of the research. This applies, for example, in relation to employments and promotions, in peer review of publications and projects, or when researchers evaluate initiatives where they also have other roles and ties.

Research institutions must safeguard openness and deliberation about roles and interests.¹³

4. Supervisors and project leaders

Supervisors and project leaders have a general and comprehensive responsibility for research ethics in projects conducted under their purview.

Supervisors and project leaders have a general and comprehensive responsibility for ensuring that all projects under their purview is conducted in accordance with recognised norms of research ethics. The responsibility for research ethics applies in all stages of a project, from conceptualization to completion. The responsibility includes research ethics in a broad sense – from co-authorship and data sharing to integrity and social responsibility.

Supervisors should provide guidance on research ethics both through teaching and during project implementation. Project leaders are responsible for addressing ethical challenges that may arise in collaborations and sub-projects. Institutions must ensure that both supervisors and project leaders are made aware of their responsibilities.

5. The supervisory relationship

Supervisors and students/PhD candidates must treat each other with respect. Supervisors should not misuse their position to their own advantage. This applies in both academic and personal matters.

Supervisors and students/PhD candidates must treat each other with respect. Supervisors should be attentive to asymmetrical power relations, and not use their academic authority to their own advantage or in ways that violates other people's integrity. If a supervisor wishes to make use of material in his or her own research, the supervisor needs to ensure that the students'/PhD candidates' right to their own material has been secured. Institutions should prepare agreements for use in such cases.

 $^{^{13}\,\}mathrm{See}$ also for valtningsloven § 6.

A supervisory relationship may involve both academic and private relations, which can result in conflicts of roles and interests when evaluating the work of the student/PhD candidate or in the research community more generally. If the relationship between a supervisor or PhD student becomes too close, for instance, of an intimate, sexual, or therapeutic nature, the supervisory relation must cease. In such cases, institutions must prevent students/PhD candidates from suffering any damage.

6. Openness, accountability, and critique

Research material and results should be made available to others as openly as possible to facilitate learning, accountability, and critique.

Openness in research is a precondition for scientific development, accountability, and critique. Public sharing of data, research material, and results is a precondition for developing knowledge, comparing research results, and assessing the analyses, interpretations, and conclusions of academic peers. Data material as well as results should therefore be shared with other researchers as openly as possible.

Openness as a norm must often be balanced against other ethical principles in research. The concern for originality dictates that the researchers responsible for collecting the material should have priority in analysing and publishing the results. After a limited embargo period, the material should normally be made publicly accessible. Concerns for persons and the demand for confidentiality may justify limited openness and sharing of data material and results. The conditions for consent may also be unclear or prevent open sharing of personal information. Such exceptions from the norm of openness should be explicitly justified.

7. Scientific publication

Scientific publication and other modes of publication are important both to ensure the quality of the research and to protect fundamental norms regarding originality, accountability, and critique.

Researchers should be free to choose the scientific publishing channels in which to publish their findings. Researchers are also responsible for making their findings and results public in other academic arenas, for instance, in national and international academic conferences or debates.

A researcher may have different roles in academic publishing, be it as an author, a peer reviewer, a member of an editorial board, or an editor. Research ethics applies to all of these roles and relations. Scientific activity presupposes critical assessment by competent and independent peers. Researchers who contribute with peer reviews and participate in editorial work must ensure the integrity of the research. Research institutions should encourage and support employees to participate actively in the collegial work of scientific publication (see part D).

Researchers must avoid *duplication* – reuse or redundant publication of the same result without providing the appropriate references – and *salamisation* – dividing the result into smaller parts than what is academically justified for the sole purpose of increasing the number of publications. Researchers should refrain from publishing their work in journals that pretend to be scientific but lack sufficient systems for peer review (so-called predatory journals).

8. Good citation practice

All research should follow good citation practice. Recognition of the work of others is important to maintain a collegial culture and it is a precondition for accountability and critique.

Good citation practice is about recognising the work of others. Researcher should build on others' work in a respectful, thorough, and accountable manner, in line with good citation practice.

Good citation practice is necessary to verify claims and arguments. Researchers should provide accurate references to all sources they make use of. This also applies when reusing text from one's own publications and when using sources that are not scientific. References should be sufficiently specific to allow others to locate, evaluate, and interpret the content in its original context.

The research community has a collective responsibility to comply with and communicate norms for good citation practice. Teachers and supervisors must ensure that students and PhD candidates are taught good citation practice.

9. Co-authorship

Researchers shall respect the contributions of others and comply with recognised norms of co-authorship and collaboration.

When several researchers collaborate on a project and intend to publish, ambiguity and disagreement about their respective contributions and responsibilities may arise. Co-authorship and authorship order should be clarified as early as possible. When students, PhD candidates, and junior researchers are involved, asymmetrical power relations give researchers must ensure the rights of co-authors. Early clarification is particularly important in larger interdisciplinary projects, in projects with many authors, or in international collaborations, as this may increase the likelihood that different practices and expectations are involved. If responsibilities and research tasks change during the project, these agreements must be updated to ensure just involvement and recognition.

Everyone who has *contributed significantly* to the project should be offered the opportunity to participate in the further work towards publication. Contributions related to data collection, supervision, or funding are not sufficient to be listed as a co-author. Rather, such contributors should be credited or acknowledged in footnotes, in a preface, or in a final remark. All forms of so-called honorary authorship are unacceptable. A person who has not contributed significantly should not be listed as an author.¹⁴

10. Plagiarism

Stealing someone else's work and presenting it as one's own is incompatible with good scientific practice.

In research ethics, plagiarism involves stealing the work of others, fully or partially, and presenting it as one's own. The most obvious form of plagiarism is direct reproduction of text, although it also encompasses paraphrasing if the statement is close to the original source. Plagiarism may also imply presenting the ideas, hypotheses, concepts, theories, interpretations, data, design, illustrations, or results of others as one's own (the list is not comprehensive). Plagiarism is incompatible with good scientific practice.

¹⁴ See also the Vancouver recommendations by the *International Committee of Medical Journal Editors* (ICMJE), and other relevant resources by the *Committee on Publication Ethics* (COPE).

11. Fabrication and falsification

Fabricating or forging research material or results is incompatible with good scientific practice.

Fabrication implies counterfeiting research material, such as fake sources, fictitious data, or deceptive descriptions. Falsification refers to misleading manipulation of the materials, variables, or results of the research, for example, by making changes to sources, data, descriptions, or other relevant information without academic justification. Both fabrication and falsification are incompatible with good scientific practice.

12. Distortion and concealment

Distorting or concealing relevant interpretations or analyses is incompatible with good scientific practice.

Distortion implies misleading usage of scientific methods, such as tendentious interpretations of sources, skewed selection of data, or misleading use of statistics. Concealment implies misleading by withholding relevant interpretations and analyses, such as deceptive representations of other research or withholding significant critique. Both distortion and concealment are incompatible with good scientific practice.

13. Safety and security

Researchers are responsible for continuously assessing their own safety and the safety of others. Research institutions should have routines for handling risk and security.

Research may involve high risk, not just to the researchers but also to students, collaborators, research participants, co-workers, and interpreters. They may be endangered due to their participation in research beyond direct physical and mental harm by facing threats to their safety and well-being.

Researchers are responsible for assessing their own safety and for not exposing partners and participants to unacceptable risks. Caution is required when collecting and storing research material, registering consent, and assessing the terms for confidentiality, source protection, self-censorship, and restrictions on access. When researchers intend to communicate controversial themes and results, they should assess the risks of threats, sanctions, and damage.

Research institutions should have routines for risk assessment and specific action plans for safety and security. The research community has a collective responsibility to support researchers who are in danger or have fled because their academic freedom is threatened.

14. International collaboration

Researchers at institutions in Norway must comply with Norwegian rules and guidelines when conducting research in other countries.

The research community is international, and research results should be shared across borders. However, research in other countries and collaboration across borders may entail particular ethical challenges. Research ethics is managed differently in different countries and in different parts of the world. Researchers at Norwegian institutions are obligated to comply with recognised norms of research ethics, including when doing research in other countries. The institutions are responsible for making sure that researchers who arrive from or are visiting from other countries are informed about research ethics governance in Norway.

Researchers at institutions in Norway who collaborate with colleagues and partners in other countries must ensure that the research they contribute to is ethically responsible. Similarly, colleagues and partners in other countries have to comply with their own national rules and guidelines. Continuous ethical reflection and discussion are often necessary to clarify and understand mutual expectations, obligations, and responsibilities.

Researchers must be attentive to responsibilities that arise from global asymmetries in power and financial resources. When performing research in low- and middle-income countries, there should be a close dialogue between the collaborators to balance mutual interests, secure the quality and relevance of the research, and maintain mutual engagement and willingness to adapt.

B) RESEARCH PARTICIPANTS

Researchers have responsibilities towards all persons involved in or affected by research. Researchers should respect the participants' human dignity and consider their personal integrity, safety, and well-being. Participation in research should, as a rule, be based on information and consent.

15. Consent to participate in research

As a main rule, researchers are ethically obliged to obtain consent from the research participants. Ethical consent to participate should be voluntary, informed, and unambiguous, and it is preferably documentable.

Research should respect personal integrity and privacy. Research ethics dictate that research participation as a main rule should be based on information and consent from all participants. This applies regardless of whether personal data or sensitive information are collected or whether participants are anonymised in the published research. The legal requirements concerning personal data protection are less comprehensive that the ethical obligation to inform and obtain consent.¹⁵

Ethical consent to participate should be voluntary, informed, and unambiguous, and it preferably documentable. 16

Voluntary consent means that participants gave it without external pressure or restriction on freedom of choice. Invitations to participate in research should be neutrally formulated. Researchers must ensure that pressure is not exercised, whether intentionally or unintentionally, to secure participation. Direct pressure includes promises of rewards, restricted rights to decline, repeated inquiries despite active decline, or indicating that non-participation could have negative consequences. Indirect pressure is exerted for instance if participants feel obliged to participate because the consent is collected by an authority figure. When providing rewards for participation, researchers must make sure that the incentives do not influence the voluntariness of the consent. Researchers must make sure that the participants understand their right to withdraw and to end their participation, without

¹⁵ The ethical demand for consent to participate in research applies independently of a possible demand concerning the legal basis for the processing of personal data.

 $^{^{16}}$ See personvern forordningen (GDPR) art. 4 no. 11 og art. 7 no. 1 for demands for legal consent.

having to provide a reason and without facing negative consequences. People should have a real possibility to decline and to withdraw if practically possible.

Informed consent means that researchers provide sufficient and clear information about what participation implies. The information should make clear to participants why they are asked to participate, what type of data is being collected, how it will be used, who will make use of the data, and for which purposes. The information should specify the purpose, method, and approach of the research; it should contain a plan for the processing, storage, use, and sharing of data; it should specify conditions for confidentiality and anonymisation; it should highlight potential risks of injury or disadvantage; and it should provide information about interests due to funding and organisational or other relations that may be of importance to the participants. The information should be adapted to the participants' age and background, and it should be communicated in a language and manner that they understand. Participants can be informed about potential societal benefits of the research when relevant, but the information must be accurate and not create unrealistic expectations. Where relevant, researchers must clarify that participation in research does not influence access to public services or the outcome of cases and applications they are involved in. The need for information is particularly strong when the research involves risk of harm or disadvantage. However, well-informed and unambiguous consent may enable research that involves some disadvantage and discomfort (see point 28. Risk of harm and disadvantage). Throughout the entire research process, researchers must ensure that participants understand the implications and possible consequences of participating.

Unambiguous consent means that the participants actively and unmistakably communicate that they agree to participate in the research.

Consent should be *documentable* to highlight the researchers' responsibility and to secure the rights of the participants. In many cases, this may be secured through a letter of consent, and the consent can be documented in writing, by an audio recording, or on film. In some cases, for example when documentable consent presents a security risk, the participants may provide their consent in other ways. Independently of the type of documentation, researchers are responsible for safeguarding the participants' freedoms, rights, and human dignity.

The researchers' responsibility does not cease once the participants have agreed to participate. In projects where objectives, roles, and relations change over time, obtaining consent at the start of the project is not sufficient. Researchers must consider if and when there is a need to update or adjust the consent during the course of the project.

In exceptional cases, obtaining *passive* consent may be appropriate, provided that the demand for information and the right to reservation have been secured.

16. Impaired capacity to consent

When research participants' capacity to provide consent is impaired or absent, researchers must safeguard their freedoms, rights, and human dignity.

In some types of research, obtaining consent may be difficult due to the participants' impaired or absent competence to protect their own needs and interests. In such cases, both the competence to consent and the ability to refuse participation are affected. This might for example be relevant in research with children or with individuals with mental health problems, intellectual disabilities, dementia, or substance abuse problems.

Individuals who are incapable of providing free and informed consent may only be included in research if a) the research is *necessary* because it cannot be done with people who have full capacity to consent, b) the research is *valuable* to the person or to the group that is the subject of the research, and c) the risk and inconvenience are *insignificant* to the participants. All three conditions must be fulfilled. When potential research participants have impaired or absent capacity to consent, consent should also be obtained from parents or guardians.

17. Protection of children

Children who participate in research have a particular right to protection. As a main rule, researchers must obtain consent both from the parents and from the children themselves. In some cases, children may consent on their own.

The best interest of the child is a fundamental concern in all research.¹⁷ Children have the right to be heard in research, and their voices are important.¹⁸ Research objectives and methods must be adapted to align with what is best for each individual child and children as a group. Children's well-being and integrity override the interests of science and society.

As a main rule, researchers must obtain consent to participate in research from parents.¹⁹

¹⁷ UN's Convention on the Rights of the Child, article 3 on the best interests of the child. Also, see the Norwegian Constitution § 104, point two.

 $^{^{18}}$ UN's Convention on the Rights of the Child, article 12 on the right to be heard. Also, see the Norwegian Constitution 104, point one.

¹⁹ Legally, children cannot, as a main rule, consent to sharing personal information. Therefore, considering other grounds for data processing apart from consent may be necessary, for instance that the research is in the general interest of the public, see personvernforordningen (GDPR) art. 6 og 9.

Additionally, assent or acceptance from participating children is required. Children are in a process of development and have different needs and abilities. Biological age alone does not determine a child's maturity. Researchers must have sufficient knowledge of children to be able to adapt the objectives and methods of their research to accommodate the age and developmental stage of the children. Researchers must assess the child's *capacity to consent* and ensure that the conditions for participation have been understood (see point 15. Consent to participate in research). Children always have the right to refuse to participate in research, even if their parents have consented. Researchers must understand and respect children's *capacity to refuse*. Children may express refusal in different ways, depending on their age and developmental stage.

In some cases, there may be a conflict of interest between children and their parents. Children are entitled to privacy, but situations may arise where researchers are obligated to convey information to parents (see point 21. Confidentiality). Parents may also have a self-interest in concealing information, for instance, about violence and abuse. In such cases, allowing children to participate in the research without the consent of their parents may be ethically sound, if the benefits and value of the research to the child clearly exceed the disadvantages of participating.²⁰ In all cases, the researcher must ensure that the best interests of the child and the right to be heard are protected in a responsible way (see point 22. Duty of notification).

18. Exceptions from the demand for consent

In some situations, including persons in research even though ethical consent is not obtained may be responsible. Researchers are nonetheless responsible for providing information.

In some situations, including persons in research without obtaining ethical consent may be reasonable, for instance, when studying historical sources, artworks, or public statements. There may also be exceptions where there is no direct interaction between the researchers and those involved, provided that the information provided is not sensitive, that participants are not identifiable, and that the benefits of the research clearly exceed the possible disadvantages

²⁰ Within medical and health research children between the ages of 12 and 16 may in some cases provide their own consent to participate, provided that the project has been approved by a regional committee (REK). See The Ministry of Health and Care Services (Helse og omsorgsdepartementet) (2017), Forskrift om barn mellom 12 og 16 år sin rett til selv å samtykke i medisinsk og helsefaglig forskning.

of participating in the research. In such cases, researchers must nevertheless be careful and respect the freedoms, rights, and human dignity of the participants, and explicitly consider the benefits and disadvantages of the research and the lack of alternative methods.

Four factors are particularly relevant to an ethical assessment concerning requirements for consent: the public character and context of the statement, the sensitivity of the information, the vulnerability of those involved, and the interactions and consequences of the research. In these cases, both the 'reasonable expectations of publicity' and 'contextual integrity' should be considered.²¹

In some cases, obtaining consent for participation in research may be impracticable or impossible. Critical research on people in powerful positions may in some cases be performed without consent if society's need for relevant knowledge clearly exceeds the possible disadvantage to actors who wish to avoid public attention. Examples of such cases are research which is necessary to reveal injustice and abuse of power or research on certain criminal offenses. In other cases, concealing the purpose of a study from the participants may be necessary. Exceptions to the principle of consent may also be made if obtaining consent entails a security risk to the researchers and/or the research participants.²²

When obtaining consent is impracticable or impossible, researchers must justify the expected value of the results. Researchers are responsible for informing those involved about the aims and results of the project. Providing general information about the project may be possible prior to the research, to be supplemented by more specific information after the research is done about the project and why consent was not obtained at the outset.

19. Transparency about roles and responsibilities

Researchers are responsible for clarifying to the participants the boundaries, expectations, and requirements associated with the role of a researcher.

In situations where researchers have multiple roles, they are responsible for clarifying the boundaries of the research relationship. Examples include when researchers also provide treatment to the participant, when evaluating a policy they have also taken part in developing, when doing research on their own teaching, in artistic development work, or in long-lasting

 $^{^{21}}$ For more on these concepts, see NESH (2018), A Guide to Internet Research Ethics.

²² See personvernforordningen (GDPR) art. 6 point 1 letter e and art. 9 and also personopplysningsloven § 9.

research relationships. If the close relationship between the researcher and the participants is likely to influence professionalism and independence, the researchers must consider whether the project should be altered or stopped.

20. Anonymity

Researchers must ensure that anonymity is protected when it has been agreed upon or otherwise is prudent.

Researchers must consider whether protecting the identity of the research participants is necessary. If the participants have been promised anonymity, the researcher is obliged not to disclose their identity in research and dissemination. The anonymity of the participants must be secured, both in publications and other forms of dissemination. Additionally, when collecting information in other ways, such as through observation or from historical sources, researchers must consider whether the persons involved should be anonymised.

Anonymisation is a means to protect the research participants' identity and integrity. Collecting anonymised data is different from de-identifying information after it has been collected. Anonymisation means to remove the connection between individuals and information in order to prevent the information from being traced back to particular individuals. Data is pseudonymised to prevent unauthorized entities from being able to trace the information back to particular individuals, while the researcher or other authorized entities may link the information to individuals through a pseudonym or other type of key.²³ The need for protection may change over time, and anonymisation is in practice often a question of degrees rather than either/or.

Re-identification refers to a residual risk that individuals may be identified, including by non-researchers, even if the initial information does not identify any individuals. Re-identification may require that additional consent be obtained from those who are identified. If re-identification entails a risk of harm or unreasonable disadvantage, the researcher must consider whether a change in the methodological approach is possible and whether the project may be responsibly completed.

²³ «Pseudonymization» is also a legal concept, see GDPR art. 4 point 5 and art. 89 point 1.

21. Confidentiality

Researchers shall handle the data confidentially when it has been agreed upon or otherwise is prudent. If researchers plan to use data collected by others on the condition of confidentiality, they must ensure that permission to depart from this condition has been secured.

If researchers promise participants confidentiality, they are obliged to treat the information confidentially and not disseminate it in ways that violate this agreement. This is a condition both for the credibility of the researcher and the participants' trust in research. However, confidentiality can be limited by the duty to notify (see point 22. Duty of notification).

Some professions are legally obligated to respect confidentiality because they gain access to information in confidential situations, for instance, in relationships between doctors and patients, psychologists and clients, teachers and students, or public employees and individual citizens. Researchers must ensure that exemptions from this obligation is granted before they can make use of such information in research. Researchers are legally obligated to respect confidentiality when they gain access to information that is subject to confidentiality.²⁴

In cases where rules or agreements on confidentiality are abused to prevent critical perspectives on important social affairs, departing from the demand for confidentiality may be ethically responsible.

22. Duty of notification

Researchers have a duty to notify when the participants are endangering themselves or others. In certain situations, researchers must depart from the demand for confidentiality to safeguard the duty to notify.

The ethical *duty to notify* is activated if researchers become aware that research participants may constitute a danger to themselves or others. In research where the duty to notify may be relevant, researchers must provide explicit information about the limits of confidentiality when they obtain consent. Researchers should develop a risk assessment and a contingency plan before the project starts to know in advance whom to contact in such situations. In some cases, collaboration with institutions that may provide participants with support and treatment is advisable when developing a contingency plan.

²⁴ Forvaltningsloven § 13 e.

In some situations, researchers are legally obliged to share confidential information, for example, with parents, child protection services, or the police. *The duty to avert a criminal offense* in the Penal Code implies that researchers informed about criminal acts have a legal duty to avert such acts, which in most cases means reporting them to the relevant responsible authority. Such situations include ongoing or planned criminal acts, such as espionage, terror, homicide, rape, severe bodily injury, and abuse in intimate relationships. *The duty to inform* in the Child Welfare Law implies that researchers who receive information or have a suspicion about neglect or abuse of children must report their concerns to the Child Protection Services. Children have a particular right to protection, and the duty applies without regard for the duty of confidentiality. ²⁶

23. Privacy and family life

Researchers should respect privacy and family life.

Privacy is a fundamental human right, and researchers must respect personal integrity and protect people from unwanted interventions and unwanted disclosure. The right to privacy encompasses, among other things, information about diseases and health, political and religious views, and sexual orientation. Researchers must be careful when studying private affairs, and they should avoid putting pressure on participants. What is regarded as sensitive information may vary between persons, groups, cultures, and across times. Distinguishing the private from the public may be difficult. Researchers should consider variations in what people regard as sensitive, private, and/or public.

24. Storage and sharing of research material

Research data and other research material should be stored and shared responsibly.

Prior to collecting data or other research material, plans should be made for how the material will be stored/archived/shared or deleted/destroyed when the project is completed. If the material is to be stored/archived/shared, the researchers must inform the participants clearly about how, in which format, and at which institutions this will be done prior to obtaining consent.

²⁵ The Penal Code § 196.

²⁶ Barnevernloven § 6−4.

Research institutions are accountable for providing responsible storage. They must have routines to ensure the quality, verifiability, re-use, sharing, and deletion/destruction of data. The institutions shall preserve research material for future generations.

If storing personal data or other sensitive material is necessary, it must be done in a secure and legal manner.²⁷

25. Reporting the results

Researchers shall report the results to the participants in a clear and responsible way.

Research participants and others who are indirectly involved in research are entitled to be informed about the results of the research. This also applies to research in which institutions and large groups of participants are involved. If direct contact with each informant is disproportionately difficult or impossible, this obligation may be fulfilled through public dissemination of the results.

Participants should be given the opportunity to correct factual errors where possible. Researchers must present the results in ways and languages that are understandable to the participants. The researchers are still fully responsible for the final interpretations and conclusions in the research. Researchers also have a responsibility for public dissemination to broader audiences (see part E).

26. Direct and indirect involvement

Researchers have a responsibility towards persons who are directly or indirectly affected by the research.

Through interviews, archival studies, and observation, researchers may gain information about more people than those who are central to the study. In some cases, for instance when observing groups of people, excluding those who have not provided their consent or who have actively declined to participate in the research can be difficult. The research may also have consequences for privacy and close relationships to people who are not themselves part of the research, but who are nevertheless indirectly involved or affected.

Researchers should be attentive to possible unforeseen effects and negative consequences of the research, for example, that members of a group may experience unreasonable exposure.

²⁷ Personvernlovverket; arkivlova.

Demands for documentation and reasonable interpretations become particularly important when the research may have consequences for the reputation or integrity of specific persons. In such cases, researchers must include mentions of alternative interpretations and/or emphasise scientific uncertainty. The possible disadvantages to people outside the research project should be balanced against the critical function of the research.

27. Values and motives

Researchers should respect different values and attitudes. Researchers should not attribute irrational or dishonourable motives unless they can provide convincing documentation or justification.

Interpreting motives for actions is often a central and legitimate part of research. Scholarly interpretations should build on research-based theories, concepts, and perspectives. Exploring motives may imply uncertainty, not least when studying other cultures or historical epochs. Researchers should therefore distinguish clearly between their descriptions and their analysis. Scholarly interpretation is substantially different from misleading distortion (see point 12. Distortion and concealment).

Researchers should respect the self-understandings of the research participants and avoid descriptions that may challenge their legitimate rights or promote stigmatisation. However, motives may often be derived from individuals' social roles. Critical research attributing dishonourable motives to individuals, or motives departing from the participants' self-understanding, calls for particularly meticulous documentation and justification.

28. Risk of harm and disadvantage

Researchers are responsible for avoiding exposure of research participants to harm and unreasonable disadvantages in the course of doing research. Participants may consent to a certain degree of risk of discomfort and disadvantage.

Research should not inflict harm on participants or expose them to unreasonable physical or mental disadvantages, such as re-traumatisation. Risk of harm may infringe upon individuals' reputation, integrity, and human rights, for instance through stigmatisation or formal and informal sanctioning of research participation.

Research may inflict less serious or reasonable disadvantages on the participants, provided that the research clearly has utility to society and value to the participants. In such cases, researchers should provide specific information about the expected utility and value before, during, and after the research.

Researchers and research institutions must ensure that participants are offered relevant and professional help or treatment for possible injuries and disadvantages resulting from their participation in the project. The higher the probability of injury and disadvantage, the greater the responsibilities borne by researchers and research institutions.

29. Posthumous legacy

Researchers should respect the legacy of deceased people.

Research on deceased people must meet the same standards for respect, documentation, and accountability as research involving living people. Respecting the deceased and those left behind requires that researchers are careful in their presentation of the findings. Archives and documents may contain sensitive information about the deceased or those left behind. Such information should be handled with care, preferably in dialogue with relatives. When studying graves and human remains, researchers must treat these with respect (see point 33. Cultural heritage).

30. Future generations

Researchers have a responsibility towards future generations.

Research may have unwanted and unforeseen consequences to the society, health, and environment of future generations. Scientific uncertainty and risk of harm and disadvantage increase the responsibility of researchers towards future generations. If the research may have negative consequences for future generations, the research must be justified in ways that these generations realistically could have accepted.

C) GROUPS AND INSTITUTIONS

Disadvantaged and vulnerable groups have a particular need for protection. Specific attention may be required in research across cultures or on cultural heritage. Public offices and private organisations have a joint responsibility to ensure that their participation in research is in accordance with recognised norms of research ethics.

31. Disadvantaged and vulnerable groups

Researchers must protect the integrity and interests of disadvantaged and vulnerable groups.

The research community has a social responsibility to gain experience with and develop knowledge about members of vulnerable groups. Historically, disadvantaged and vulnerable groups have often been subject to abuses of power and unethical research. Conducting research on weak and vulnerable groups simply because these groups are easily accessible is irresponsible. Researchers must always ensure that research is performed in accordance with recognised norms of research ethics concerning respect, protection, and justice, particularly when acquiring free and informed consent. The capacity of participants to consent should be evaluated based on individual competence, not on group characteristics.

Members of disadvantaged and vulnerable groups may wish not to be subjects of research, for instance for fear of stigmatisation or other negative consequences. At the same time, excessive protection of weak and vulnerable groups is inappropriate. This might result in their perspectives being excluded in research, and society might not gain knowledge about important topics. When performing research on weak and vulnerable groups, researchers must avoid using classifications or terms that invite unreasonable generalisations, are defamatory and/or could lead to group stigmatisation. Researchers must be clear about their roles and responsibilities both in research and in dissemination.

32. Respect for cultural differences

In research on culturally defined groups, gaining knowledge about and respect the local context and social relations is important. Understanding the significance of cultural differences is crucial to research, but does not necessarily entail acceptance of all cultural practices.

In research on culturally defined groups, respecting and gaining knowledge about the local context and social relations is important. Here, culture is understood in a broad sense that includes subcultures, religious groups, and minorities, whether or not they are vulnerable. Some groups, such as indigenous people, have collective rights, which must be respected.²⁸ Researchers should engage in dialogue with their recognised representatives in addition to local authorities and the local population where relevant (see point 40. User participation). Participation, influence, or control could conflict with requirements for quality and independence in research. In planning and conducting research, the value placed on participation should be balanced against the concern for independence in research.

Members of culturally defined groups may wish not to be subjects of research, for instance for fear of stigmatisation or other negative consequences. At the same time, excessive protection of cultural groups is inappropriate. This might result in their perspectives being excluded in research, and society may not gain knowledge about important topics. When performing research on cultural groups, researchers must avoid using classifications or terms that invite unreasonable generalisations, are defamatory, and/or could lead to group stigmatisation. Researchers must be attentive to the difference between descriptions of norms and practices on the one hand and normative or critical discussion on the other. In addition, they must be clear about their roles and responsibilities both in research and in dissemination.

In cases where cultural practices obviously conflict with general human rights or international legal obligations, the concern for such fundamental values should take priority over the concern for respect and recognition of cultural values.

33. Cultural heritage

Knowledge of the past is important to the present and the future. Institutions and researchers shall treat all types of cultural heritage responsibly.

Cultural heritage and cultural environments are sources of knowledge about humans who have lived before us. These sources encompass both cultural and natural heritage, and they may be landscapes, places, memorials, objects, texts, and archives, as well as oral sources and immaterial cultural heritage.²⁹ Research on human remains is subject to particular ethical

 $^{^{28}\,\}mathrm{UN}$ (2007). Declaration on the Rights of Indigenous Peoples.

²⁹ Cultural objects that are also pieces of art demand particular consideration, as they are sources, original artifacts and intellectual property; see kulturminneloven.

considerations.30

Research resulting in the destruction of the source material raises distinctive ethical dilemmas. The value of the research must be balanced against the degree to which the material is destroyed or altered. All invasive measures, such as handling, repatriation, and analysis of cultural objects or art works, should be documented with respect to future research or accountability. Research must not proceed in ways that prevent future researchers from learning what they might consider important.

Researchers and research institutions must be responsible and only acquire cultural heritage and cultural objects in an open, fair, and accountable way. Researchers and research institutions must not contribute to looting, theft, or the illegal sale of cultural heritage artefacts. If the ownership (provenance) is controversial, unknown, or unclear, the researchers should consider the source and history of the object and clarify rightful ownership of the material to ensure that the research is responsible. Due diligence in research involving such materials requires that the researchers and research institutions provide an ethical justification and contribute to transparency about the provenance of the materials.³¹

Preservation of sources in archives, libraries, and museums is a precondition for historical research. Perspectives and interests in research may change from one generation to another, and our society is responsible for securing documentation of our past and present, thus providing future generations with the possibility to have a past. When acquiring and documenting new sources, ethical standards should be maintained both with regard to the participants (see part B) and to the funding and organisation of the research (see part D).

34. Public administration

Public offices should enable independent research on their activities and data.

The public has a legitimate interest in understanding how public institutions work. Public offices have a duty to document and archive information about their own activities, and this information should be made available to researchers as far as possible and without great cost or delays.³² Similarly, public offices should provide for research on their own work.

³⁰ Nasjonalt utvalg for vurdering av forskning på menneskelige levninger (2018), *Forskningsetisk* veileder for forskning på menneskelige levninger; (2018), Veileder ved funn av menneskelig levninger.

³¹ International Council of Museums (2017), ICOM Code of Ethics for Museums.

³² See also offentleglova on how access to public data may be limited by concerns for confidentiality of personal information, overarching national interests or security concerns.

Public data should be accumulated in ethically responsible ways that enable reuse in research. Public offices funding or facilitating research should provide open and non-discriminatory access to research data to enable accountability and further research.

35. Private companies and organisations

Private companies and organisations should provide for research on their activities and data.

The public has a legitimate interest in understanding how private companies and non-governmental organisations work. Companies and organisations have considerable power and potential to influence the lives of individuals and the development of society both positively and negatively. Private companies and organisations should thus make their activities and data available for research, even if the purposes of the research do not align with their institutional interests. Openness about data and equal treatment of researchers is important, independently of the purpose of the research.

Private companies and organisations may have access to detailed data about customers, employees, and other groups of interests to them. Research on such data may challenge the integrity of research in various ways, such as manipulated data, lack of transparency in decision-making processes, and unreasonable differences in access to products and services. Researchers have a specific obligation to consider whether research on such data can be responsibly undertaken.

Private companies and organisations may have legitimate reasons to limit access to information about their activities, such as competitive advantage. Nevertheless, in specific cases research may be ethically justifiable if the value to society clearly exceeds the concern for such interests. In such cases, the method of acquiring data must be explicitly justified, and the researchers must ensure that any needs for anonymity are respected (see point 21. Confidentiality).

D) COMMISIONERS, FUNDERS, AND COLLABORATORS

Researchers and research institutions have obligations towards commissioners, funders, and collaborators. Similarly, other research actors have obligations towards researchers and research institutions. Research ethics balance the norms of openness and independence against demands for social utility and relevance.

36. Independence in research

All research actors must protect the independence of the researchers against pressure and control.

Independence is a precondition for the credibility of research and for societal trust in research. The independence of individual researchers may come under pressure due to external influences and control by commissioners and funders or due to demands and pressures from within the researcher's own institution. Ambiguity may also arise as users and collaborators are involved in carrying out the research. Different modes of control, connections, and conflicts of interest may increase the risk of distorting results or interpretations. They may also discourage researchers from posing critical questions and pursuing topics that might lead to disagreement. For these reasons, securing the real independence of the researchers is important.

Close relations between research environments and external partners creates a conflict of interest and ambiguity about roles and responsibilities. It may also result in shared interests, to the extent that real tensions and normative conflicts are downplayed and kept hidden. In both cases, the social contract of research as a source of credible and reliable knowledge is weakened.

Overly close relations weaken the responsibility and credibility of the research. To secure public trust in research, protecting the independence of researchers from other interests is important, both in research policy and in the funding and organisation of individual projects.

All actors who participate in the funding and organisation of research, whether they are employers, public authorities, commissioners, funders, collaborators, or other groups of interest, are obliged to protect the true independence of the researchers. Different models for funding, standard contracts, forms of collaboration, and reward systems must not undermine recognised scientific and ethical norms.

37. The responsibility of the research institutions

Research institutions must ensure that all research is conducted in accordance with recognised norms of research ethics. This is particularly important when such norms are under pressure.

Research institutions have an overarching responsibility to ensure that all research is performed in accordance with recognised scientific and ethical norms. The institutions are obligated to protect their employees against undue pressure and control that may contribute to weakening research ethics.³³

Research institutions interact with the society at large. When public or private actors fund research, they expect to get something in return. External partners have legitimate expectations of gaining useful and relevant knowledge, which is compatible with responsible research. However, research ethics articulate clear requirements for independence and openness regarding contracts, ownership, and the right to publication.

Research institutions are responsible for protecting their employees against undue pressure and control from all sources, including external actors. The institutions must ensure that all their research is conducted in accordance with recognised ethical norms and that all external partners participating in the research are familiar with the recognised norms of research ethics.³⁴

Research institutions must also ensure that the agreements they sign are ethically responsible. This applies regardless of the contribution from the external partners, whether in the form of funding, data, or access to arenas and groups for data collection. A fundamental principle in research ethics is that research should be open and independent. If responsible agreements cannot be made or maintained, the project should not proceed.

38. Commissioners and funders

Commissioners and funders are jointly responsible for ensuring that their participation in research is in accordance with recognised norms of research ethics. Strategic adaptation of projects to bypass ethical norms should not occur.

Commissioners and funders who manage research funds and influence research policy have a considerable impact on the organisation and initiation of research. They influence

 $^{^{33}}$ Universitets- og høgskoleloven $\ 1-5$; The Research Ethics Act $\ 1$.

³⁴ The Research Ethics Act § 5 b.

researchers and research institutions directly in research projects, and they can often influence how research projects are conceptualized and carried out. Commissioners and funders have a joint responsibility to ensure that their participation in research projects is in accordance with recognised norms of research ethics. Strategic adaptation of projects to bypass ethical norms should not occur.

Commissioners and funders must avoid providing incentives and guidance that place independence and research ethics under pressure. They may guide the choice of topic and influence the choice of research questions, but they should not determine the selection of data, methods, conclusions, or the presentation of results. The researchers must be able to raise critical questions and reach different conclusions than what the commissioners expected, even in cases where the results challenge the policy or strategy of the commissioners. Such events should not entail cuts in funding, reduced support for ongoing projects, or lower likelihood of future funding.

Commissioners who organise and fund research, whether publicly or privately, must have competence in research ethics. Commissioners and funders must ensure that the researchers and research institutions address relevant ethical challenges throughout the project, from project design and execution to publication and dissemination.

39. Collaborative projects

Collaborators have a joint responsibility for ensuring that their participation in research is in accordance with recognised norms of research ethics. Research ethics must be guaranteed in all agreements and collaboration arrangements.

All collaborators in research are jointly responsible for ensuring research ethics. This is particularly important when external actors participate in research projects while at the same time contributing with funding and/or in other ways exercise power. Research ethics must be guaranteed in all agreements and modes of collaboration.³⁵

40. User involvement

Research ethics must be ensured in all modes of user involvement.

User involvement may strengthen the quality and relevance of research, promote democratic

³⁵ ALLEA (2017), European Code of Conduct for Research Integrity, point 2.6. Collaborative Working.

rights, and reduce discrimination. However, it may also create ethical challenges, for instance, in relation to confidentiality, impartiality, and conflicts of interest.³⁶ Users, clients, and caregivers must not be reduced to symbols devoid of any real influence.

In some contexts, the users involved in research projects include public authorities or private actors. These actors may have several roles within a project, including as commissioners, as users, and as actors exercising power and authority. Transparency about different roles and possible conflicts of interest is important, both to promote good research and to protect society's trust in research. Different roles and expectations should be clarified in written agreements defining the mutual responsibility to adhere to research ethics.

Commissioners and funders who facilitate user involvement have a joint responsibility to ensure compliance with research ethics. Researchers must safeguard the independence and integrity of research while acknowledging the competence and interests of the users.

41. Transparency about funding, roles, and interests

All research actors are responsible for securing transparency about funding and interests.

Transparency about funding and interests is important to ensure the credibility and legitimacy of research. Transparency about funding makes it easier for researchers to protect themselves against undue pressure, thereby securing the independence of research. Commissioners and funders should publicly indicate what research they have supported and whether there are other interests and power relations that might influence the research.

When researchers publish and utilise results, they have an independent responsibility to be transparent about any ties that might influence the confidence in the research. Transparency does not exempt researchers from their broader responsibility to abide by research ethics.

42. Use of research results

All researchers are responsible for ensuring that the use and presentation of their results are ethically responsible.

Commissioners and funders cannot withhold unwanted results and thereby contribute to a distorted picture of facts and findings. Bending the results to arrive at desired conclusions or to present the results in a misleading or questionable way is unethical (see point 12. Distortion

³⁶ Veileder for brukermedvirkning i helseforskning i spesialisthelsetjenesten, May 2018.

and concealment). Researchers are free to discuss their mandate as a part of the reporting, for example, by clearly elaborating academic or relevant perspectives, interpretations and concerns that have been omitted (see point 1. Free and independent research). In such cases, researchers must discuss alternative interpretations of their findings or acknowledge scientific uncertainty. If the results are used in a misleading or questionable way by the commissioners, researchers have a right as well as a duty to point this out and demand that the reporting be corrected.

43. The right to publication and public presentation

All research actors have a responsibility to promote open research in scientific publications and other modes of public presentation.

Commissioners and funders must respect researchers' right to publish complete descriptions, data sets, and other results from their research. This also includes the right to publish findings and results in outlets the researchers deem most appropriate. Public and private actors may have legitimate reasons for limiting public presentation. In such cases, the ethical considerations must be explicit, and possible limitations to the right to publish should be justified, clear, and defined at the outset of the project.

Researchers have the right to speak publicly about the research in ways beyond publication, and commissioners and funders cannot limit the freedom of speech or academic freedom of the researchers.

44. Publication ethics

Scientific publishers must promote norms of research ethics.

Scientific publishers and academic journals should have their own guidelines for ethical oversight, such as peer review, good citation practices, co-authorship, and declaration of funding and conflicts of interests. They should also have routines for handling complaints and appeals regarding scientific misconduct. If a publication later deviates from good scientific practice, it must be corrected, labelled, or retracted.³⁷

³⁷ For more information about publication ethics, see *Committee on Publication Ethics* (COPE).

E) DISSEMINATION OF RESEARCH

Researchers and research institutions have a responsibility to disseminate scientific results, methods, and attitudes from their own and others' research to the society at large. Dissemination of research includes dialogue across disciplines, interaction with different actors in society, and participation in public debates.

45. Dissemination as a social responsibility

Researchers have a social responsibility to disseminate research.

Research dissemination is the communication of scientific results, methods, and attitudes to people outside the research community and the scientific disciplines. Dissemination is a dialogue between science and society, and researchers must promote public discourse with respect for argumentative reasoning and critical thinking. The aim is to strengthen individual autonomy and freedom of speech and to contribute to open and informed public discourse.³⁸ Researchers should provide critical correctives to authorities and other powerful actors in society, and they should challenge the misuse of research in the form of pseudo-science, politicisation, and propaganda. A well-functioning, knowledge-based, and democratic society relies on research as a source of trustworthy knowledge.

The dissemination of research encompasses many different activities with different purposes, and the activity may be directed towards the public, specific users, or researchers in other disciplines. Researchers may communicate their own findings and results or the work of peers, as well as other forms of academic knowledge and established insights. Moreover, they may disseminate in different social capacities, for example, as public intellectuals, through think tanks, or as experts on public committees and surveys. Research dissemination should always follow recognised norms of research ethics.

Dissemination of research through national fora is important to maintain and develop Norwegian and Sámi languages as scholarly languages, and the population must be able to access relevant research on complex issues through public debates. Dissemination of research in international fora is important for ensuring that relevant research is available to actors in other countries, whether they are affected by the research, researchers in other fields, or other organisations or institutions.

³⁸ The Norwegian Constitution § 100 'The authorities of the state shall create conditions that facilitate open and enlightened public discourse.'»

46. Dissemination as an institutional responsibility

Research institutions should facilitate dissemination of research and other forms of dialogue and interaction.

Dissemination of research is an institutional responsibility.³⁹ Thus, institutions should develop a strong culture for research dissemination, and they should remove barriers to dissemination and skewed incentive and reward systems that may contribute to the weakening research dissemination. Institutions should ensure that research dissemination always is in accordance with recognised principles of research ethics.

Research dissemination may entail collaboration with other institutions and professions. Research institutions have a responsibility to ensure that everyone who participates in the dissemination of research is acquainted with research ethics.

Research dissemination may result in pressure, hate speech, threats, or sanctions towards the researcher. A politicised public sphere characterised by personal attacks and culture wars may limit academic freedom and undermine democracy. Research institutions must therefore ensure that researchers are able to fulfil their social responsibility safely and securely. Institutions should conduct risk assessment and make contingency plans to support the safety and integrity of researchers when they are put under pressure (see also point 13. Safety and security).

47. Dissemination and accountability

The demand for accountability in dissemination is the same as in research.

When researchers disseminate specialised knowledge, the audience may not be in a position to reappraise the arguments presented. Therefore, dissemination of research is subject to the same demand for accountability as scientific publishing. The referencing requirements are not the same, but references to sources may guide the public towards specialised academic literature, either to search for further information or to verify the arguments presented.

Researchers may share hypotheses, theories, and preliminary findings with the public while a project is ongoing, but they should not present preliminary results as if they were decisive. Researchers should clearly communicate both scientific uncertainty and academic limitations.

³⁹ Universitets- og høyskoleloven § 1–1 c; § 1–3 c and e.

⁴⁰ Aune-utvalget (NOU 2020: 3), Ny lov om universiteter og høgskoler, ch. 15 Akademisk frihet.

In addition, they should clarify the limitations of their own academic perspective and their own competence related to the relevant issue, thus making it easier for the public to consider whether other scholarly perspectives might lead to different conclusions. Researchers must be open about possible funding, ties, and interests in their research dissemination.

48. Dissemination and factuality

The demand for factuality is the same in dissemination as in scientific publication.

Dissemination of research must maintain fundamental norms of factuality and demands for scientific discourse. Researchers should express themselves clearly, thus making it possible for other researchers from different fields and other participants in the public debate to consider their arguments and claims. Factuality implies not to deviate from the matter under discussion and avoiding tendentious accounts. Representations of others' contributions must not be distorted, and one should not ascribe to opponents erroneous points of view. ⁴¹ Norms of factuality are compatible with the use of humour and other rhetorical devices. The content is crucial, not the style.

49. Participation in interdisciplinary dialogue

Researchers should communicate across specialised academic fields.

Researchers should communicate across academic fields and participate in interdisciplinary dialogue. Researchers from different fields should treat each other appropriately and respectfully. Differences in academic traditions and points of view notwithstanding, interdisciplinary dialogue should follow the fundamental norms for scientific discourse. Scientific argumentation and critique are important to find shared solutions and to handle disagreements and diversity. All researchers have a shared responsibility for communicating these fundamental norms, through their practice as well as in theory.

⁴¹ Arne Næss (1975), En del elementære logiske emner. 11th. ed., ch. 7.

50. Participation in public debate

Researchers shall bring scientific results, methods, and attitudes into the public discourse.

Researchers can and should contribute to public debate by communicating relevant knowledge, adopting a reasoned position on controversial themes, and addressing new topics. Researchers are responsible for expressing themselves in an factual and careful manner to limit the possibility that their findings and results will be interpreted tendentiously or be misused for political, cultural, social, and economic ends. Researchers should engage in discussions about reasonable interpretations of results. Researchers should also point out and correct misleading representations and misuse of research in the public debate.

The distinction between participating as a researcher and as a citizen may be unclear. A researcher who participates in public debate as a researcher is obliged to communicate scientific results, methods, and attitudes. Personal opinions or politicised views should not be presented as research. Researchers should provide information about academic disciplines and fields of expertise, not just their degree or position, when they present themselves as researchers. A researcher participating in public debate as a citizen should not use his or her title or refer to his or her specific scientific competence unless required to allow others to assess his or her interests or academic background.

ATTACHMENT

About NESH

The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) is an advisory body working to promote good and ethically responsible research. NESH also contributes to preventing scientific misconduct. The committee is granted independence, and its work is based on recognised scientific and ethical principles, as outlined in the Research Ethics Act of 2017 (forskningsetikkloven).

NESH is part of the Norwegian National Research Ethics Committees (FEK), and the committee is appointed for four years by the Ministry of Education and Research (KD) based on a proposal by the Norwegian Research Council. The members have competence in relevant disciplines as well as ethics and law. The current committee (2018–2021) has 13 members, including two lay representatives and two deputy members (see the attached overview of current and previous members). NESH's tasks are authorised in the Research Ethics Act and anchored in the dialogue between FEK and KD.⁴²

NESH's main task is to develop guidelines for research ethics to promote good scientific practice. This work is anchored in the research community through broad involvement and national consultations. Furthermore, NESH assists by giving advice and supervision linked to specific projects. Both researchers and research institutions may address NESH as well as people who participate in or are affected by research.

NESH can make public statements on research projects that raise specific ethical questions. The committee decides which cases to discuss. A statement by NESH is advisory and may contribute to further reflection and possible changes in practice. NESH can also raise new and important ethical issues on its own initiative

NESH is neither a controller nor a court. It does not provide means of punishment or enforce sanctions. NESH does not provide ethical preapproval of research projects.

History of NESH

NESH was set up by the Norwegian Parliament in 1990 together with the National Committee for Natural Science and Technology (NENT) and the National Committee for Medical and Health Research (NEM).⁴³ The three national committees provide ethical guidelines, handle

⁴² The Research Ethics Act. See also researchethics.no.

⁴³ St. medl. nr. 28 (1988–1989). *Om forskning*, s. 70–73.

controversial research topics, communicate knowledge of ethical questions to the public, and foster an open and informed public discourse. The first edition of NESH's guidelines was published in 1993, and they have since been revised in 1999, 2006 and 2016.

The background for the initiative from the Parliament was the report *Forskning og etisk ansvar* (Research and ethical responsibility) (1981), which was authorised by a national commission for 'Research and ethics' formed in 1979. The report outlined the international development of research ethics since the Second World War in the aftermath of the atom bombs and the Nuremberg trials. It discussed how the fundamental norms and values of science were articulated in 'the ethos of science' and how this normative structure may be put under pressure by other social interests. The report outlined different ethical challenges linked with genetic research, military research, research on humans and animals, as well as commissioned research and research dissemination. It also discussed the risks associated with emerging technologies.⁴⁴ It concluded that research ethics councils should be established, both within institutions and on a national level.

In the report, it was important to clarify the relation between research ethics and legal acts concerning the protection of personal data. Part of the background on this issue was 'Prosjekt Metropolitt' ('Project Metropolis') in the 1960's, in which personal data from pupils were used in longitudinal studies without consent from the children and their parents. In the 1970's, 'Gro-saken' ('the Gro affair') led to a debate about research-based abuse of vulnerable children in institutions. In 1978, Norway introduced a new law on public registers that also established the legal basis for the processing of personal data in research; the Norwegian Data Protection Authority was established in the same year. It was also suggested that a research ethics council for social sciences should be established.⁴⁵ Thus, research ethics was institutionalised prior to the legal regulation, and in 1990 research ethics in Norway was formalised in three national committees, with NESH covering both the social sciences and the humanities. The Research Ethics Act was introduced in 2007, and it was replaced by the recent act in 2017.

The institutionalisation of research ethics in Norway also evolved through interaction with international development. The Belmont report (1979) served as a joint starting point for research on human beings, emphasising fundamental principles such as respect, benevolence, and justice. Since 2007, the World Conferences for Research Integrity (WCRI) have also

⁴⁴ Hovedkomiteen for norsk forskning (1981), Forskning og etisk ansvar. Ledet av Knut Erik Tranøy.

⁴⁵ Norges allmennvitenskapelige forskningsråd (1979), *Forskningsetikk og personopplysninger*.

developed various guidelines for interdisciplinary research and international collaboration.⁴⁶

The European Commission recently developed *The European Code of Conduct for Research Integrity* (2017), which applies to all research funded by Horizon Europe.⁴⁷ These international resources may be of use in international and interdisciplinary collaboration.

Ethical guidelines and legal acts

Ethical norms state what we can and should do in a particular situation. The source of authority for research ethical norms and guidelines resides in the research community, in accordance with the principle of academic self-regulation, and the research community is responsible for maintaining the norms and formulating the guidelines. Ethical considerations are often concerned with real dilemmas, where different concerns must be balanced, and the NESH guidelines are advisory, indicative and preventive. The guidelines are formulated as demands, advice, concerns, or ideals to aim for. Thus, NESH's guidelines are a tool and a source of ethical reflection. They indicate what researchers should consider to ensure that research is ethically responsible.

Both ethics and law are based on norms. At the same time, there are several important differences between ethical and legal norms. Research ethics has broader scope than protection of personal data (The Personal Data Act) and the legal regulation of scientific misconduct (The Research Ethics Act), and research ethics must be addressed even if the research does not deal with personal data.

The distinction between ethics and law may also create challenges and misunderstandings when obtaining consent from research participants. The Personal Data Act defines legal demands for the processing of personal data. Guidelines for research ethics, however, address broader ethical concerns, which must also be ensured when obtaining consent to participate in research. Therefore, ethical consent will often have a broader scope than legal consent.

Distinguishing between ethics and law may be difficult because the institutionalisation of research ethics is also regulated by the Research Ethics Act. The act presents different demands, including how to handle cases of misconduct. In cases of possible breaches of recognised research ethical norms, the legislation determines whether legal sanctions may be relevant. In some cases, the legislation may conflict with research ethics. In such cases, researchers have a particular responsibility to consider whether implementing the project is responsible.

⁴⁶ Singapore Statement (2010); Montreal Statement (2013).

 $^{^{47}}$ ALLEA (2017), Europeiske retningslinjer for forskningsintegritet, Norwegian in 2019.

The national research ethics system

The responsibility for research ethics is divided between researchers, research institutions, and other research actors, as presented in the introduction to NESH's guidelines. Furthermore, within the national system of research ethics, the administration of research ethics is distributed between a range of different institutions.

The Norwegian National Research Ethics Committees (FEK) is an administrative body under the Ministry of Education and Research (KD), which was established in 2013. FEK is the central scholarly body for research ethics, and its main goal is to ensure that both public and private research takes place in accordance with recognised norms of research ethics. FEK consists of a secretariat, which assists the three original committees, NEM, NENT and NESH, in addition to GRU and SKJ (see below). Committees and commissions in FEK are scholarly independent.⁴⁸

The National Committee for Medical and Health Research Ethics (NEM) was established in 1990 to advise on research ethics and develop guidelines for relevant fields of research. NEM addresses complaints under the Health Research Act on decisions from the Regional Committees for Medical and Health Research Ethics (REKs). NEM also coordinates the REKs (see below).⁴⁹

The National Committee for Research Ethics in Science and Technology (NENT) was established in 1990 and provides advice and supervision on research ethics within natural sciences and technology, industry, agriculture, and fishery as well as the parts of the life sciences not covered by medicine. NENT has developed separate guidelines for its fields of research.

The National Commission for the Investigation of Research Misconduct (GRU) was introduced in the former Research Ethics Act of 2007. According to the revised Act from 2017, the commission is responsible for considering and addressing allegations of suspected breaches of good scientific practice. GRU is also a national appeals body in cases where research institutions have concluded with scientific misconduct.⁵⁰

The National Commission for Research Ethics on Human Remains (SKJ) was established in 2008 as a national commission for considering research on human remains. The background for setting up the commission was a discussion on returning remains of Sami people from scientific collections. The commission is advisory and contributes to promoting ethically

⁴⁸ The Research Ethics Act § 3.

⁴⁹ The Health Research Act.

⁵⁰ The Research Ethics Act § 7.

good and responsible research on human remains, for instance, in archaeological excavations or museum collections.⁵¹

Regional Committees for Medical and Health Research Ethics (REKs) consider all projects within medical and health research, which according to the Health Research Act from 2009 require pre-approval by REK.⁵² Since 1978, ethical issues in medical research have been considered by an ethics commission, under a national research council (NAVF), which was a precursor of NEM. In 1985, five regional committees for medical research ethics were established, which were precursors of the REKs. Independently of the Norwegian legislation, the international Helsinki Declaration is a central resource for medical research ethics.⁵³

Other units

Additionally, there are several units responsible for handling other aspects of research, particularly the legal basis for treating personal data:

Data Protection Officer (Personvernombudet)

Legal issues concerning the processing of personal data are regulated by the Personal Data Act of 2018. Institutions are responsible for complying with the law, and the institution's Data Protection Officer is responsible for ensuring that the collection and processing of personal data is legal. If a project is likely to involve a high risk to the research participants, a Data Protection Impact Assessment (DPIA) is required, and, if necessary, advice must be sought from the Norwegian Data Protection Authority (Datatilsynet) (depending on the nature, extent, purpose and context of the research). This legal requirement is *not* an ethical assessment. In addition, the institutions are responsible for ensuring adherence to research ethics.⁵⁴

Norwegian Centre for Research Data (NSD/Sikt)

Many research institutions acquire advice on data management from the Norwegian Centre for Research Data (NSD), which since January 2022 has been part of Sikt, the new Norwegian agency for shared services in education and research. The NSD provides advice on specific projects based on submitted notification forms for personal data. The institutions are themselves responsible for ensuring that the data management is legal.⁵⁵

⁵¹ Kulturminneloven.

⁵² The Health Research Act § 10.

⁵³ WMA Declaration of Helsinki.

⁵⁴ The Research Ethics Act § 5.

⁵⁵ Personvernlovverket.

Former members of NESH

2018-2021

Elisabeth Staksrud (Chair) Kirsten Johanne Bang Lene Bomann-Larsen

Kjetil Fretheim

Rakel Christina Granaas Kristian Berg Harpviken Heidi Østbø Haugen Kjetil Ansgar Jakobsen

Roar Johnsen Ivar Kolstad Markus Hoel Lie Hadi Strømmen Lile

Anne Nevøy

Tove Klæboe Nilsen May-Len Skilbrei

Vidar Enebakk (Director)

2014-2017

Bjørn Hvinden (Chair) Kirsten Johanne Bang

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Ingegerd Holand
Roar Johnsen
Ivar Kolstad
Tor Monsen
Anne Nevøy
Erling Sandmo
May-Len Skilbrei
Elisabeth Staksrud
Knut Martin Tande

Pål Ulleberg Lisbeth Øyum

Hallvard Fossheim / Vidar Enebakk

(Directors)

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Bjørn Hvinden (Chair)

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Lynn Nygaard
Hilde Pape
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Einar Spurkeland

Elin Thuen Arne Tostensen Lisbeth Øyum

Knut Martin Tande

Helene Ingierd / Espen Gamlund / Hallvard Fossheim (Directors)

2006-2009

Anne-Hilde Nagel (Chair) Alexander Cappelen Hallvard J. Fossheim Arne Grønningsæter Kristian Berg Harpviken

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Hilde Pape

Jone Salomonsen

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Ragnvald Kalleberg (Chair)

Asta Balto

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Helge Rønning
Jone Salomonsen
Per Schreiner
Anne Julie Semb
Ann Helen Skjelbred
Ole Peter Askheim
Bjarte Vandvik

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