

Ethics

Ethical principles for scientific research in the Humanities and Social Sciences adopted by the Swedish Council for Research in the Humanities and Social Sciences (HSFR) in March 1990.

Scientific research is important and necessary for the progress of both individuals and society. Society and its members therefore have a legitimate claim that research should be conducted, that it should focus on important issues and that it should be of a high quality. This claim, henceforth called the *Research Claim*, involves the development of knowledge in breadth and depth and the improvement of research methods. At the same time, however, the members of society have a justified claim to be protected against illegitimate interference in their personal lives. Nor should individuals be subjected to psychological or physical harm, humiliation or intrusion. This requirement, henceforth called the Claim for Individual Protection, is the self-evident prerequisite for ethical considerations in research.

Neither the Research Claim nor the Claim for Individual Protection are absolute, however. They always must be weighed against each other. Before the initiation of any scientific study, the value of the expected gain in knowledge

should be weighed against the possible risks of negative consequences for suppliers of information, for participants and possibly for some third party. Such an assessment should consider short-term as well as long-term effects.

Questions regarding the general direction of research, or the responsibility for the use of research results in general, fall outside the scope of the present discussion of ethical principles. This is not to say that such questions are unimportant. However, the following discussion will focus on those persons who are directly affected by the research process.

In some cases, the position of scientific research vis-a-vis the State, organisations and individual persons is weak. In accordance with the overall Research Claim, it may be justified in such cases to propose rules or recommendations that strengthen the position of scientific research. In other cases, where the position of individual persons is weak, consideration for their interests may call for rules or recommendations which strengthen the position of individuals.

The Research Claim carries considerable weight in many instances. For example, it would be bordering on the unethical to refrain from conducting scientific research on matters which might lead to an improvement in people's health and living-conditions, the removing of prejudices or a heightening of people's awareness of richer ways of making use of their own resources. Examples of such research are studies of the relationship between environmental factors in the

working place and mental and physical disturbances, or developmental studies of mechanisms giving rise to individual and social suffering, such as alcoholism, criminal behaviour or similar problems.

The ethical principles presented here have as their aim to provide norms for the relationship between, on the one hand, researchers and, on the other, suppliers of information and participants in scientific studies, thereby facilitating a proper trade-off between the

Research Claim and the Claim for Individual Protection. The principles constitute guidelines for the scrutinising of research projects from an ethical point of view by the Ethics Committee of the HSFR. They also aim to guide the individual researcher during the planning of research projects.

The principles are not intended to be comprehensive. Since problems may vary considerably from case to case, the principles have deliberately been given the character of guide lines rather than detailed prescriptions. They are not supposed to be a substitute for the personal responsibility and judgement of individual researchers.

Of course, conflicts may occur between the Claim for Individual Protection, on the one hand, and requirements of scientific methods or other purely practical considerations, on the other. When such a conflict of principles exists within a research project, the weighing of conflicting considerations should be discussed in detail in applications for funding made to the HSFR. In uncertain cases, the ethical conflict will be judged by the ethics committee of the HSFR.

FOUR MAIN REQUIREMENTS

The basic Claim for Individual Protection may be made more explicit by four general main requirements of research. These four requirements are called the *Informational Requirement*, the *Requirement of Consent*, the *Confidentiality Requirement* and the *Requirement of Restricted Use*. Each of these requirements may be further elaborated in a number of rules, a few of which are set out below. Beside these main rules, it may be proper to issue advisory statements or recommendations.

The Informational Requirement *The researcher should inform those affected by a particular piece of research about the aim of the undertaking.*

This general requirement may be elaborated as in Rule 1.

Rule 1

The researcher should inform suppliers of information and people studied in a research project (throughout the following text we refer to these individuals as *participants*) about their role in the project and the conditions attached to their participation. In particular, they should be informed of the fact that their participation is voluntary and that they have the right to decline or withdraw at any time. They should be provided with all information about the study that may reasonably be thought to affect their willingness to participate.

The information given may be more or less detailed. In order to facilitate contact with the researchers responsible for the project, the preliminary information should include the name of the person in charge as well as the department to which the project is linked. The aim of the study should be stated and a description should be given of how the study will be conducted in general. In order to motivate participation, the researcher should stress the benefits regarding the gains in knowledge etc. to which the research in question may contribute.

It is important that possible risks of unpleasant or harmful side-effects are explained. In addition, it should be made clear that participation is voluntary and that the information obtained by the research will not be used for any other purpose than research. It is also desirable that information is given on how and where the results of the research will be made public, and on the identity of the funder of the project. Such information should be given orally or in writing. At the latest, it should be given in connection with the distribution of questionnaires, or before experiments, tests, interviews, etc., are begun.

In this context, it is important to distinguish between three kinds of studies, which differ from each other in the degree of activity of the participants:

1) The participants are studied from a particular angle; he or she is interviewed, fills out a questionnaire, participates in an experiment etc. In these cases, information should be given in advance. However, in certain cases where information in advance would endanger the study (for example, in the case of participatory observation or certain psychological experiments), other options than advance information may be considered. If such options are chosen, information should be given as soon as possible afterwards.

2) The participants do not actively participate. Information about them which is interesting for a research project is collected from already existing public records. If and how information is given to subjects in such cases may be judged from case to case. In this, the primary consideration ought to be the actual inconvenience to the affected parties that may arise from the absence of information [versus?] from merely indirect information being given to them (for example through the mass media). Also, the size of the project, types of variables used and other practical factors may be considered.

Cases like these presuppose that permission has been granted by the public authority in question, and perhaps also from the Data Inspection Board. In cases of doubt, the Ethics Committee of the HSFR should be consulted.

3) The third kind of study is a combination of the first two, so-called mixed studies. In these, the researcher collects information through different forms of active participation by the participants (see 1 above), but also has or is going to obtain access to information regarding these persons in the record of public authorities (see 2 above). Of course, in the part of the study which involves active participation, as substantial information as possible must be given. Normally, information should also be given regarding further collecting of data planned to take place in the future, for example from records. If for some reason giving participants such information appears difficult or improper or unethical in view of the

problem addressed by the research, the question should not be determined by the researcher alone, but should always be submitted to the Ethics Committee of the HSFR for judgement.

The Requirement of Consent.

Participants of a scientific study have the right to determine for themselves whether or not to participate.

This requirement may be elaborated in the following rules:

Rule 2

The researcher should obtain consent from participants for their participation in a study. In some cases, consent should also be obtained from the parents or guardians (for example, if the participants are less than 15 years old and the study is of an ethically sensitive nature).

This rule, like Rule 1, is dependent on the nature of the activity required by participants. In studies involving active participation, consent should always be obtained. In cases where information regarding the participants is obtained from existing public records and information has not been given, either directly to the participants or, for example, through

mass media, the researcher does not need to ask for the participant's consent. Studies of Type 3 above, so-called mixed studies, should be submitted to the HSFR Ethics Committee for assessment.

When information about large groups is obtained by questionnaires sent by mail, consent in advance is not required. On the assumption that comprehensive information accompanies the questionnaire, individual consent may be considered as having been given once a completed questionnaire is returned.

In some cases, when the study does not involve questions of a personal or ethically sensitive nature, consent may be obtained through persons representing the participants and possibly affected third parties (for example, school management, teachers, employers, trade unions). This presupposes that the study is conducted within the limits of regular working tasks and during the regular working hours of the participants.

The forms and circumstances for obtaining consent should be considered thoroughly in cases where there is reason to believe that the obtaining of consent may violate the Claim for Individual Protection (for example, if the request for consent might reactivate a personal crisis, disclose unknown negative information about the individual's nearest and dearest, or make known earlier criminal behaviour or illness which the individual does not want to be made public). In

extraordinary circumstances, it is therefore possible to consider conducting the study without obtaining consent. In doubtful cases, the Ethics Committee of the HSFR should resolve the issue.

Extraordinary care should be taken when minors or people with lesser capacities for understanding the information given to participants are involved. As far as possible, the Requirement of Consent should be applied. When this is not possible, guardians or people close **to** the intended participants should be given this responsibility. In doubtful cases, consultation with other researchers in the field and/or the HSFR Ethics Committee is recommended.

Rule 3

Participants of a study should have a right to decide freely if they will participate, how long, and under what conditions. They should be able to terminate their participation without any negative consequences to themselves.

This rule is fairly unproblematic in research where the participants are active. if, for example, a participant wishes to terminate his or her participation in the middle of an interview, he or she is free to do so. This right of the participant to terminate his or her participation does not automatically mean that the researcher has to destroy information obtained

earlier from the person in question. Whether or not that would be deemed proper depends, among other things on how the initial information to the participant has been designed. The researcher has the right to try to motivate the participant to continue to participate in the research project. However, this influence should not be exercised in such a way that it appears coercive and the participant feels constrained against opting out.

If a participant requests to be deleted from a research material, this should be granted, if possible. The procedures for withdrawal from a research material may vary and are primarily, as was said above, dependent on the agreements that have been made in connection with advance information. If such agreements do not exist, a request to be deleted from a research material should be considered in terms of the actual harm that may be caused to the research material by a deletion of one or several individuals, weighed against the actual inconvenience it might mean to remain in the material against one's own will. A common form of withdrawal is the so-called 'anonymisation', which means that data are left untouched but all possible means of identification are removed.

It is the responsibility of the researcher to terminate the study, in cases where possible gains in knowledge are not in reasonable proportion to the inconvenience which may be brought upon the participants themselves or on other affected parties.

Rule 4

Participants should not be subjected to inappropriate pressure or influence. Neither should a relationship of dependence exist between the researcher and intended participants.

In view of the overall Research Claim, dependence may occasionally be impossible to avoid completely. In such cases, the study should be organised in such a way that it is impossible for the researcher to identify who has supplied the information. If such a measure is impossible or would put at risk the aim of the study, persons should be invited to participate only after careful weighing of the expected gains in knowledge against conceivable negative consequences in the short and long run for those persons who are in a position of dependence in relation to the researcher. It is important that a person who is invited to participate is not given the impression that refusal to participate or subsequent withdrawal after participation has begun may entail disadvantages such as a deterioration in care or treatment.

The Confidentiality Requirement

All information about participants of a study should be given the highest possible confidentiality, and should be stored in such a way that it cannot be accessed by unauthorized persons.

The issue of confidentiality is closely connected to the general issue of right of access to public records versus protection of privacy. The researcher should observe that the legislation in this area is difficult to interpret and is subject to ongoing reform.

This general requirement may be elaborated in the following rules:

Rule 5

All staff on research projects which involve the use of ethically sensitive information about individual, identifiable persons should sign an agreement of professional secrecy regarding such information.

What is regarded as ethically sensitive may, of course, vary from society to society and from one time to another. The point of departure should be what the affected parties and, subsequently, their survivors (not the researcher) may be assumed to conceive as unpleasant or harmful. In doubtful cases regarding what should be included under the heading of professional secrecy, consultation with other researchers in the field, or the Ethics Committee of the HSFR, is recommended.

Rule 6

All information about identifiable persons should be recorded, stored and reported in such a way that individual persons may not be identified by outsiders. This applies in particular to information that may be considered to be ethically sensitive. This means that it should be impossible in practice for outsiders to access the information.

The notion of reporting here denotes written publications as well as oral accounts made to others than the staff of the project. Rule 6 thus means that personal information is must to be given to outsiders and that reporting should be conducted in ways that make the identification of individual persons impossible. Of course this rule is not valid in all cases. In, for example, biographical studies of historical persons, information of a private nature may be included. In such cases, directly or indirectly affected parties should, if possible, be consulted before publication. In particularly sensitive cases, it may be legitimate to postpone or abstain from the publication of certain information.

The researcher should be aware of the fact that, even if personal information is made public without the mentioning of the names of the persons in question, it may, if the information is sufficiently detailed, be possible for at least some readers to identify a given individual. Where this risk exists, measures should then be taken to make it more difficult for

outsiders to identify individual persons or groups. This is especially important when persons or groups are involved who in some sense may be considered to be weak and exposed and/or to possess typical and easily identifiable distinctive features.

In weighing the value of the expected gains in knowledge against possible negative consequences for the affected parties, one should take into account the risk of individuals being accidentally identified.

The Requirement of Restricted Use

Information obtained about individual persons is only to be used for the purpose of research.

This general requirement may be elaborated in the following rules:

Rule 7

Information about individuals, obtained for research purposes, should not be used or made available for commercial or other non-scientific purposes.

In general, personal information obtained for research purposes should only be made available to other researchers who agree to comply with the assurances made to participants by the researchers who originally obtained the information.

Rule 8

Personal information obtained for research purposes should not be used for the making of decisions or adopting of measures which would directly affect the individual (health care, committal, etc.), unless special permission for this has been granted by the individual concerned.

A participant of a study should be permitted to claim the research results in connection with his or her own requests for help or treatment from, for example, health or social care authorities. However, as already indicated, research results are not to be used by, for example, social care authorities for the effecting of compulsory treatment, committal or similar measures.

In the planning of research projects, the leader of the project should consider the risk for results being used in ways that contravene Rules 7 and 8, and if possible apply suitable countermeasures. Consultation with other researchers or with the HSFR Ethics Committee is recommended in doubtful cases.

RECOMMENDATIONS

As a rider to the principles and rules set out above, the HSFR wishes to issue some recommendations. These cannot be claimed to carry the same weight as the above eight rules. They point, however, to certain attitudes within the research process which the HSFR considers to be important and desirable.

Recommendation 1

The researcher should give suppliers of information, participants and other affected parties the opportunity to study ethically sensitive sections, controversial interpretations etc. occurring in reports on the research before these are published.

This recommendation must not be interpreted to mean that, for example, participants should be able to stop the publication of results which are personally damaging to them. If individual participants or other affected parties feel ill at ease with or unjustly criticised by the interpretations and conclusions of the researcher, the value of the expected gains in knowledge should be weighed against the negative consequences of possible publication for those affected.

Recommendation 2

On an appropriate occasion, the researcher should ask participants and other affected parties if they would like to know where the research results are going to be published, and to receive a report or summary of the study.

One simple way to map the interest in this kind of information among participants in questionnaire-based studies is to give them the opportunity to state on the questionnaire itself their interest in receiving bibliographical data and a summary of the main results. The participants may have a justifiable claim to know how their information has been used and what conclusions the researchers have come to. Such an opportunity to study the results may also encourage them to view their participation more positively. From the point of view of the scientific community, it is important to communicate research results to those who are in some way concerned or affected by them. The social sciences in particular depend to a high degree on the willingness of people to participate in various kinds of empirical studies. For this reason, too, it is important that research results are made known.

Responsibility for ethical consideration in research

The ethical responsibility rests primarily on the leader of a research project. This is still the case after the project has been scrutinised by the HSPR Ethics Committee. The leader of the project is also responsible for all staff being acquainted with the ethical principles involved, and for the collection and storage of personal information being carried out confidentially.