

Institute of Evolutionary Medicine (IEM)

Code of Ethics

New principles for an Ethical base of Research on Human Remains

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This second draft of the IEM's self-given, internal code of ethics consists of an introduction, a preamble, and recommended standards that will serve as an ethical decision basis for the researcher on the ground.

The introductory part presents the organisation, procedural considerations, and scope of application of the code of ethics. The preamble summarizes the intended goal of the IEM to engage in practical ethics. The recommended standards finally present guidelines for conduct that we impose ourselves to follow. The formulation of this code is particularly narrow and specific since the code is tailored to the particular needs of the IEM researchers.

In case of interest or feedback you want to share with us, please contact: info@iem.uzh.ch

Summary:

- 1. This code of ethic is the basic ethical framework under which the researcher at the IEM works. We do not impose our views on other institutes or researchers.
- 2. The IEM are research institutions that undertake research of human remains. This research will either be covered by existing legal frameworks for modern remains or this code of ethics which is our internal framework for historic and prehistoric human remains.
- 3. Researchers have to be qualified and aware of greater implications (legal, etc.) of their work.
- 4. Sampling should be minimally invasive, using least damaging techniques and with consultation with other stakeholders.
- 5. Research has to have clear goals.
- 6. If collection or sample processing is taken off site then the same anti contamination, preservation, etc. measures should be met.
- 7. Everything should be labeled, documented, secured and kept in appropriate conditions.
- 8. Removal offsite or destructive sampling of remains must be properly recorded

Research should be published by scientifically and publically in an appropriate and respectful manner with the role of the IEM acknowledge and to legal standards.

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1 Introduction and Applicability

1.1 Applicability

The IEM follows all UZH, Kanton Zürich and Swiss laws, regulations and ethical standards. This code of ethics is in addition to these and applies to research projects where ancient and historical human remains, parts of human remains or raw data on individuals (as applicable) (in the following always summarily addressed as 'human remains') are used in scientific, educational, or professional areas of work. This is not limited to a specific educational or scientific background (e.g. medical scientists), but open to any individual affiliated with the IEM. This includes any level of affiliation, such as Master students or technicians of the IEM as well as any other persons that are not paid by the IEM, but do direct work for us or publish under the name of the IEM. As such, the code makes no recommendations for ethical issues arising from either excavations or exhibitions (or only to the extent relevant for IEM researchers).

Affiliation to the IEM requires the commitment to comply with the standards of the IEM's code of ethics, its procedures and a will to enforce them. In case of misconduct or inappropriate behaviour according to the code, the IEM reserves the right to take internal actions that are not explicitly listed in here, but are specified in the labour legislation on which all contracts of personnel of the overall employer, the University of Zürich are based on.

Any kind of research on historical human remains that is not realized within a clear legal set of permissions and rules (such as body donations at Anatomy Departments at educational institutions) – and can therefore not base itself on any kind of consent by the person whose remains are being researched – can be regarded as an invasion of privacy, a violation of personal rights, the right to peace of death and the right to bodily integrity after death. We'd like to stress at this point the most relevant issue of appropriateness, which is important for all categories and a general, underlying basis for all categories and standards presented hereafter.

The IEM code of ethics takes this into account and accepts it as a fundamental truth of the field of research that cannot be remedied. Therefore the IEM code of ethics asks for a commitment of all affiliates of the IEM to independently judge the appropriateness of their research against the degree of invasiveness, concepts so important and central, they are discussed as the initial and first standard in the code itself.

The commitment to all recommended standards that are going to be presented in the following, also calls for a more general request for loyalty and integrity that the IEM expects from its affiliates. The code is not conceptualized as a strict set of compliance-based rules, but should be understood as an integrity-based instrument to support and foster ethically desirable conduct.

2 Code of Ethics

2.1 Preamble

The IEM as a part of the University of Zurich and thus as an institution of research and higher learning, is committed to three main goals:

(1) contribute to scientific progress, (2) inform and teach a larger public and society in general about our research, and (3) show transparency in the goals that we follow, our protocols, and our research results. This code wishes to be understood as a communicative action of the researchers of the IEM, collaborators and affiliated persons rather than a prescriptive set of rules or guidelines. It is formulated with the distinct wish to initiate a further discussion about the ethical dimensions and implications of medical research on human remains, and to contribute to the more general goal of actively shaping sustainable research conditions.

The research on human remains is something that has been important for medical sciences since the early stages. After a long phase of no attention to either the person or the individual while alive, today any kind of clinical research is regulated by a clear set of legal and ethical norms and specific controls. (Cf. <u>Guidelines of the Swiss Department of Healthcare for research on humans; Human Tissue Act (UK)</u>)

Such sets of rules or norms of conduct are unfortunately completely absent from the research field of historical human remains in respect to their use in medical and diagnostically interested research.

To that end, the IEM is committed to an on-going discussion and formulation of an ethical code of practice that asks for a strong personal commitment and is continuing work to improve guidance for the researcher in particular, but also the general public discourse, to reach an understanding of what it means to act ethically in the highly competitive and invasive research field of evolutionary medicine.

This code of ethics comes from a specific unease in regards to the under-definition of certain problematic situations in studies on mummified bodies, parts, bones or any other kind of historical human remains. As such it addresses only these specific problematic situations that arise from current work at the IEM, which is primarily interested in evolutionary aspects of medicine – i.e. evolution of body morphology or DNA degradation over time; for further examples, please refer to the research projects on our webpage –;. In addition, our main focus is research. We explicitly reinforce that our affiliates at no point take sides in political or military conflict when taking part in collaborations or sample collection abroad (e.g. excavations). IEM researchers refuse to be associated with any such struggle, but instead we are only interested in preserving the historical human remains and in the scientific progress to which the IEM hopes to contribute.

2.2 Adherence to the code of ethics

Adherence to the code of ethics is a matter of personal responsibility. Affiliates of the IEM are thus requested to take the intention of this code as an additional guideline for their professional decisions. This is to ensure an aim for the highest possible standards of evidence based research with human remains and for all aspects of research, such as sampling, processing, data information, and publication.

2.3 Agent and Object

The theoretical foundation of this code of ethics is the link between the two elements of the research chain: the researcher and their object. Each category will be introduced by describing the background and thus the occurrence of problematic issues. The background information is then completed with the corresponding recommended standard.

2.3.1 Human Remains

Background: The issue of human remains has to be explained with regards to further aspects. The first differentiation has to be made for the question of parts or full bodies of human remains. Under the aspect of bodily integrity a full body has more importance than if the body was already disintegrated in parts. For the purpose of our research, parts of human remains in form of small pieces of samples are needed for the most part. The second differentiation is with regard to the question of the identity of the human remains. This means that if human remains are either defined or undefined for the researcher with regard to a) type of preservation and b) socio-cultural origin. Type of mummification, if remains are mummified, is further to be explored as either artificial or natural, even if this has no influence on the value attributed of the corpse. Further specific issues arising from socio-cultural aspects of the context of these human remains might occur, specifically issues of religious and cultural source.

Recommended Standard: The process of identification either parts or the full body is most important. The progress from unknown/undefined to known/defined, for example, understanding the cultural background is the first step before the beginning of research per se (e.g. sample processing). Researchers at the IEM are asked to identify the object (part/full) under investigation as accurately as possible in order to collect information (continuum unknown to known) that are in turn will further identification of a) health status and b) socio-cultural context. Thus the main goal of this standard should be to come as close as possible to reconstructing the person behind the remains. The process of "information preparation" should act as the reference point for all members of the IEM and play a key role not only at the beginning of the research process, but also for the subsequent process (e.g. communication of research results).

2.3.2 The Researcher and the Scientific Community

Background: The process of research requires a strong engagement and interest of the researcher to have knowledge not only about the identification of the object of investigation, but also about the state of 'ownership' of the sample, and the situation concerning the interests linked to the sample; including consciousness about the legal situation, clarification of requirements such as special permissions or the chain of permission, the involvement of subcontractors and collaborators. This is especially important with regard to the safeguard of the already mentioned responsibilities to identify and protect the object, and in order to guarantee and enhance the scientific quality, and to strengthen the trust of stakeholders (e.g. collaborators, society, and further) in scientific procedures.

Recommended Standard: The researcher needs to have the specific qualification for his part of work with human remains. Qualification includes on-going education, communication and publication of research results, and to lead by example.

2.4 Sampling and Processing

Besides the elementary link between the researcher and human remains as an object of investigation, further considerations are necessary for the acts of sampling and processing; again supplemented with background information in advance to the recommended standard.

2.4.1 Invasiveness

Background: The issue of invasiveness is interlinked to the two possible ways of posthumous harm. Posthumous harm can either occur with regard to the bodily integrity of a person or with regard to their personal identity. In either case the concept of posthumous harm is related to posthumous interests and emerging duties that are now transferred to the researcher and in need of a profound theoretical reflection (theoretical philosophical groundwork).

Practical issues and duties are either related to the process of sampling (damage or destruction as violation of bodily integrity), or on the level of presentation and diversification of research results (display of data as possible violation of personal identity; see Data 2.5).

At this point we continue with the issue of invasiveness as violation of bodily integrity. The degree of invasiveness is thereby related to different forms and degrees of destruction. For human remains destruction or the degree of destruction or damage is neither defined, nor regulated. The actual damage can range between immediate sorts of destruction (e.g. extraction of bodily pieces) or less predictable, long-term damages (e.g. x-ray favouring DNA destruction). So far there is no standard defined for what counts as the appropriate scientific proof (method and research question) in relation to the expected damage that would in turn allow for clear decision path towards a minimal invasiveness.

Recommended Standard: The main guiding rule should always be "as minimally invasive as possible" in relation to scientific and technological progress. This requires a higher-level judgment, expected from the researcher, concerning the method(s) and the sample size needed for the research question, bearing the main guiding rule in mind to be as little destructive than possible. These decisions need to be made by consultation between those who supply the sample, and those who study it.

This includes constant self-questioning and evaluation and avoiding possible redundancies of results. If proof is already sufficiently clear with less invasive methods, then an additional procedure can be judged to be redundant which in turn will heighten its invasiveness and lower its appropriateness. New or fresh investigations should always be counterbalanced against the appropriateness and degree of destruction as far as it can be projected. For all of these reflections all human remains have to be considered as unique in itself, even if there might be samples that are considered historically more important and thus seem generally more 'special' and 'protect worthy' or vice versa more 'researchable'. In general it is important to foster a discourse on "best practices" within all branches of research that involve human remains (including anthropology, archaeology) in order to minimize the problem of the so-called "Methodenunschärfe". "Methodenunschärfe" understood as the general problem of technological limitations, but also with regard to the still underdeveloped standard or diverse acceptance of which method a certain type of research purpose.

2.4.2 Appropriateness

Background: In a first instance the appropriate use of human remains has to be in compliance to general (local and Swiss law). Beyond that further questions of appropriateness correspond to the process of taking the sample, sample size, or possible redundancy of the diagnostic results. By then the issue of appropriateness is tightly linked to questions of invasiveness and turns special attention to the formulation of the research question.

Recommended Standard: The judgement of appropriateness is in responsibility of the researcher on the ground. The researcher is requested to always work out a clear research question that is of guiding importance for decisions, respective to all ongoing processes dealing with human remains. This includes situation awareness by the researcher on the ground, which in turn has prevalence to our formulated standards. The minimal required standard is to be in compliance with local and Swiss law. This includes that the researcher is requested to look for all written confirmation of permission documents that contest the correctness of sampling, transport, or ongoing processes such as research with human remains.

2.4.3 Sample Processing

Background: Sample processing automatically involves the question of locality. The researcher has to decide where to take the sample and with whom to collaborate. This includes questions of doing research on the ground or to move the object under investigation to another environment (e.g. home laboratory) and to avoid problematic issues such as, contamination, preservation, conditions of transport, and storage.

Recommended Standard: If human remains are removed, the IEM researcher is requested to collaborate with local researcher and as soon as the sample is in his/her own responsibility, affiliates have to meet special requirements:

- 1. Removal and preparation for transport: Preservation and protection of contamination; special equipment for transport as provided by the IEM.
- 2. Transport: the researcher is responsible to guarantee the transport of the sample to the IEM. The researcher must provide the necessary written permission and documents (purpose of research, permission for sampling, transport and processing; local letter head and IEM Official Document). For the transport preference must be given to a professional supplier for transport (e.g. UPS, DHL, etc.). If the researcher carries the sample by herself/himself the researcher has to know at any point in time where the sample is (requires access to the sample at any time, carry on your person or hand luggage); in special cases such as the transfer to a private person (Colleagues or other person affiliated to the IEM) this person needs special briefing in adherence to the code of ethics of the IEM.
- 3. Arrival and Registration: each sample has to be registered in the respective form (inventory number, room, registration) by the researcher carrying the new sample
- 4. Storage: The sample is entered into the designated storage room and into the box of the respective project (see further 2.5.4 Storage).

2.4.4 Storage

Background: Samples are fragile and for that they have to be stored and handled with caution (secure, control of access, controlled conditions of humidity, temperature, and light).

Recommended Standard: All IEM members are requested to store samples according to the IEM manual of storage. For new incoming samples, each sample must be entered into storage in the 'General Sample Collection' in room or the ancient biomolecules laboratory at the Institute of Anatomy (University of Zürich) and correctly registered with an inventory number (sequence number, project number, and name of the project leader, researcher). Samples are to be stored in project and/or collection specific boxes. The conditions of storage that guarantee the preservation of the samples are put into place in the IEM storage rooms.

Besides the special handling of incoming samples, the IEM also demands special attention and procedures for outgoing samples. In the case of samples that are lent to other institutions for the general purpose of scientific progress the research member of the IEM who is in charge of the project with a second party or institution has to ask for a clear research proposal (research question, methods). Additionally the process has to be registered and filed in accordance to the form for outgoing samples.

A second case of temporarily borrowed samples is with regard to probes or samples that need special verification (e.g. in terms of scientific accuracy). This sometimes requires methodological investigation that is not available or actable at the IEM. Such verification might involve the use of methods that are destructive and thus turn the status of lending from temporal to permanent. In the case of "verification probes" the researcher at the IEM also must fill out the form for outgoing samples and to motivate his or her action in accordance to the general attempt of the code of ethics for doing research. All and any processes of outgoing samples need to be in compliance with the general legal basis of the University of Zurich and its regulations.

Generally relevant for all questions of storage is that access to the storage room is limited to members of the IEM and the Institute of Anatomy. In addition a IEM researcher is in charge of the storage room and will supervise organisational details of the sample collections. This person is also responsible for coordinating all incoming and outgoing samples and tending to the sample inventory.

2.5 Data

After considering the process of sampling and processing, the next logical steps of data generation, its interpretation, and publication need special focus and recommendations.

2.5.1 Data generation

Background: The issue of data generation links back to the question of 'invasiveness versus appropriateness' and the importance to preserve human remains at all costs (posthumous rights, cultural heritage, or as research object for next generations). Data generation – such as aDNA analysis – often requires invasive techniques – e.g. bone powdering – where samples are destroyed. Other techniques, e.g. imaging, in turn can lead to DNA destruction on the molecular level that is not directly observable.

Recommended Standard: In generating data from samples of human remains, the affiliate/researcher is guided by the recommended standard of appropriateness. In general the IEM is committed to

medical research and thus scientific progress. Through that, all affiliates of the IEM are asked to contribute to this overall goal while including considerations of appropriateness and invasiveness. It is the researcher who has to judge the most appropriate method for data generation in order to meet the research question, but at the same time needs to consider possible violations of posthumous rights and guarantee the preservation of the samples (e.g. proper use and handling of samples).

2.5.2 Interpretation, Diversification & Publication

Background: researchers are obligated to publish their research results and inform the scientific community, but also society at large (Forschungsauftrag, that is to contribute to scientific progress by following a sustainable and responsible research agenda, and Bildungsauftrag, that is to inform the scientific community and the broader society about research programs and their gained output). This is linked to the overall responsibility for a proper use of grant money, fostered through peer reviewed publications including a thorough presentation of research question, methods, and results. Any such publication of results (e.g. data on sex, health, or diseases), and any digital distribution of graphical material (e.g. pictures, 3D reconstructions) always reveal identity aspects (loss or decrease of anonymity).

Recommended Standard: To meet the responsibilities of the Forschungsauftrag and the Bildungsauftrag affiliates of the IEM are prompted to responsibly handle the communication of their research results. This includes sensitive handling of graphical, and detailed information on methodological procedures. Transfer of graphical material can only be granted if the recipient and the purpose of use are explicitly known (this includes third party transfer) and delimitated. The use (e.g. display or print) of graphical material provided by the IEM must ensure the appropriate designation (e.g. caption or legend). To provide additional information and to prevent the use of graphical material that the IEM regards as inappropriate and as such does not want be associated with, the IEM provides a special press disclaimer and selected graphical material on its homepage that are for public domain. (Cf. Press Corner)

A second standard we want to promote is with regard to our publication standards. In case of space restrictions in scientific journals, publications of the IEM are supplemented with additional information of the methodological setting that is transparently displayed at our homepage.