

ETHICS

Constructing Ethical Guidelines for Biohistory

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The blood-stained cloak allegedly worn by Mary Todd Lincoln on the night of the assassination. Locks from Elvis' GI haircut. Pieces of Beethoven's corpse, Albert Einstein's brain. This odd array of historical artifacts is at the center of a new ethical conflict for life scientists. Should technologies of bioanalysis, such as DNA testing, be used to try to answer questions about historical figures? If so, what social, legal, and scientific standards should be used?

Bioanalysis has been used to investigate historical figures' behavior, disease, cause of death, and lineage. Einstein's brain tissue was analyzed to attempt to determine the source of his genius (1, 2) and to learn whether he had a genetic predisposition to aneurysm (3). Beethoven's hair was analyzed to see if lead poisoning was the cause of certain behaviors (4). A proposal was made to test Abraham Lincoln's blood to determine if he had Marfan syndrome (5). Such testing has also been proposed to study less famous people from earlier eras, such as those buried in New York's African Burial Grounds.

Bioanalysis of historical artifacts and remains has also been suggested for authentication of museum artifacts (such as clothes or bed sheets) that allegedly belonged to historic figures. Genetic testing has been used internationally on remains to determine if certain corpses were actually those of Pizarro, Butch Cassidy and the

Sundance Kid, Jesse James, or Czar Nicholas II of Russia and his family (6, 7).

Currently there are no professional guidelines specifically addressing biohistorical analysis. A researcher or hobbyist can obtain a strand of hair or spot of blood from a historical figure and undertake bioanalysis. Some investigations are invasive, including disinterment of the dead or release of private medical information, for dubious scientific or societal gain.

Justifications for biohistorical research are often based on insufficient historical or scientific evidence. There has been little attention paid to the impact on living relatives' insurance or employment possibilities if a public figure's DNA shows a costly-to-treat genetic disease. Sometimes biohistorical analysis is undertaken for commercial considerations or mere sensationalism.

Biohistorical research exists at the intersection of various disciplines including genetics, chemistry, history, and anthropology. Existing professional ethics codes provide a starting point for developing guidelines for biohistory, but most assume that the way to handle particularly thorny ethical issues is to keep confidential the identity of the research subject. Biohistory by its very nature deals with an identifiable subject, generating information about that figure and often about his or her family. Developing specific guidelines for undertaking biohistorical analysis is important to clearly establish researchers' ethical and scientific responsibilities. We examined professional codes from 23 organizations (with members including, for example, historians, chemists, sociologists, archaeologists, and anthropologists) to identify factors that provide direction for the biohistorical enterprise (see table, p. 216, and sup-

porting online material). Analogizing from these codes, we are in the process of constructing ethical guidelines for biohistorical analysis to protect individual rights and to assure scientific integrity. The guidelines we suggest would apply not only to the famous but to all individuals whose biological material is used to answer an historical question.

Existing professional codes indicate that research should not occur in scientific isolation. At least five codes require consultation with the public or affected populations before the research is undertaken (8–12). In some cases, potentially affected individuals may have complete veto power over the research (13). Informed consent for the particular research intervention and the protection of confidentiality were frequently listed.

Guidelines addressing biohistorical research should require conformance with all

applicable state, federal, and international regulations regarding treatment of the dead. It may also be useful to require researchers to assess whether writings or statements indicate that the individual would have agreed to testing for such a purpose.

In certain instances, informed consent might be required of descendants of the historical figure. A descendant might argue that her

privacy, property, and other rights, as well as religious beliefs or cultural feelings require that she be consulted before testing is done. This is already the norm in studying remains of Native Americans.

Family members may face risks from bioanalysis. If unexpected lineage is shown (or disproved), a living individual may gain (or lose) land rights or burial rights. For example, Thomas Jefferson's descendants qualify for burial at Monticello. Descendants may also experience emotional distress. A researcher who worked on Einstein's brain admitted, "The family suffered, I think immeasurably, when Thomas Harvey whipped the brain out of Einstein at the autopsy and did not even tell the family." (14, p. 264)

Ethical issues are also raised when ownership of historical objects is claimed by a group that defines itself by religious affiliation, tribe, or family line. Group consent



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ANALYSIS OF PROFESSIONAL CODES

Topic	N
Confidentiality	14
Public Access	
Educational role*	2
Community role*	5
Public access to research results or materials	8
Informed Consent	10
Group Consent	6
Intrusiveness/Preservation	11
Valuing research	5
Scientific Concerns	
Peer review	3
Accurate reporting	7
Complete record	2
Objectivity	2
Competence	1
Social Concerns	14
Conflicts of Interest	
Avoiding and/or handling	12
Appearance and real	6

*Institutional, organization, or professional

Comparison of ethics codes. Number (N) of professional organizations that address topics relevant to biohistorical analyses

is extremely complicated because of the elusive nature of cultural property and its ownership. Existing codes provide little guidance regarding the identification of a relevant group and the duties owed. Investigators should foster a partnership with the group through consultation before initiating the project, ensuring that proper mechanisms are in place both to prevent exploitation of the group and to deal with the impact of the research. At the very least, investigators should disclose to the group the investigative question posed, the type of testing, the level of destructiveness to the artifact, funding sources, and any other issue of concern to group members. If the project includes testing DNA from a living individual, the research should comply with federal institutional review board (IRB) procedures, as well as pertinent privacy, confidentiality, and informed consent regulations.

Even if a particular proposal to undertake bioanalysis of a historical figure or artifact can be conducted with proper respect for related individuals and groups, the project should still be assessed for its scientific worth and the social impact of the results. Some of the codes examined address such standards as peer review for research, complete record-keeping, maintaining ob-

jectivity, and competence. However, in the bioanalysis arena, a multitude of farther-reaching questions arise with respect to the authenticity of the sample, the utility of testing, the probable accuracy of testing, the scientific integrity of the test, the researcher's experience with such testing, and the degree of destructiveness to the sample. For example, investigators frequently assume that samples they are testing are authentic, although the provenance of many historical artifacts is incompletely or poorly documented.

Another concern is whether an existing bioanalytic tool and genetic analysis can accurately answer the question being posed. It is not clear that DNA testing will work accurately on samples as old as those on Mary Todd Lincoln's cloak. Pilot studies might be necessary, undertaken on less precious samples (e.g., blood from Civil War bandages). The degradation of biological samples over time and the potential contamination of artifacts with biological material from other people who have handled it create scientific complexities not encountered when bioanalysis is undertaken on a fresh blood or tissue sample from a living individual. In addition, there should be an obligation to assure that bioanalysis does not utilize an entire sample so that other biohistorians can verify the results and so that the sample can be retested later with more advanced technologies.

Often, investigators fail to pose an investigative question capable of resolution by genetic testing. For example, Eugene Foster's 1998 comparative Y-chromosomal study of the descendants of Thomas Jefferson and his slave Sally Hemings was intended to establish whether the president had fathered Hemings' children (15). Yet the study protocol was inappropriate for determining the paternity of Hemings' children—the only possible conclusion was that some of Jefferson and Hemings male-line descendants had common relatives.

The professional codes also show concern for the outcome of the research, in terms of both social impact and interpretation and dissemination of results. Seven of the organizations' codes address accuracy in reporting results, including careful presentation of interpretations and judgments to stimulate a discussion of alternative interpretations (16), avoidance of intentional withholding or omission of findings or opinions leading to misinterpretation or distortion (17), and accuracy of public communications and disclosure of underlying theories, methods, measures, and research designs (18, 19). Bioanalysis guidelines should address each of these issues, as well as outreach about results to groups affected by the research and the general population.

Although scientific tools hold promise for new avenues of historical research, recent biohistorical investigations have generated an abundance of ethical concerns and a paucity of meaningful analysis. Yet the frequency of these investigations will undoubtedly rise, given public and professional fascination with celebrity, biotechnology, and DNA analysis.

Museums, universities, or research facilities that sponsor biohistorical research should develop interdisciplinary review committees to analyze research proposals prior to their initiation. The committee (which might, in some instances, be an existing IRB) should address the ethical, legal, social and scientific issues raised by proposed research. Where an unaffiliated researcher or individual with legal possession of an artifact desires to undertake such a biohistorical investigation, a similar level of review should be performed, either by application of the guidelines or by submission of the proposal to an outside interdisciplinary review committee. With the development of guidelines specific to the biohistoric enterprise, institutions and individuals undertaking this research can be held accountable to their relevant professions and society as a whole.

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Supporting Online Material

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